REPORT:

Disparities in LTSS Needs and Supportive Resources at Age 55, and Outcome Disparities During the Next Decade

December 2023

Acknowledgment

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KEY TAKEAWAYS

→ Among individuals aged 55 and living in a community setting in the U.S., Black individuals experienced long-term services and supports (LTSS) needs 114% more often than white individuals, while Hispanic individuals experienced LTSS needs 72% more often than white individuals. Individuals living in rural counties experienced LTSS needs 23% more often than individuals in urban counties.¹

→ Using longitudinal survey data, we identified disparities and differences in resources (finances, insurance, and social supports) and long-term outcomes among individuals experiencing LTSS needs at age 55 and as they approached age 65, by race and ethnicity, gender, and geography, including:
  
  o **Private Financial Resources (including assets and income):** Black individuals and Hispanic/Latino individuals, women, and individuals living in rural counties had fewer private financial resources than white individuals, men, and individuals living in urban counties.

  o **Health Insurance Coverage:** Black individuals and Hispanic/Latino individuals had health insurance coverage less often than white individuals, though Black individuals and Hispanic/Latino individuals were more likely to gain Medicaid coverage over the subsequent ten years when compared to white individuals.

  o **Social Supports:** Black individuals, women, and individuals living in rural counties had fewer social supports than white individuals, men, and individuals living in urban counties.²

  o **Cognitive Decline:** Black individuals and Hispanic/Latino individuals experienced higher rates of cognitive decline in the decade after 55, compared to white individuals.

  o **Asset Change:** Black individuals experienced high rates of total asset loss in the decade after age 55, compared to white individuals.³

→ States and the federal government may consider policy and programmatic opportunities such as providing financial counseling, structuring caregiver programs toward improving social supports, and expanding access to LTSS coverage. (See Conclusion and Policy and Program Recommendations.)

Background and Study Purpose

In this report, we examine disparities and differences in the prevalence of LTSS needs among individuals aged 55 living in a community setting in the U.S., along with resources for accessing support, and outcomes among those experiencing LTSS needs. LTSS encompass the supports that are needed by individuals experiencing difficulty with activities of daily living, self-care, and disease management; in 2020, an estimated 7.7 million individuals used LTSS in the U.S. LTSS can be offered in an institutional setting or in the community, and include paid and unpaid personal care assistance, such as help with bathing, dressing, and homemaking, as well as making meals and taking medications. We use longitudinal data from the Health and Retirement Study to explore LTSS needs among the study population.

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¹ When we describe results, including individuals’ experiences, we are referring to responses reported through surveys administered by the Health and Retirement Study.

² Social supports include living arrangements (living with others and specifically living with a spouse or partner) and family structure (being in contact with children).

³ Total assets include housing and real estate, investments, savings, and debts.
Individuals’ access to LTSS can be constrained by the cost of these services; one year of LTSS in the home or facility settings typically cost $59,000 to $108,000 in 2021, far above the U.S. median income ($38,000). Medicaid is the most common source of LTSS coverage, but Medicaid is a means-tested program and is mostly limited to individuals who have low incomes and asset levels. Challenges associated with gaining Medicaid coverage, including the often time-consuming application process and the complicated asset test, can also make it difficult even for individuals who qualify for Medicaid to enroll in Medicaid. Some individuals experiencing high-cost LTSS needs who do not initially have low asset levels enter Medicaid after depleting their savings. Disparities in resources and outcomes among individuals experiencing LTSS needs may also have long-term intergenerational effects that can disproportionately affect people of color. LTSS costs can deplete an individual’s assets, resulting in a diminished estate value inherited by children and heirs. Additionally, gaining Medicaid coverage for LTSS can invoke estate recovery after an individual’s death, which can require heirs to transfer any remaining assets to the state, including the home of the recently deceased individual who received Medicaid LTSS benefits.

At the same time, unpaid caregivers, including family and friends, provide the majority of LTSS nationwide to individuals experiencing LTSS needs, given the high cost of LTSS and the desire among individuals to stay in their homes. Social supports also offer protection from loneliness and related health risk. Studies have validated the link between feelings of loneliness and poor outcomes including institutionalization and premature death. Specific to adults under age 65 living with disabilities, an international study found higher rates of loneliness among individuals living alone compared to those living with other people. Individuals who cannot access paid or unpaid LTSS due to financial constraints or a lack of social supports often go with their LTSS needs unmet. Individuals with unmet LTSS needs have higher mortality rates, after adjusting for demographic traits and health status.

Evidence indicates inequities in the prevalence of LTSS needs and in access to and utilization of LTSS, but much of this evidence focuses on older adults over the age of 65. Prior research has established that Black, Hispanic/Latino, and female individuals disproportionately experience LTSS needs. Disparities in LTSS access and utilization can result in poorer health outcomes for marginalized populations, such as higher rates of hospital admissions.

