



## DIVERSITY IN CAREGIVING NEEDS AND NETWORKS: DIFFERENCES BY RACE-ETHNICITY IN THE CARE OLDER ADULTS RECEIVE

### KEY POINTS

- Black men and Black women have lower life expectancy, yet spend more of their late-life years with moderate and significant disabilities than do White people. This is true even for Black people with higher incomes.
- At the same time, Black people with long-term services and supports needs are less likely than White people to have spouses in their care networks.
- Both Hispanic people and Black people are more likely to live with extended family than White people.
- Both Black people and Hispanic people face higher rates of adverse consequences due to unmet long-term services and supports needs than White people, even though they receive greater amounts of unpaid care.

### BACKGROUND

Long-term services and supports (LTSS) includes a range of assistance individuals may need to meet their health or personal needs over an extended period. Most LTSS is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called activities of daily living (ADLs), which include such tasks as bathing, dressing, toileting and eating.<sup>1</sup> Informal care networks are the primary source of LTSS for the older population in the United States. These networks are instrumental to older people's ability to remain in the community.<sup>2</sup> If informal care is not available, persons with disabilities may receive paid LTSS or not have their needs met. Health insurance does not cover LTSS costs, and Medicare, the major public insurance program for older Americans, does not cover most LTSS expenses. Medicaid provides LTSS, but it is only available for individuals who meet income and other eligibility requirements.<sup>1</sup>

Research suggests that need for care can vary by race and ethnicity, with Blacks and Hispanics having higher rates of disability requiring assistance than Whites. Whether this higher need can be met through friends and family also varies by race and ethnicity.<sup>2</sup> The alternative--privately paid care at home--is costly and therefore likely to be unsustainable for many older adults, particularly those who are unmarried or have lower incomes.<sup>2</sup> This brief uses simulation modeling to add to our understanding of how caregiving needs and networks among older adults vary by race and ethnicity. It shows that the level and timing of the risk of needing long-term services and supports (LTSS) varies widely by race and ethnicity. Black and Hispanic older adults need care sooner and for longer periods than White older adults. They receive more unpaid care, are more likely to co-reside with family, and are more likely to report adverse consequences from unmet LTSS needs than their White counterparts.

## METHODS

Using estimates from the Health and Retirement Study (HRS)<sup>i</sup> to describe current experiences, and projections from the Dynamic Simulation of Income Model (DYNASIM) to highlight needs over time, we describe differences in care needs, potential family caregiver availability, family care networks, and paid care use, for adults ages 51 and older. We focus on differences by race and Hispanic origin.<sup>ii</sup>

We focus on a more narrow measure of old-age disability, which mirrors the “benefit triggers” for tax-advantaged long-term care insurance policies specified in the Health Insurance Portability and Accountability Act of 1966 (HIPAA). These HIPAA-based criteria focus on more significant disability, identifying people with chronic need for help with two or more ADLs, including incontinence, and adding severe cognitive impairment as a separate criterion. Besides establishing a benchmark for private insurance, the measure has become more common for approximating high need for long-term care services generally and eligibility for Medicaid services specifically, although considerable variation across state programs remains.<sup>2</sup>

DYNASIM is a large-scale dynamic microsimulation model that starts with a nationally representative population and then endeavors to model directly all the underlying processes (disability, care needs, formal and informal care use, eligibility for and use of public programs, unmet need), including their evolving interactions. To dynamically age the population, we use algorithms that generate transition probabilities from year to year. The underlying data for the model includes the HRS (pooled waves 2016 and 2018), the National Health and Aging Trends Study (2015) and the National Health Interview Survey (2018).

