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DATAWATCH

Excess Deaths Of Medicaid Home And Community-Based Services Recipients During COVID-19

Using health plan data, we calculated excess mortality rates for Medicaid home and community-based services recipients during March–December 2020. For younger recipients, excess mortality was 7.4 times that of other community-dwelling Medicaid beneficiaries and 26.6 times that of the general population. As a proportion of expected mortality, excess mortality rates for older recipients and nursing home residents were comparable.

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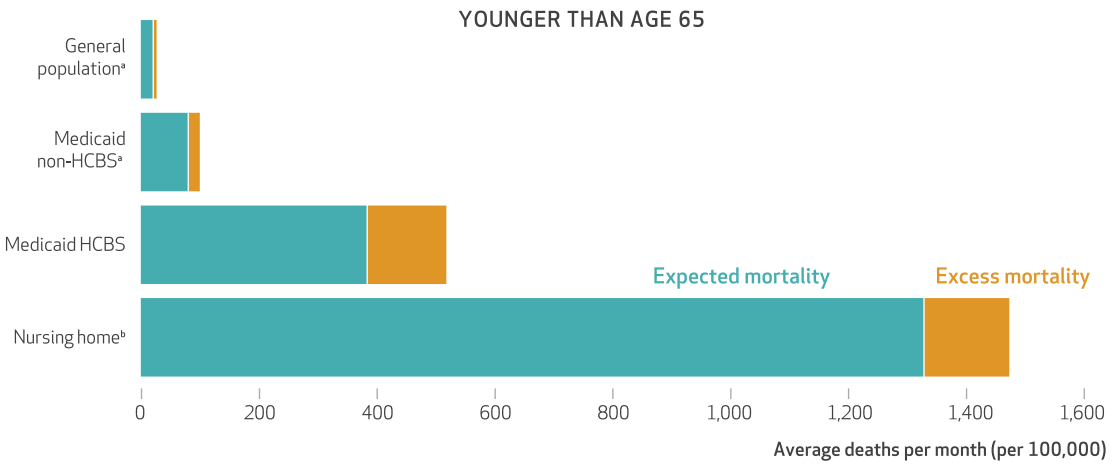
The COVID-19 pandemic has had a devastating impact on people receiving long-term services and supports (LTSS) in nursing homes. More than 23 percent of all COVID-19-related deaths have been linked to long-term care facilities.[1] However, as a result of a lack of public reporting and timely data, very little is known about the impacts of COVID-19 on the vast majority of people with LTSS needs: those living in the community.

We obtained data from fourteen health plans across twelve states to examine excess mortality among people receiving Medicaid long-term services and supports (LTSS) in the form of home and community-based services (HCBS) during the initial months of the COVID-19 pandemic in the US, March–December 2020. As shown in exhibit 1, among younger recipients (those younger than age sixty-five), the average month-

EXHIBIT 1

Expected and excess average monthly mortality among people younger than age 65, by long-term services and supports receipt and setting, March–December 2020



SOURCE Authors' analyses of data obtained from the National Center for Health Statistics, Centers for Disease Control and Prevention (general population and nursing home), and from health plans (Medicaid home and community-based services [HCBS] and Medicaid non-HCBS). **NOTES** Excess mortality can be expressed as a percent change over expected mortality. These percentages were as follows. General population: +21 percent; Medicaid non-HCBS: +22 percent; Medicaid HCBS: +35 percent; and nursing home: +11 percent. Expected monthly mortality was calculated by averaging the mortality rate for the same month over 2018 and 2019. Excess monthly mortality was calculated by subtracting actual from expected monthly mortality. [a]Does not include people in nursing homes and other institutional long-term services and supports settings. [b]Does not include nursing home residents who died in hospitals.

ly excess mortality rate for Medicaid HCBS recipients, defined as actual minus expected mortality rate, based on 2018–19 data, nearly equaled that of nursing home residents in the same age group (133 deaths per month per 100,000 population versus 143 per month per 100,000, respectively). It was also 7.4 times the rate of Medicaid beneficiaries in the community not receiving HCBS, and in the most pronounced study finding, it was 26.6 times that of the general population. Both of these comparison groups excluded residents of nursing homes and other long-term care institutions. As shown in exhibit 2, among older Medicaid HCBS recipients (ages sixty-five and older), the average monthly excess mortality rate during the pandemic was comparable to that among nursing home residents in the same age group (+31 percent versus +28 percent, respectively).