Research on individuals experiencing LTSS needs predominantly focuses on older adults; data on LTSS needs among individuals younger than 65 is limited. This report aims to address that gap by focusing on individuals aged 55 experiencing LTSS needs. At this age, many individuals experiencing LTSS needs have experienced disabilities throughout their lives. In these cases, decades-long periods of LTSS needs have the potential to strain financial resources, limit employment opportunities, and restrict individuals’ ability to manage chronic conditions. Past research on LTSS needs in this younger age group, though limited, suggests that their LTSS needs go unmet more often compared to older adults, and

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4 See also ATI Advisory’s “Blueprint for Reforming Medicaid Long-Term Services and Supports and Creating Good Caregiving Jobs,” for more on Medicaid program design changes that could improve equitable access to high-quality in Medicaid LTSS.
that financial strains were a greater barrier for individuals younger than 65 accessing LTSS needs than for older adults.\textsuperscript{xix}

Additionally, individuals younger than 65 experiencing LTSS needs are distinct from those older than 65 in that most individuals younger than 65 receive their LTSS in the community.\textsuperscript{xxi}

In this data report, we use the Health and Retirement Study to analyze demographic inequities in the prevalence of LTSS needs and related resources among U.S. adults aged 55 and living in the community, including racial and ethnic disparities. We examine disparities and differences in private finances, insurance coverage, and social supports as resources for accessing LTSS, and we analyze health, LTSS, and financial outcomes over the next decade. We provide evidence on the disparities that exist among individuals younger than 65 experiencing LTSS needs in terms of access to resources and long-term outcomes, which can inform future policy and programs tailored to these populations.

**Methods**

This report shows the demographics and resources of individuals aged 55 in the U.S., and then analyzes outcomes experienced by those individuals over the next 10 years of their lives. We analyze data from the University of Michigan Health and Retirement Study (HRS), a longitudinal survey of adults in the U.S. older than 50, and we include respondents who did not live in an institutional setting at age 55.\textsuperscript{v}

We analyze data from 6,232 respondents who were surveyed at age 55 during the period 2008–2018 for the point-in-time prevalence, demographic, and resources sections. For the outcomes analysis, we analyze 10 years of longitudinal data from 594 respondents who participated in surveys starting at age 55 during the period 2002–2008 (using follow-up data from interviews through 2018).

Respondents are identified as experiencing LTSS needs if they experienced at least one of the following disabilities: difficulty with any late-loss activities of daily living (ADLs);\textsuperscript{vi} difficulty with all four instrumental activities of daily living (IADLs) related to executive functioning; and having any ADL or IADL difficulty while experiencing cognitive impairment or living with intellectual or developmental disability. This inclusive definition of LTSS needs is meant to represent a variety of conditions that characterize non-aging related LTSS needs experienced by individuals approaching age 65. For more details on methods and key definitions, please refer to the Appendix.

\textsuperscript{v} Respondents included in this study are surveyed after their 55th birthday and before turning 57. A respondent could be age 56 at the soonest survey after their 55th birthday because the HRS interviews are conducted every two years. Ten years of follow-up interviews provide outcomes data used in this report.

\textsuperscript{vi} Late-loss ADLs are defined as bed mobility, transferring, toileting, and eating in this report. See “MDS 3.0 Quality Measures User’s Manual - v7.0,” Centers for Medicare & Medicaid Services, April 2013, p. 35.
Results

PREVALENCE OF LTSS NEEDS AND DEMOGRAPHIC PROFILE OF INDIVIDUALS EXPERIENCING LTSS NEEDS

Analyzed population: individuals in the U.S. who lived in the community when they turned age 55 from 2008 through 2018.

Overall, 15% of individuals aged 55 experienced LTSS needs, reflecting limitations in daily living due to functional or cognitive impairment, or intellectual or developmental disability. Significant disparities in LTSS needs existed by race and ethnicity, as well as by geography. These disparities are shown in Figure 1, with brackets indicating group-to-group comparisons that are statistically significant. Black individuals experienced LTSS needs 114% more often than white individuals, and Hispanic/Latino individuals 72% more often white individuals. Black individuals and Hispanic/Latino individuals therefore more likely experienced challenges associated with needing LTSS, such as difficulty managing chronic conditions.

LTSS needs prevalence differed by geography as well: individuals in rural counties experienced LTSS needs 23% more often than individuals in urban counties. Individuals in rural areas may face distinct challenges in accessing health care and LTSS, such as long travel times to care. The prevalence of LTSS needs did not vary significantly by gender or sexual orientation.

Figure 1. Prevalence of LTSS Needs, by Race and Ethnicity and by Geography, among Individuals Aged 55 in the U.S.8

Note: The Health and Retirement Survey data includes an “Other” race category that includes Asian, American Indian and Alaska Native, Middle Eastern and Northern Africa, and Native Hawaiian and Pacific Islander individuals. This report’s disparity analyses exclude this category because it is difficult to interpret comparisons involving an aggregated group that includes so many racial and ethnic identities.

8 Brackets in figures mark statistically significant differences between groups at the 5% level.
We also analyzed how the demographic profile of individuals experiencing LTSS needs differed from those without LTSS needs, shown in Table 1. The racial and ethnic composition of individuals experiencing LTSS needs differed significantly from the individuals without LTSS needs (additional graphical representation in Figure 2). Black individuals and Hispanic/Latino individuals made up a 96% and 48% larger share, respectively, of individuals experiencing LTSS needs compared to those without LTSS needs. White individuals, while still a majority, made up a 23% smaller share of individuals experiencing LTSS needs compared to those without LTSS needs. Past analyses specific to individuals with Medicare (of all ages) also found demographic differences between individuals experiencing LTSS needs compared to other individuals.\textsuperscript{xiii}

Additionally, a 20% higher share of individuals experiencing LTSS needs lived in rural areas compared to those without LTSS needs. Individuals experiencing LTSS needs and those without LTSS needs did not differ by gender or sexual orientation.