## THE DIVERSITY OF LTSS NEEDS

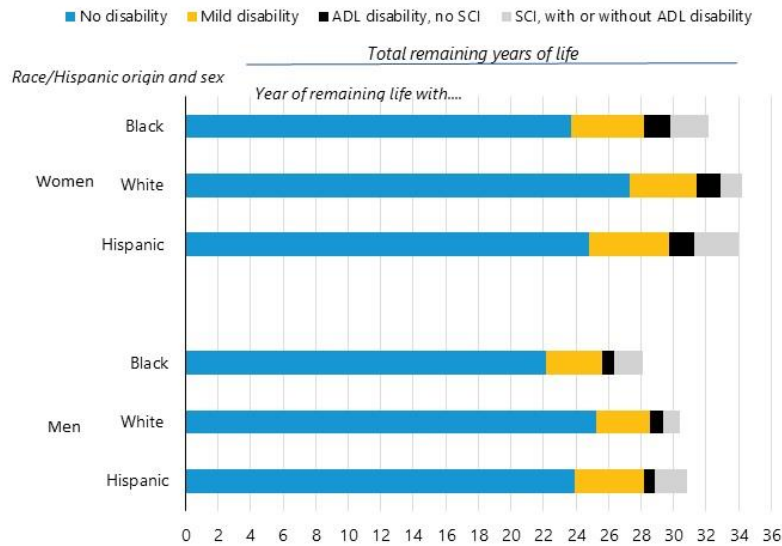
Adults enter their older years with different personal networks, health challenges, and financial resources to address their LTSS needs. As they age, many will encounter a range of difficulties. Some will be able to manage age-related functional decline using assistive devices and supportive services, while others will become physically frail or develop cognitive impairment that will require round-the-clock supervision to remain safe.

Most older Americans can expect to need LTSS as they age,<sup>3,4</sup> and a growing literature documents that needs and care experiences will vary by race and ethnicity.<sup>5,6,7,8,9,10,11,12,13</sup> Some of the hypothesized reasons for widely observed disparities in health outcomes, including LTSS needs, are socioeconomic disparities, psychosocial pathways related to discrimination, behavioral norms, comorbidities and genetic factors.<sup>14</sup> Our analysis found that some difference in LTSS needs by race and ethnic origin vary for men and women (**Figure 1**).

Non-Hispanic Black (hereafter referred to as Black) people are more likely to experience significant disability. It happens earlier in life, and their mortality is also earlier than Non-Hispanic White (hereafter referred to as White) people. For example, from age 51, a Black man can expect to survive 2.2 fewer total years and 3.1 fewer non-disabled years than a White man. Black people are more likely to experience the onset of significant LTSS needs early in life. This means that they may need to stop work sooner and have less opportunity to accrue retirement wealth that they could use to support paid care or residence in a supportive setting. For example, over 20% of Black people experience onset of significant disability in their fifties and sixties, compared to 11% of White people. Hispanic men and women and White men and women have similar total remaining life expectancy, but White people spend greater shares healthier than Hispanic men and women (see **Figure 1**).

**Figure 1. Remaining Life Expectancy with and without Disability after Age 50 by Sex and Race/Hispanic Origin, People Born between 1960 and 1964**

*Black men and women spend more of their shorter late-life years with moderate and significant disabilities*



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample includes people who survive until at least age 51 and excludes unauthorized immigrants. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. People are classified as having less significant LTSS need if they report difficulty with at least 1 ADL or instrumental ADL, or if they have mild cognitive impairment. Significant LTSS need can be broken into 2 categories: “ADL disability” indicates a need for assistance with at least 2 ADLs that one is unable to perform due to a condition that is expected to last at least 90 days. “SCI” indicates severe cognitive impairment with a need for substantial supervision due to health or safety threats. People with mild disabilities report difficulty with at least 1 ADL, instrumental ADL, or mild cognitive impairment. People with “no disability” report none of the enumerated disabilities.

