# **Benefit Design Barriers Race and Disability**

Special (EX) Committee on Race & Insurance
Workstream #5
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# **Benefit Design & Disability**

- Benefit design subtlety of historical exclusions & coverage gaps when it comes to disability
- In 2011, about 26.5% of the U.S. adult population had at least one type of disability
- People with disabilities typically have higher health care costs and out-of-pocket costs than people without disabilities, even in 2016 after the ACA's full implementation
- 14% of working-age Blacks in the US have a disability compared with 11 percent of Non-Hispanic Whites and eight percent of Latinos

# What Happens Before Benefit Design?

- In 2021, a study on people with intellectual and developmental disabilities (I/DD) living in the community, focusing on perceived healthcare barriers in three racial & ethnic groups
- Lack of knowledge and lack of trust must be addressed as a matter of equity before we ever get to the kinds of changes that we generally think of as benefit design
- Effective benefit design must include provider training, culturally aware and fully accessible outreach and education, and data-sharing across public and private insurance lines

### Persons with I/DD, Race/Ethnicity, & Birth

- Study of 2,110 delivery-associated hospitalizations among women with I/DD, including 1275 non-Hispanic white women, 527 non-Hispanic Black women, 308 Hispanic women: significant disparities in still birth rates & labor/delivery charges
- Culturally sensitive maternal health measures such as coverage of doulas must be part of benefit design and should incorporate disability awareness and training
- Non-discriminatory benefit design includes looking at when for what, and how cost-sharing, caps, and other coverage limitations are imposed, even when the language is neutral

### Race & Mobility Disabilities

- Mobility (serious difficulty walking or climbing stairs) is the most common single disability, affecting 1 in 7 adults
- Disability is significantly associated with poor education, poverty, and unemployment
- Physical disability is more prevalent among Black, American Indian/Alaska Native (AIAN), Native Hawaiian and other Pacific Islander (NHPI), and multiracial respondents
- The prevalence of physical disability for Blacks in any given age group is similar to the prevalence for non-Hispanic whites who are 10 years older
- Women are more likely than men to have physical disabilities in each age & race group

#### What Changes are Needed

- Go beyond discrimination that is apparent on the surface offering "the same benefit" does not mean a benefit that is equally available
- Ask and expect issuers to explain how they have designed a benefit, especially coverage of durable medical equipment, rehabilitation therapy, and other treatments used by people with disabilities, to ensure availability to diverse racial & ethnic groups
- GET DATA on benefit use, stratified by race, ethnicity, disability,
   LGBTQ+ status, and so forth
- Obtain random samples of EHB benefit denial notices and analyze them for patterns of consistent denial that are substantively unrelated to clinical evidence or actual provider practice in specialty areas

#### Thank You, Questions & Contact Info

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