### Table 1. Demographic Profile of Individuals Aged 55 in the U.S. Experiencing LTSS Needs Compared to Those Without LTSS Needs\textsuperscript{9}

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Individuals Experiencing LTSS Needs</th>
<th>Individuals Without LTSS Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENDER</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>45%</td>
<td>49%</td>
</tr>
<tr>
<td>Women</td>
<td>55%</td>
<td>51%</td>
</tr>
<tr>
<td><strong>RACE AND ETHNICITY</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>19%*</td>
<td>10%*</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>15%*</td>
<td>10%*</td>
</tr>
<tr>
<td>Other Race/Ethnicity</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>White</td>
<td>57%*</td>
<td>73%*</td>
</tr>
<tr>
<td><strong>SEXUAL ORIENTATION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LGBTQ+</td>
<td>7%</td>
<td>4%</td>
</tr>
<tr>
<td>Straight</td>
<td>93%</td>
<td>96%</td>
</tr>
<tr>
<td><strong>GEOGRAPHY</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>28%*</td>
<td>24%*</td>
</tr>
<tr>
<td>Urban</td>
<td>72%*</td>
<td>76%*</td>
</tr>
</tbody>
</table>

\textsuperscript{9} Asterisks in tables and figures mark statistically significant differences between individuals experiencing LTSS needs and individuals without LTSS needs.
Figure 2. Racial and Ethnic Composition of Individuals Aged 55 in the U.S. Experiencing LTSS Needs Compared to Those Without LTSS Needs

As shown in Table 2, individuals experiencing LTSS needs were under-resourced in terms of private finances, insurance coverage, and social supports compared to those without LTSS needs. For example, individuals experiencing LTSS needs had less than half (38%) the annual median income, had 12% the median total assets, and had paid employment 58% less often, compared to individuals without LTSS needs.

Asterisks in tables and figures mark statistically significant differences between individuals experiencing LTSS needs and individuals without LTSS needs.
Table 2. Resources of Individuals Aged 55 in the U.S. Experiencing LTSS Needs Compared to Those Without LTSS Needs

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Individuals Experiencing LTSS Needs</th>
<th>Individuals Without LTSS Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PRIVATE FINANCES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual Household Income (Median)</td>
<td>$30,120*</td>
<td>$80,198*</td>
</tr>
<tr>
<td>Total Assets</td>
<td>$20,500*</td>
<td>$174,500*</td>
</tr>
<tr>
<td>Non-Housing Assets</td>
<td>$3,000*</td>
<td>$53,000*</td>
</tr>
<tr>
<td><strong>EMPLOYMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Employed</td>
<td>66%*</td>
<td>19%*</td>
</tr>
<tr>
<td>Employed</td>
<td>34%*</td>
<td>81%*</td>
</tr>
<tr>
<td><strong>INSURANCE COVERAGE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any Health Insurance</td>
<td>83%</td>
<td>87%</td>
</tr>
<tr>
<td>Medicare</td>
<td>32%*</td>
<td>4%*</td>
</tr>
<tr>
<td>Any LTSS Coverage</td>
<td>35%*</td>
<td>15%*</td>
</tr>
<tr>
<td>Medicaid</td>
<td>27%*</td>
<td>5%*</td>
</tr>
<tr>
<td><strong>SOCIAL SUPPORTS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lived Alone</td>
<td>21%*</td>
<td>15%*</td>
</tr>
<tr>
<td>Lived with Three or More People</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Partner in Home</td>
<td>57%*</td>
<td>72%*</td>
</tr>
<tr>
<td>Living Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>Three or More</td>
<td>48%</td>
<td>42%</td>
</tr>
</tbody>
</table>

Asterisks in tables mark statistically significant differences between individuals experiencing LTSS needs and individuals without LTSS needs.
RESOURCE DISPARITIES AMONG INDIVIDUALS EXPERIENCING LTSS NEEDS

Analyzed population: individuals in the U.S. who experienced LTSS needs and lived in the community when they turned age 55 from 2008 through 2018.

Among individuals experiencing LTSS needs, we noted disparities and differences when comparing resources by race and ethnicity, gender, and geography. Resources can influence whether individuals experiencing LTSS needs have access to LTSS.

Private Finances

Private financial resources, such as household income and assets, contribute to an individual’s ability to pay for LTSS, particularly when an individual lacks coverage through Medicaid. In addition, an individual’s disability and health challenges can compound existing financial strain through higher medical costs and reduced employment opportunities.

Private financial resources differed substantially between racial and ethnic groups among individuals experiencing LTSS needs. Black individuals and Hispanic/Latino individuals typically had significantly fewer private financial resources compared to white individuals (Figures 3 and 4). When compared to white individuals, Black individuals typically had approximately half the annual income ($21,450 vs $39,165), 9% of the total assets ($4,000 vs $45,800), and 5% of the non-housing assets ($500 vs $9,800).

Similarly, Hispanic/Latino individuals had comparatively fewer private financial resources than white individuals. Compared to white individuals, Hispanic/Latino individuals typically had several hundred times fewer non-housing assets ($25 vs $9,800). Black individuals and Hispanic/Latino individuals typically had no ($0) housing wealth, defined as the net value of their primary residence, whereas white individuals typically held $20,000 of housing wealth. Employment rates also differed meaningfully by race and ethnicity; employment can directly affect income and future assets. Black individuals had paid employment 27% less often than white or Hispanic/Latino individuals (Figure 5).