Differences in the likelihood and duration of needing LTSS by race persist even after we take factors like earnings into account. For example, **Figure 2** compares remaining life expectancy with and without disabilities from age 51 for Black and White people (Hispanic people not shown) in the lowest, middle, and top family lifetime earnings quintiles. On average, Black people in the bottom earnings quintile can expect to have almost a year less disability-free life than White people in the same group. This gap between White people and Black people in remaining disability-free life expectancy grows to 1.6 years for the middle earnings quintile and 2.9 years for top quintile. Although Black people with higher earnings receive boosts in total and health life expectancy relative to Black people with lower earnings, they can still expect to spend significantly larger shares of late-life with disabilities than White people in each earning quintile. This is consistent with a broader literature on diminished returns (or non-equivalence) of socioeconomic status for Black and Hispanic people.<sup>15,16,17</sup>

## Figure 2. Remaining Life Expectancy with and without Disability after Age 50 by Race/Hispanic Origin and Lifetime Earnings Quintile, People Born between 1960 and 1964

Differences in disabled and non-disabled life expectancy by race persist within some earnings groups, with especially large differences in non-disabled life expectancy between Black people and White people in the highest lifetime earnings quintile



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample includes people who survive until at least age 51. Sample excludes people who report Hispanic origin and unauthorized immigrants. “ADL disability” indicates a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that one is unable to perform due to a condition that is expected to last at least 90 days or need. “SCI” indicates severe cognitive impairment for which one requires substantial supervision due to health or safety threats. People with mild disabilities report difficulty with at least 1 ADL, instrumental ADL, or mild cognitive impairment. People with “no disability” report none of the enumerated disabilities. The White and Black categories exclude people of Hispanic origin.

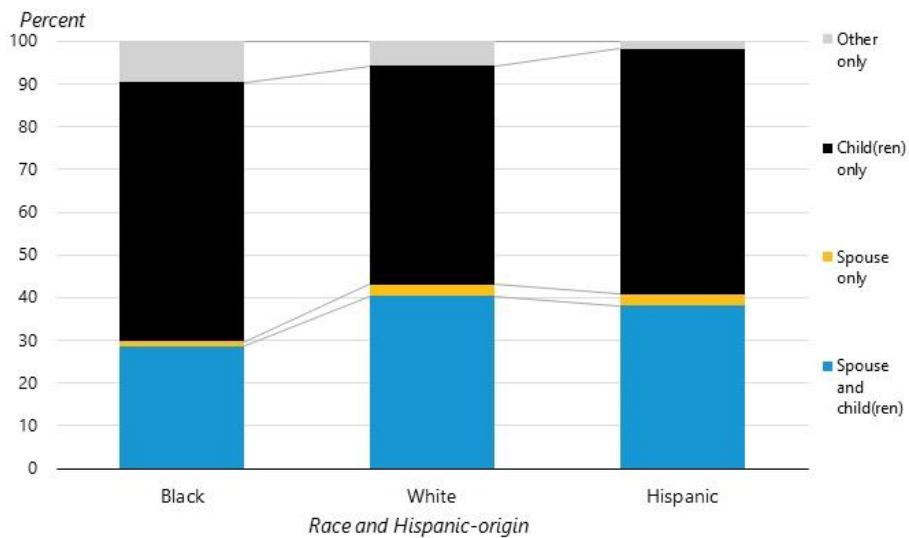
## DIVERSITY IN POTENTIAL CARE NETWORKS

Older adults have different networks to which they can turn when they become disabled and need care. As we consider family caregivers’ contributions, it is helpful to distinguish between two separate concepts: one’s *potential* care network and one’s *actual* care network. We define one’s potential network based on whether a person has a living spouse or partner or any living children and classify people into four potential care network categories: Spouse and child, spouse only, child only, and others only. A person’s actual care network is made up of the people who provide at least some care over the course of the year. More categories are needed to define actual networks than potential networks, as many care partner combinations are possible (for example, spouse only, spouse and child, child and other, child only, spouse and other, and other only). As we have shown in prior research,<sup>18</sup> care networks can be quite diverse. Although children and especially spouses tend to be the most intensive caregivers, all types of friends and family—including siblings, nieces and nephews, in-laws, ex-spouses, and grandchildren—often step in to help people with LTSS needs.