Private financial resources also differed significantly by gender and geography (Figure 6). Among individuals experiencing LTSS needs, women had fewer total assets than men ($13,000 vs $32,000). Additionally, women typically held no housing wealth ($0), while men typically held $20,000 in housing wealth. Individuals living in rural counties had a 35% lower annual income than individuals living in urban counties ($22,822 vs $35,052).
Figure 3. Income among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity

![Income Chart](chart.png)

Figure 4. Assets among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity

![Assets Chart](chart.png)

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13 Figures show analyses with statistically significant relationship comparisons, as discussed in the text of this report.

14 Housing wealth and non-housing assets sum to total assets, but the median total assets do not equal the sum of the median housing wealth and median non-housing assets because medians are not additive.

15 Brackets in figures mark statistically significant differences between groups at the 5% level.
Figure 5. Employment Rate of Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity

![Employment Rate Chart]

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Employment Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>26%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>35%</td>
</tr>
<tr>
<td>White</td>
<td>36%</td>
</tr>
</tbody>
</table>

Brackets in figures mark statistically significant differences between groups at the 5% level.

Figure 6. Total Assets and Housing Wealth by Gender, and Income by Geography, among Individuals Aged 55 in the U.S. Experiencing LTSS Needs

![Income and Assets Chart]

<table>
<thead>
<tr>
<th>Gender</th>
<th>Media Total Assets</th>
<th>Median Housing Wealth</th>
<th>Median Annual Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>$13k</td>
<td>$0k</td>
<td>$23k</td>
</tr>
<tr>
<td>Men</td>
<td>$32k</td>
<td>$20k</td>
<td>$35k</td>
</tr>
<tr>
<td>Rural</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Brackets in figures mark statistically significant differences between groups at the 5% level.
Insurance Coverage

Health insurance and LTSS coverage can provide financial protection against the costs of medical care and LTSS. We define health insurance as having any form of health insurance reported in the HRS excluding private long-term care insurance. This definition includes commercial, employer group, Veterans Affairs, military, Medicare, and Medicaid health insurance, as well as other private and public health insurance. In addition to providing a measure of financial protection to individuals experiencing LTSS needs, health benefits usually include short-term coverage for services similar to LTSS when deemed medically necessary after hospitalization. We define having LTSS coverage as having either Medicaid, private long-term care insurance, or Veterans Affairs (VA) insurance. Medicaid is the most common source of third-party insurance for LTSS in the U.S.\textsuperscript{iv}

Health insurance coverage was 8% lower among Black individuals and 21% lower among Hispanic/Latino individuals than among white individuals. However, 49% more Black individuals had LTSS coverage than white individuals (Figure 7), largely driven by higher Medicaid enrollment among Black individuals than white individuals. Hispanic/Latino individuals had LTSS coverage approximately as often as white individuals and 25% less often than Black individuals. Medicaid enrollment patterns shifted during the study period, as some states expanded Medicaid eligibility under the Affordable Care Act beginning in 2014.

Health insurance coverage and potential LTSS coverage differences by gender and geography were not statistically different.

Figure 7. Health Insurance Coverage and LTSS Coverage (Including Medicaid) among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity\textsuperscript{17}

<table>
<thead>
<tr>
<th>Category</th>
<th>Black</th>
<th>Hispanic/Latino</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Health Insurance</td>
<td>80%</td>
<td>69%</td>
<td>88%</td>
</tr>
<tr>
<td>Any LTSS Coverage</td>
<td>46%</td>
<td>34%</td>
<td>31%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>35%</td>
<td>31%</td>
<td>23%</td>
</tr>
</tbody>
</table>

Brackets in figures mark statistically significant differences between groups at the 5% level.
Social Supports

The presence of other people living in the home can help individuals experiencing LTSS needs live in the community without depending entirely on paid professional LTSS for support. Home-based social supports can provide individuals experiencing LTSS needs with a source of caregiving, safety, and supervision when managing LTSS needs in the home. Social supports outside the home, including an individual’s children, are also a potential source of care or financial resources for an individual experiencing LTSS needs.¹⁴

Social supports differed significantly by race and ethnicity among individuals with LTSS needs (Figure 8). Social supports were more common among Hispanic/Latino individuals than other racial and ethnic groups, with Hispanic/Latino individuals living with a partner 68% more often than Black individuals and living with at least three other people 153% more often than white individuals. Additionally, Hispanic/Latino individuals had three or more living children 56% more often than white individuals. Black individuals had fewer home-based social supports than white individuals: compared to white individuals, Black individuals lived alone 31% more often and lived with a partner 37% less often, though Black individuals had at least three living children 38% more often.

We also noted differences in home-based social supports by gender and geography (Figure 9). When compared to men, women experiencing LTSS needs lived with a partner 23% less often. Additionally, individuals living in rural counties lived with at least three other people in the home 47% less often than individuals living in urban counties.

Figure 8. Social Supports among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity¹⁸

<table>
<thead>
<tr>
<th>Social Supports</th>
<th>Black</th>
<th>Hispanic/Latino</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived with 3+ People</td>
<td>19%</td>
<td>39%</td>
<td>15%</td>
</tr>
<tr>
<td>Lived with Partner</td>
<td>26%</td>
<td>39%</td>
<td>61%</td>
</tr>
<tr>
<td>Lived Alone</td>
<td>14%</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>3+ Living Children</td>
<td>41%</td>
<td>56%</td>
<td>64%</td>
</tr>
</tbody>
</table>

18 Brackets in figures mark statistically significant differences between groups at the 5% level.
Figure 9. Social Supports among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Gender and Geography

19 Brackets in figures mark statistically significant differences between groups at the 5% level.
DIFFERENCES IN HEALTH, LTSS, AND FINANCIAL OUTCOMES OVER A 10-YEAR SPAN FOR INDIVIDUALS EXPERIENCING LTSS NEEDS COMPARED TO ALL OTHER INDIVIDUALS

Analyzed population: individuals in the U.S. who lived in the community when they turned age 55 between 2002 and 2008, followed over the next 10 years.

Individuals experiencing LTSS needs at age 55 fared worse over the subsequent decade in terms of their health status, LTSS needs, and financial status compared to adults without LTSS needs at age 55 (Table 3).20 Individuals experiencing LTSS needs had a net loss of 9% of their wealth, compared to a net gain of wealth by 15% among those without LTSS needs.

Table 3. Ten-Year Health, LTSS, and Financial Outcomes among Individuals Experiencing LTSS Needs Aged 55 in the U.S. Compared to Those Without LTSS Needs21

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Individuals Experiencing LTSS Needs</th>
<th>Individuals Without LTSS Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mortality</td>
<td>19%*</td>
<td>6%*</td>
</tr>
<tr>
<td>Hospital Admissions per 1,000 Person-Years</td>
<td>430</td>
<td>147</td>
</tr>
<tr>
<td>LTSS Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Impairment Decline</td>
<td>5%*</td>
<td>2%*</td>
</tr>
<tr>
<td>ADL Functional Decline</td>
<td>14%*</td>
<td>9%*</td>
</tr>
<tr>
<td>Nursing Facility Entry</td>
<td>4%*</td>
<td>1%*</td>
</tr>
<tr>
<td>Financial Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change in Total Assets</td>
<td>-9%*</td>
<td>+15%*</td>
</tr>
<tr>
<td>Change in Annual Household Income</td>
<td>-1%*</td>
<td>0%*</td>
</tr>
<tr>
<td>Medicaid Entry</td>
<td>16%*</td>
<td>6%*</td>
</tr>
</tbody>
</table>

20 All analyses include decedents, treating their death as the end of the outcomes period.
21 Asterisks in tables mark statistically significant differences between individuals experiencing LTSS needs and individuals without LTSS needs.
HEALTH, LTSS, AND FINANCIAL OUTCOMES OVER A 10-YEAR SPAN FOR INDIVIDUALS EXPERIENCING LTSS NEEDS

Analyzed population: individuals in the U.S. who experienced LTSS needs and lived in the community when they turned age 55 between 2002 and 2008, followed over the next 10 years.

Significant disparities and differences exist when comparing outcomes among individuals experiencing LTSS needs by race and ethnicity, gender, and geography.

Health Outcomes

Among those experiencing LTSS needs, Black individuals were 186% more likely, and white individuals 146% more likely, to die in the decade after the individuals turned 55 when compared to Hispanic/Latino individuals, a mortality rate for both Black and white individuals more than twice that of Hispanic/Latino individuals (Figure 10).

Even though white individuals experiencing LTSS needs had higher income, had more assets, and more often had health insurance, they died at higher rates in the decade after age 55 compared to Hispanic/Latino individuals. This validates and builds upon prior research that found that the Hispanic/Latino mortality advantage extends to individuals with disabilities.22

Mortality rates also differed meaningfully among individuals experiencing LTSS needs by gender. Women experiencing LTSS needs were 59% as likely to die between age 55 and 65 when compared to men experiencing LTSS needs (Figure 11). Mortality rates did not significantly differ by geography. Additionally, hospital admissions did not differ by race and ethnicity, gender, or geography.

Figure 10. Mortality among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity22

10-Year Mortality Rate After Age 55
Individuals Experiencing LTSS Needs, by Race and Ethnicity

- Black: 23%
- Hispanic/Latino: 8%
- White: 20%
Figure 11. Mortality among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Gender

LTSS Outcomes

Among outcomes related to LTSS needs and utilization, cognitive decline differed significantly by race and ethnicity (Figure 12). Black individuals and Hispanic/Latino individuals experienced 214% and 178% higher rates of cognitive decline compared to white individuals, respectively. Individuals were identified as having cognitive decline if they experienced cognitive impairment for the first time during the decade after age 55, or if they developed severe impairment (dementia) after starting with milder cognitive impairment (not dementia) in the same period.

However, we did not observe statistically significant differences in cognitive decline by gender or geography. Additionally, ADL functional decline and rates of nursing facility entry did not significantly differ by race and ethnicity, gender, or geography. It should be noted that prior research, using a full data set of assessments required in most US nursing facilities, has found that Black individuals make up a larger share of individuals who lived in nursing facilities at ages 50–64 compared to those at ages 65 and older.\textsuperscript{xxi}
Financial Outcomes

Significant disparities exist in changes in total assets among individuals experiencing LTSS needs by race and ethnicity (Figure 13). Black individuals experiencing LTSS needs typically lost 64% of their total assets between age 55 and 65, compared to white individuals who typically lost 3% of their total assets. Considering the median total assets for Black individuals at age 55 were already more than 10 times fewer than the median total assets for white individuals, the further 64% reduction in assets among Black individuals suggests these individuals typically approach age 65 with particularly limited financial resources.