One of the most common sources of care are spouses. Spouses tended to provide more hours of care than other care partners.<sup>18</sup> Yet the presence of a potential spousal caregiver varies by disability status, race and Hispanic origin, and sex of the care recipient. Among those ages 51 and older, people with significant LTSS needs are less likely than other people to have a spouse in their potential network.<sup>iii</sup> This largely reflects the higher average age for people with disabilities; with age, more once-married older adults become widowed. Also, Black people are less likely than White and Hispanic people to have a spouse in their potential caregiving network, in part due to lower marriage rates and higher rates of widow(er)hood among those who marry.<sup>2</sup>

**Figure 3. Distribution of Potential Care Networks by Race-Hispanic Origin, People with Significant LTSS Needs**

*Black people with significant LTSS needs are less likely to have spouses in their care networks*



SOURCE: Urban Institute estimates from 2016 HRS. Sample is people age 51 and older.

NOTES: The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. The term “spouse” includes legal spouses and also unmarried co-residents who identify as partners. The White and Black categories exclude people of Hispanic origin.

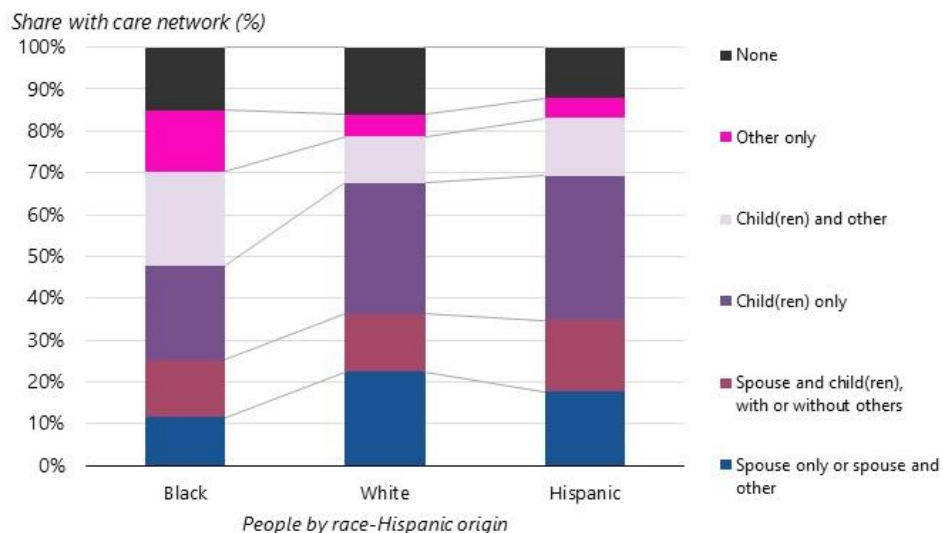
## DIVERSITY IN ACTUAL CARE NETWORKS

People with spouses, children or other potential caregivers may not necessarily receive care from them and may instead, for example, rely on paid help. However, differences in the potential network of caregivers translate into observed differences in actual caregiving networks.

People who have significant LTSS needs and are White or Hispanic are more likely to receive spousal care than people who are Black (**Figure 4**). Black people with significant needs are more likely to rely on children as caregivers and others exclusively compared to White people, and to a lesser extent Hispanic people.

**Figure 4. Distribution of Actual Care Networks by Race-Hispanic Origin, People with Significant LTSS Needs**

*Black people are less likely to have a spouse and more likely to have no care providers or people other than a spouse in their care provider networks*



SOURCE: Urban Institute estimates from 2016 HRS.