Individuals experiencing LTSS needs living in a rural setting experienced no change in total assets compared to individuals living in an urban setting who experienced a loss of total assets by 21% (Figure 14). We did not observe statistically significant differences in total asset change by gender. Research suggests that individuals with lower incomes before age 65 more often face financial hardship during later years.²⁸

We also analyzed the rate at which individuals experiencing LTSS needs gained Medicaid coverage, by race and ethnicity, gender, and geography. Although there was no significant difference by gender or geography, Black individuals were 153% more likely to gain Medicaid coverage than white individuals and Hispanic/Latino individuals were 194% more likely (Figure 15). Gaining Medicaid coverage, while potentially expanding individuals’ access to medical care and LTSS, can indicate that those individuals are experiencing financial challenges.²⁹

No significant differences were observed in changes in income, whether compared by race and ethnicity, gender, or geography.
Figure 13. Change in Total Assets among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity

**Median Percent Change in Total Assets**
*Individuals Experiencing LTSS Needs, by Race and Ethnicity*

- **Black**: -64%
- **Hispanic/Latino**: -34%
- **White**: -3%

-70% -60% -50% -40% -30% -20% -10% 0% +10%

Figure 14. Change in Total Assets among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Geography

**Median Percent Change in Total Assets**
*Individuals Experiencing LTSS Needs, by Geography*

- **Rural**: -21%
- **Urban**: 0%

-25% -20% -15% -10% -5% 0% +5% +10%

24 Brackets in figures mark statistically significant differences between groups at the 5% level.
Figure 15. Medicaid Entry (Gaining Medicaid Coverage over Ten Years) among Individuals Experiencing LTSS Needs Aged 55 in the U.S., by Race and Ethnicity25,26

Analysis only includes individuals who lacked Medicaid at age 55.

Brackets in figures mark statistically significant differences between groups at the 5% level.

25 Analysis only includes individuals who lacked Medicaid at age 55.
26 Brackets in figures mark statistically significant differences between groups at the 5% level.
Conclusion and Policy and Program Recommendations

Our research highlights disparities and differences in the prevalence of LTSS needs at age 55, as well as the availability of resources (finances, insurance, and social supports) and the long-term outcomes among individuals experiencing LTSS needs. Disparities and differences occurred along racial and ethnic, gender, and geographic lines. Policymakers can leverage these findings to prioritize policies and programs that could yield long-term benefits among individuals with LTSS needs, particularly to improve equity in outcomes and LTSS access. Past work from ATI Advisory identified complex causes of LTSS access barriers and potential solutions to improve LTSS access. In “A Blueprint for Reforming Medicaid Long-Term Services and Supports and Creating Good Caregiving Jobs,” solutions include workforce investment and Medicaid LTSS eligibility modernization.

Building on these earlier findings and the findings presented in this report, the policy opportunities below have the potential to address disparities in the prevalence of LTSS needs, the availability of supportive resources, and outcomes. Additionally, policymakers can account for the distinct needs of the population younger than age 65 when considering these opportunities.

1 Promote policies that reduce disparities in financial resources.

This study found large disparities in financial resources and in wealth changes over time, which can negatively impact intergenerational wealth. New economic policies can address the racial and ethnic, gender-based, and geographic disparities in terms of access to income and wealth among individuals with LTSS needs – resources that can ultimately have a positive impact on long-term health. Policymakers can try to address these disparities by designing more progressive means testing for programs to increase access to LTSS, or through programs that provide employment supports and financial counseling, such as Medical-Financial Partnerships. Investments in educational opportunities and homeownership can also directly mitigate income and wealth disparities when serving individuals from communities that have experienced disadvantage.

Mitigating income and wealth disparities could be particularly meaningful among Black individuals experiencing LTSS needs, who experience asset depletion just prior to age 65, and for Hispanic/Latino individuals living longer lifespans with LTSS needs but with fewer financial resources and lower insurance coverage rates to afford supports.
Mitigate barriers to Medicaid LTSS insurance coverage.

Mitigating barriers to accessing Medicaid benefits would provide financial protection for individuals and families with the fewest private financial resources, which our analysis suggests disproportionately includes Black and Hispanic/Latino individuals, women, and individuals living in rural counties. These Medicaid access barriers may be administrative in nature, cause asset depletion during an individual’s life, or cause the loss of assets passed on after an individual’s death. One approach to reducing barriers to Medicaid access is for states to provide more funding to local entities, including community-based organizations, to help individuals understand and navigate the Medicaid enrollment process. Other approaches involve changing Medicaid eligibility and enrollment policy. For example, policymakers could consider expanding spousal impoverishment rules that protect household income and assets for families trying to qualify for Medicaid. In addition, California is phasing out Medicaid asset testing in 2024 for certain eligibility pathways and plans to invest $1.85 billion over five years to build capacity for local organizations with the objective of improving equity and access in LTSS.

Tailor public programs providing LTSS for individuals without in-home supports.

Social supports can provide protection for individuals against both unmet LTSS need and social isolation and loneliness, which are associated with adverse health and LTSS outcomes. Our analysis suggests that Black individuals and women aged 55 experiencing LTSS needs live alone more often than white and male counterparts. As a result, policymakers should consider and monitor the equitable accessibility (especially to Black individuals and women) of programs and services that improve social connectedness for individuals experiencing LTSS needs. Policymakers should also consider designing LTSS programs, such as Medicaid LTSS, to address social isolation among individuals who live alone. Programs that serve individuals with LTSS needs could first assess individuals’ feelings of loneliness and desire for social opportunities.

Beyond assessment, LTSS programs in some states offer services to alleviate social isolation, while in other states culturally competent direct care workforce trainings focus on reducing loneliness. Additionally, policymakers could promote equitable access to programs that facilitate transportation to social activities and make direct connections to additional community resources. Paratransit programs provide one example: King County, Washington, conducted a full equity review of its paratransit system and implemented access improvements, such as monitoring excessive trip lengths in response to a 2017 audit.
Topics for Future Research

This analysis focused on the demographic and geographic disparities among individuals experiencing LTSS needs younger than age 65. Researchers can build on several key findings of our analysis by investigating:

- Drivers of asset depletion, especially within the Black community, and the intergenerational consequences of being low resourced during extended periods of LTSS needs.

- Disparities among individuals experiencing LTSS needs in particular populations to identify further opportunities to improve LTSS access, resources, and outcomes. This includes individuals who are younger than age 55; are lesbian, gay, bisexual, transgender, or queer (LGBTQ+); identify with a racial or ethnic group other than Black, Hispanic/Latino, or white; or live with serious mental illness. In this analysis, we are constrained by the available data from the Health and Retirement Study, which does not enable these further categories of analysis.

- Disparities in retirement income levels accessible to these individuals and their caregivers, with implications for retirement and Social Security policy.

- Reliance on unpaid caregiving by individuals with LTSS needs younger than age 65, the demographic profile of unpaid caregivers, and disparities in unpaid caregiving burden. Unpaid caregiving is one of several forms of social support that can mitigate shortfalls in an individual’s financial resources compared to the cost of needed LTSS.

- Effects of Medicaid coverage eligibility policy changes, such as estate recovery protections or asset test elimination, on reducing disparities in access to LTSS.
Appendix: Methods, Studied Populations, and Key Terms

This report studies data from the University of Michigan Health and Retirement Study (HRS), a national longitudinal survey. The survey is administered to a representative sample of over 20,000 individuals in the U.S. older than age 50, who are surveyed every two years until their death. To proxy a study-eligible population aged 55, this study focuses on individuals identified based on their interview at age 55 or 56. All data are respondent self-reported or reported by proxy. Data for all variables except cognitive impairment, traumatic brain injury, intellectual or developmental disability, sexual orientation, and geography are drawn from the RAND HRS Longitudinal File 2020 v1, which cleans and standardizes HRS data from multiple survey years. Data for the remaining variables are drawn from the University of Michigan HRS Core Final Release files, with the exception of geography data, which are drawn from the Cross-Wave Census Region/Division and Mobility File v9.0.

Our analysis identifies respondents for inclusion who were not living in an institutional setting at age 55-56. Further eligibility varies by analysis:

- **Prevalence and demographic profile, and the resources analysis:** Eligible respondents were aged 55-56 during a survey administered between 2008 and 2018. These analyses represent a point in time in the life of the respondent.

- **Outcomes analysis:** Eligible respondents were aged 55-56 during a survey administered between 2002 and 2008. Outcomes among these respondents were analyzed longitudinally using 10 years of follow-up survey data (respondents surveyed at age 55-56 in 2002 were followed for analysis until 2012; respondents surveyed at age 55-56 in 2008 were followed until 2018). Decedents were included in the study.

We use statistical tests to identify significant differences in prevalence, resources, and outcomes among demographic groups, accounting for the HRS’ complex survey design. We test significant differences between demographic groups to determine disparities using a variety of statistical tests, including chi-square tests, Mood’s median tests, and t-tests. Significance is reported at the 5% level. Analysis was conducted in R using the survey package.

To focus on meaningful disparities by race and ethnicity, gender, and geography, we only include visuals and takeaways throughout the report where we observed statistically significant differences that could have future policy and programmatic implications.

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27 Respondents included in this study are surveyed after their 55th birthday and before turning 57. A respondent could be age 56 at the soonest survey after their 55th birthday because the HRS interviews are conducted every two years.
EXPERIENCING LTSS NEEDS

Respondents are identified as experiencing LTSS needs if they experience at least one of the following disabilities. This inclusive definition of LTSS needs is meant to represent the variety of conditions that characterize non-aging-related LTSS needs experienced by individuals approaching age 65.

- **Difficulty with at least one late-loss activity of daily living** (ADL). Late-loss ADLs are bed mobility, transferring, toileting, and eating, consistent with CMS measures.28

- **Difficulty with all four executive functioning instrumental activities of daily living** (IADLs). Executive functioning IADLs are managing money, taking medications, making meals, and shopping.

- **Cognitive impairment**, in addition to difficulty with at least one ADL or IADL (ADLs include those listed above, plus dressing and bathing; IADLs include those listed above, plus making phone calls). Cognitive impairment is identified using the Langa-Weir classification.30

- **Intellectual or developmental disability** (I/DD), in addition to difficulty with at least one ADL or IADL (see ADLs and IADLs listed under cognitive impairment). I/DD is identified among respondents who reported either 1) a traumatic brain injury that still causes health or functional problems, or 2) childhood disability from causes related to I/DD.29

KEY TERMS AND DEFINITIONS

Terms used in this report are italicized.

### Demographics

- **Gender**: female and male. In narrative, we use the terms women and men.

- **Race and Ethnicity**: Black (HRS response option is “Black/African American”), Hispanic/Latino (HRS response option is “Hispanic or Latino”), Other Race/Ethnicity (HRS response option is “Other (Specify)”), and white (HRS response option is “White/ Caucasian”). If a respondent indicates that they are Hispanic/Latino, they are considered Hispanic/Latino in this report; all other race categories exclude individuals who indicated they are Hispanic/Latino. We do not include individuals who identified as Other Race/Ethnicity in this report’s racial and ethnic disparity analyses because it is difficult to interpret comparisons involving an aggregated group that includes so many racial and ethnic identities.