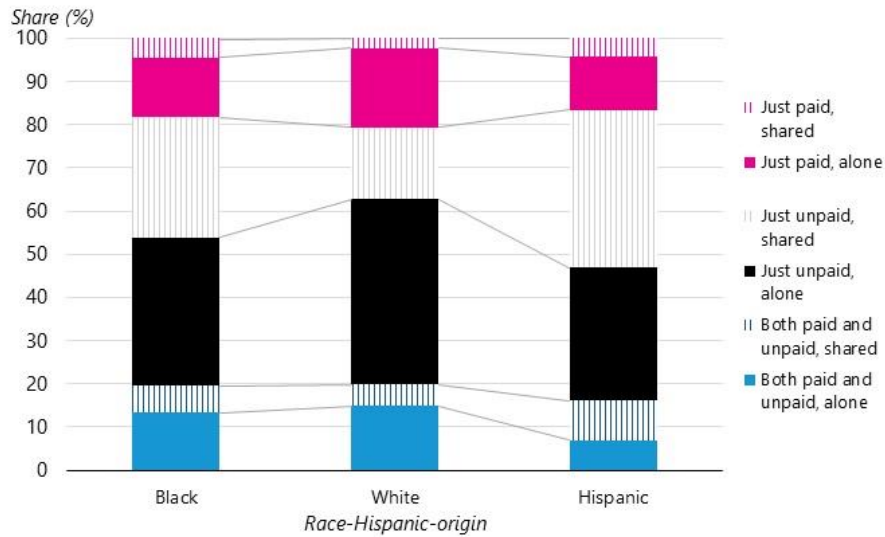
NOTES: Sample includes people ages 51 and older reporting significant LTSS needs. “Significant LTSS needs” indicates a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that one is unable to perform due to a condition that is expected to last at least 90 days or need for substantial supervision for health and safety threats due to SCI. People with less severe disabilities report difficulty with at least 1 ADL, instrumental ADL, or mild cognitive impairment. The term “spouse” includes legal spouses and also unmarried co-residents who identify as partners. The White and Black categories exclude people of Hispanic origin.

## DIVERSITY IN CO-RESIDENCE

An important component of care for older adults with disabilities is co-residence. For many people, moving in with family is an economical care option. Financial and caregiving reasons are most often cited as the reason for co-residence.<sup>19</sup> Variations in socioeconomic status, immigration, marriage patterns and health status are reasons that Blacks and Hispanics are more likely to co-reside. Other reasons may include feelings of altruism, social norms and obligations which vary among ethnic groups.<sup>20</sup> Among older people who receive some care, Black, and especially Hispanic, people are more likely than White people to share a residence with someone other than a spouse and receive only unpaid care (**Figure 5**). Importantly, co-residence varies by race and Hispanic origin at all ages, not just among older adults.<sup>iv,21,22</sup>

**Figure 5. Distribution of Actual Joint Care Choices among People Receiving Care, by Race-Ethnicity**

*Both Hispanic people and Black people are more likely to live with extended family*



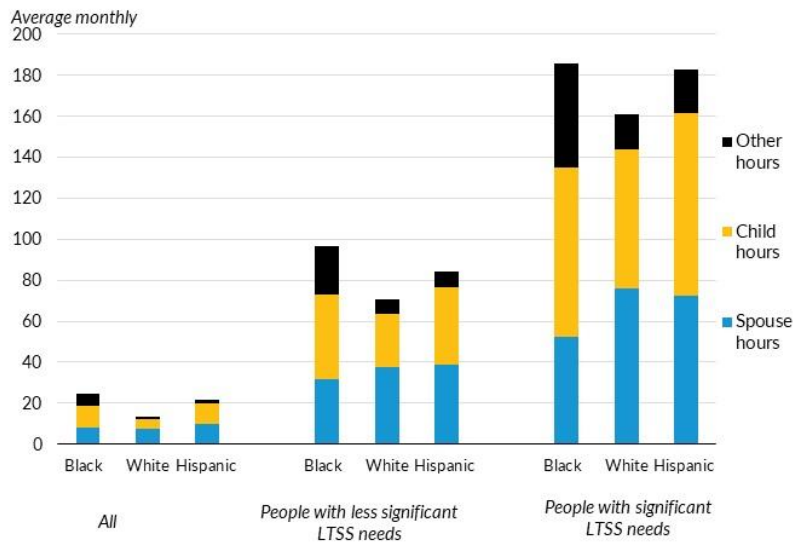
SOURCE: Urban Institute estimates from 2016 HRS.

NOTES: Sample includes people ages 51 and older reporting use of care. “Alone” indicates that a person is living by him/herself or only with a spouse or partner. “Shared” indicates that a person is living with at least 1 person other than a spouse/partner. The White and Black categories exclude people of Hispanic origin.

## INTENSITY OF CARE RECEIVED

**Figure 6. Average Hours of Unpaid Care by Relationship, Disability Severity, and Race-Ethnicity**

*Although the average amount of unpaid care hours is similar across groups, their compositions differs, with Black people receiving more care from people other than a spouse or child than others*



SOURCE: Urban Institute estimates from 2016 and 2018 HRS.

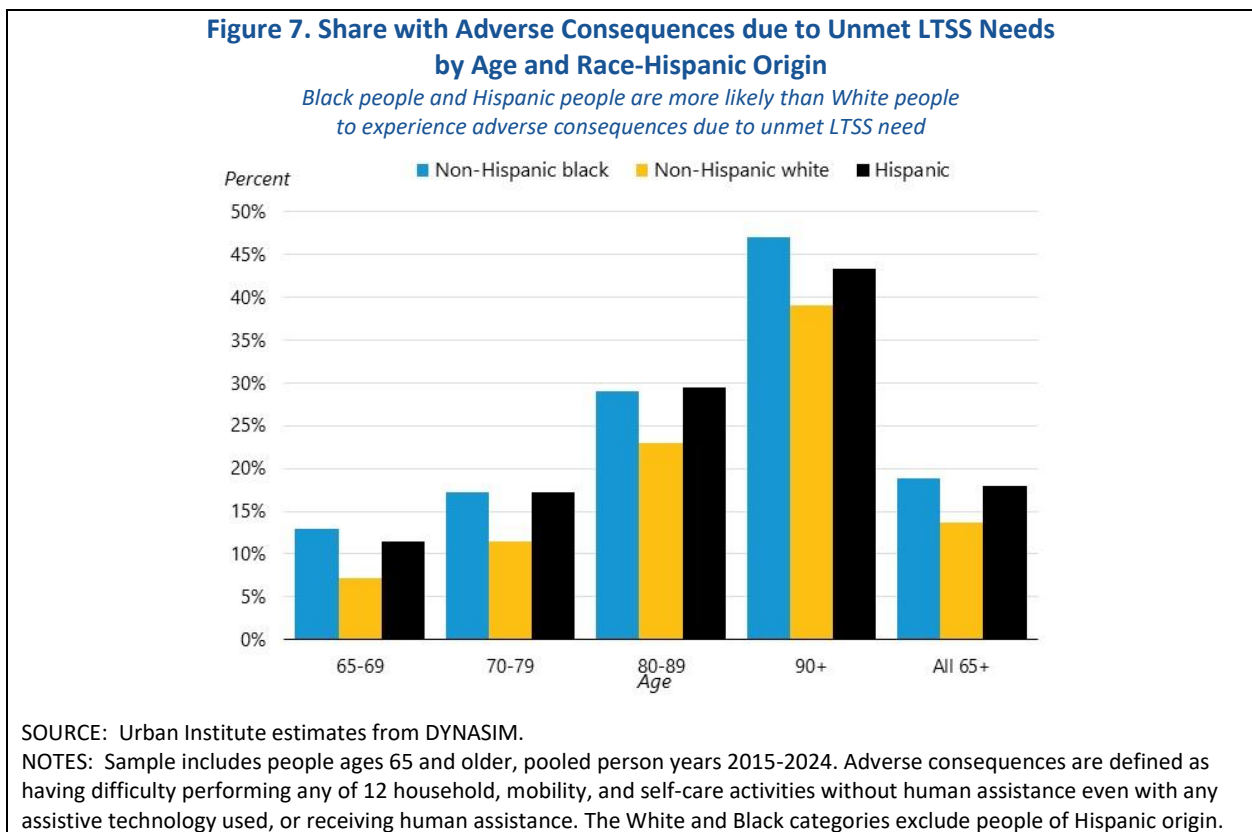
NOTES: “Significant LTSS need” indicates a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that one is unable to perform due to a condition that is expected to last at least 90 days or need for substantial supervision for health and safety threats due to SCI. People with less significant LTSS needs report difficulty with at least 1 ADL, instrumental ADL, or mild cognitive impairment. The White and Black categories exclude people of Hispanic origin.