- **Sexual Orientation**: LGBQ+ (HRS response options are “Lesbian/Gay,” “Bisexual,” and “Something Else”), and straight (HRS response option is “Straight”). The HRS first asked about sexual orientation in 2016, reducing the sample size for this analysis.31

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29 Relying on the condition categories as aggregated in the HRS data, we included the following causes: multiple sclerosis; cerebral palsy; epilepsy; Parkinson’s; ALS; seizures; neuropathy; intellectual disabilities; learning disabilities; Down syndrome.

30 We recognize the complexity around race and ethnicity identification and terminology; for example, how gender–non-binary individuals may not identify with Hispanic or Latino.

31 Due to the low number of LGBQ+ respondents experiencing LTSS needs, we did not include an LGBQ+ analysis in the resources and outcomes sections, which only included individuals experiencing LTSS needs. We included sexual orientation in the prevalence analysis and demographic profile only.
→ **Geography:** *rural* and *urban*. The HRS considers rural counties to be those with fewer than 250,000 people and is based on the 2013 version of the Rural Urban Continuum Codes. Data is gathered from the Cross-Wave Census Region/Division and Mobility File v9.0.

**Resources**

→ **Private Finances** – *annual household income*, *total assets* (housing and non-housing combined), and *non-housing assets*, and *housing wealth*.

→ **Insurance Coverage** – *any health insurance* is defined as having any health insurance plan, including public health insurance, employer insurance, and private health insurance. *Any LTSS coverage* is defined as having Medicaid, private long-term care (LTC) insurance, or Veterans Affairs (VA) insurance or other military insurance. These are three types of insurance that are potential sources of LTSS coverage, but the HRS does not identify whether individuals covered by these insurance types receive LTSS benefits.

→ **Social Supports** – *living alone*, *living with a partner in home* (includes a spouse), and *living with three or more other people* are home-based social supports. We also analyze social supports defined by having living children in contact with the individual (*no children*, or *three or more children*). We focus on three or more children because almost half of individuals experiencing LTSS needs aged 55+ had three or more children.

**Outcomes**

Outcomes are measured during a 10-year follow-up period for each respondent.

→ **Health Outcomes** – *mortality*, and *hospital admissions* (incidence per 1,000 person-years).

→ **LTSS Outcomes** – *nursing facility entry* (living in a nursing facility at any interview or at death), *ADL functional decline* (progression in ADL difficulty stage; stages are defined as [stage 1] no ADL difficulty, [stage 2] dressing or bathing difficulty, [stage 3] bed transfers or walking across a room, and [stage 4] eating or toileting), and *cognitive decline* (increase in impairment level identified by the Langa-Weir score).

→ **Financial Outcomes** – *Gaining Medicaid coverage* (measured only among those without Medicaid at age 55), *percent change in annual household income*, and *percent change in total assets*. 
Endnotes


ii “2021 Cost of Long-Term Care Study.” Genworth, 2023.


x Tony Leys, “They could lose the house — to Medicaid.” NPR and KHN, March 1, 2023.


xii National Academies of Sciences and Engineering, Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. 2020.


xiv Ari Ne’eman, Michael Stein, and David O. Grabowski, “Nursing Home Residents Younger Than Age Sixty-Five Are Unique and Would Benefit from Targeted Policy Making,” Health Affairs 41, no. 10 (October 2022).

xv Shuang He et al., “Unmet Need for ADL Assistance Is Associated with Mortality among Older Adults with Mild Disability.” The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences 70, no. 9 (September 2015): 1128–32.

xvi Rebecca J. Gorges, Prachi Sanghavi, and R. Tamara Konetzka, “A National Examination Of Long-Term Care Setting, Outcomes, And Disparities Among Elderly Dual Eligibles,” Health Affairs 38, no. 7 (July 1, 2019): 1110–18.


xviii Rebecca J. Gorges, Prachi Sanghavi, and R. Tamara Konetzka, “A National Examination Of Long-Term Care Setting, Outcomes, And Disparities Among Elderly Dual Eligibles,” Health Affairs 38, no. 7 (July 1, 2019): 1110–18.

xix Individuals with disabilities and younger than 65 incurred 50% of Medicaid spending in federal fiscal year 2019. See: “10 Things About Long-Term Services and Supports (LTSS).” Kaiser Family Foundation, September 15, 2019.


xxv Brenda C. Spillman and Liliana E. Pezzin, “Potential and Active Family Caregivers: Changing Networks and the ‘Sandwich Generation.’” The Milbank Quarterly 78, no. 3 (September 2000).


xxvii Ari Ne’eman, Michael Stein, and David C. Grabowski, “Nursing Home Residents Younger Than Age Sixty-Five Are Unique and Would Benefit From Targeted Policy Making.” Health Affairs 41, no. 10 (October 2022): 1449–59.


xxx See Background section for a detailed explanation of this topic.


xxxv See Background section for a detailed explanation of this topic.


xxxvii New York State MLTC Report Measures (in Appendix 4) include assessment of users living alone and time spent alone, as well as feelings of loneliness, stress, depression, and anxiety. “Quality Strategy for the New York State Medicaid Managed Care Program.” New York State Department of Health, October 2015.


xxxix Jeff Switzer, “Metro is taking action to address cost, quality, and equity in Access paratransit.” Metro Matters (Blog), July 18, 2017.

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