The amount of care that older adults receive depends on the severity of their functional limitations and the composition of their networks (**Figure 6**). Regardless of disability level, estimates from the HRS suggest that Black and Hispanic older adults receive more hours of unpaid care than White older adults. One likely contributor to these differences is that people who are White are more likely to use assisted living than others.<sup>23</sup> Levels of care provided by children and people other than spouses and children (e.g., siblings, grandchildren) are higher, especially for Black older adults.

## ADVERSE CONSEQUENCES OF UNMET NEED

Black people and people of Hispanic origin are more likely to report adverse consequences from unmet need, especially relative to White people at younger ages (**Figure 7**). Although caregivers often devote extensive energies to helping older adults with disabilities, many older adults with disabilities experience adverse consequences because not all of their LTSS needs are met. In defining adverse consequences, we include such events as going without a hot meal, clean laundry, or shopping for needed items, being unable to go outside the home, get out of bed, bathe, or dress, or having a toilet accident. Even after accounting for age, the likelihood of experiencing adverse consequences differs depending on race/Hispanic origin.



## DISCUSSION

As the large cohorts of baby boomers reach ages when LTSS needs grow rapidly, their family caregivers may face increasingly difficult choices about how to combine paid and unpaid care. These choices differ across racial/ethnic groups, with people who are Black and Hispanic needing care earlier and for longer periods. Care networks, care providers, strategies for care delivery, and care outcomes vary by race/Hispanic origin. While Black people and Hispanic people have higher LTSS needs and receive more unpaid care, their care networks may have more challenges in fully meeting their needs relative to White people. Black people and Hispanic



people are more likely to co-reside and rely on children than others, and more likely to report unmet LTSS needs.

In three companion briefs, we discuss the economic value of the unpaid care that family and friends provide,<sup>24</sup> how care use changes over the course of a disability,<sup>25</sup> and how care needs and networks are likely to change in coming decades.<sup>26</sup>

## ADDITIONAL METHODOLOGICAL INFORMATION

For information about DYNASIM, see Favreault and Johnson.<sup>3</sup> The specific release of the model that we use is runid 981, which incorporates economic and demographic assumptions from an interim baseline produced by Social Security's Office of the Chief Actuary.<sup>24</sup>

## ENDNOTES

- i. The HRS is a nationally representative longitudinal study of adults ages 51 and older. It oversamples Black and Hispanic people.
- ii. Our estimates by race and ethnicity focus on three groups: White people, Black people, and Hispanic people of any race. The analyses here omit non-Hispanic people of other races, including Asian-Americans, Pacific Islanders, Native Americans, Alaska Natives, and others. We do not present estimates here due to data limitations within the HRS.
- iii. We define significant LTSS need as a level of impairment consistent with the definition specified in the Health Insurance Portability and Accountability Act of 1996 for long-term care insurance plans that qualify for tax preferences. Specifically, one must need assistance with at least two activities of daily living (ADLs) among eating, toileting, transferring, bathing, dressing, and continence that one is unable to perform due to a condition that is expected to last at least 90 days or need substantial supervision for health and safety threats due to severe cognitive impairment (SCI). This disability threshold does not count limitations in performing ADLs that can be resolved with special equipment (e.g., wheelchairs, walkers, handrails, ramps, catheters, and related devices).
- iv. For example, Britton (2013) describes significant differences by race in prevalence of living with parents during young adulthood, with non-White young adults more likely to live with parents through their twenties, more likely to return to the parental home after college, and less likely to leave after returning. He finds that differences are largely explained by marital status and socioeconomic factors, and less by differences in attitudes. Reyes, Schoeni, and Choi (2020) point to differences in co-residence with mother and geographic distance to mothers by race and ethnicity, finding that they are largely driven by demographic factors, like marital status and immigration, and socioeconomic status, though health is also a factor.

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