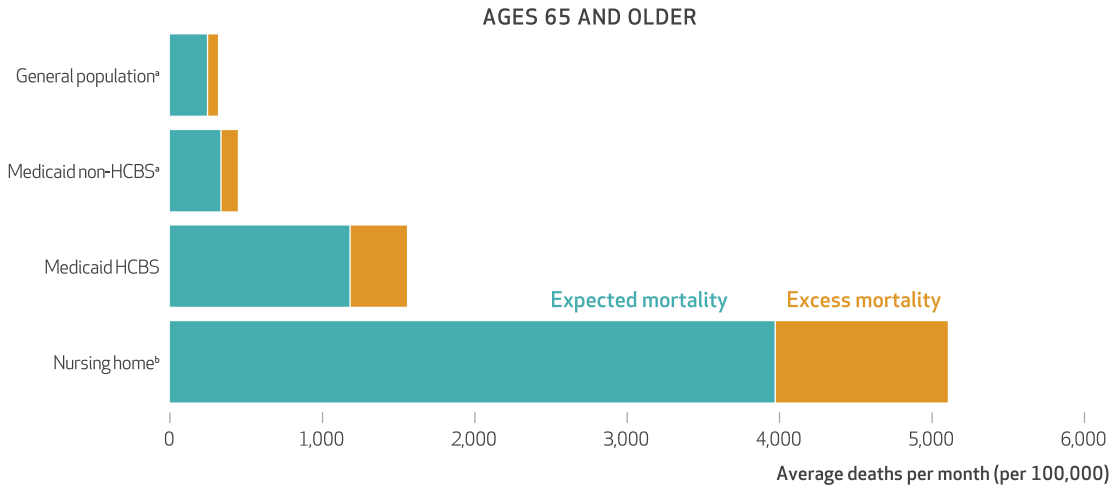
Study Data And Methods

We partnered with the Long-Term Quality Alliance and health plans within the National Managed Long-Term Services and Supports Health Plan Association that volunteered to share data for their plan participants. Our analyses used data from fourteen plans in twelve states (five states in the Midwest, three in the South, and two each in the Northeast and West). Analyses for younger HCBS recipients were based on twelve plans from eleven states. One plan was excluded because its state's managed LTSS program serves only adults ages sixty-five and older, and data from another plan were excluded because of the small sample size. Details of plan recruitment, selection process, state-level plan characteristics, and data sources for comparison groups are in the online appendix.[2]

The monthly sample for the analysis comprised about 55,000 adults younger than age sixty-five (who we refer to as "younger adults") and 90,000 adults ages sixty-five and older (who we refer to as "older adults") receiving Medicaid HCBS. For a comparison group, plans also provided data on non-HCBS Medicaid beneficiaries—those residing in the community but not receiving HCBS (that is, excluding those residing in nursing homes and other institutional LTSS settings). This population included low-income adults eligible for Medicaid through a variety of pathways including people eligible through Affordable Care Act Medicaid expansion, pregnant women, parents, and people with disabilities who were not receiving HCBS. The monthly sample for the non-HCBS Medicaid group numbered about 1.8 million younger adults and 148,000 older adults. Plans provided monthly counts of Medicaid HCBS recipients and non-HCBS Medicaid beneficiaries and deaths in each state served, by age group (younger and older adults) and sex. We requested data

EXHIBIT 2

Expected and excess average monthly mortality among people ages 65 and older, by long-term services and supports receipt and setting, March–December 2020



SOURCE Authors' analyses of data obtained from the National Center for Health Statistics, Centers for Disease Control and Prevention (general population and nursing home), and from health plans (Medicaid home and community-based services [HCBS] and Medicaid non-HCBS). **NOTES** Excess mortality can be expressed as a percent change over expected mortality. These percentages were as follows. General population: +26 percent; Medicaid non-HCBS: +31 percent; Medicaid HCBS: +31 percent; and nursing home: +28 percent. Calculation of expected and excess monthly mortality is explained in the exhibit 1 notes. [a]Does not include people in nursing homes and other institutional long-term services and supports settings. [b]Does not include nursing home residents who died in hospitals.

Many factors likely contributed to the high mortality rates of HCBS recipients, including individual risk factors, societal barriers, and indirect impacts.

for every month in 2018 (if available), 2019, and 2020.

After combining data from multiple plans within each state, we calculated monthly 2020 estimates of expected and excess mortality for that state by age group. Expected mortality was the mortality rate for the same month and population group either from 2019 or averaged over 2018 and 2019. We used data from 2018 when available and when no trend line in mortality was apparent in the monthly mortality rate, either visually or in a linear regression, during the two-year period. We calculated excess mortality in each state and by age group for each month in 2020 by subtracting actual from expected mortality. We then averaged excess mortality across states, by age group, for each month. Finally, we averaged the resulting monthly excess mortality estimates for March–December 2020, by age group, to obtain the average monthly excess mortality rates for the two age groups during the first nine months of the COVID-19 pandemic.

To compare findings from the health plan data with data on deaths in nursing homes and in the noninstitutional population, we obtained additional mortality data from an online database of death records maintained by the National Center for Health Statistics.[3] Data were obtained for the same states for which we had health plan data and were analyzed in the same way, using data from the period 2018–19 to calculate the expected mortality rate.

Limitations of the study included the lack of a nationally representative sample of Medicaid HCBS recipients. There are two reasons for this lack: The data set is limited to residents of twelve states, and enrollment in managed LTSS is voluntary for some groups in some states (see appendix exhibit A-2),[2] which allows for possible self-selection into the sample. As noted, data from additional plans and states were excluded because of quality issues; in addition, we were unable to analyze race and ethnicity disparities because of issues with reporting from several plans.

There may also be concerns regarding the comparability of data obtained from the health plans and from the national mortality database. Of note, the latter compiles mortality by place of death rather than place of residence, thereby excluding from nursing home mortality rates any nursing home residents who died in hospitals. In contrast, the health plans aggregate deaths of HCBS recipients irrespective of place of death. In addition, our data for the general population may have included some people receiving Medicaid HCBS.

Study Results

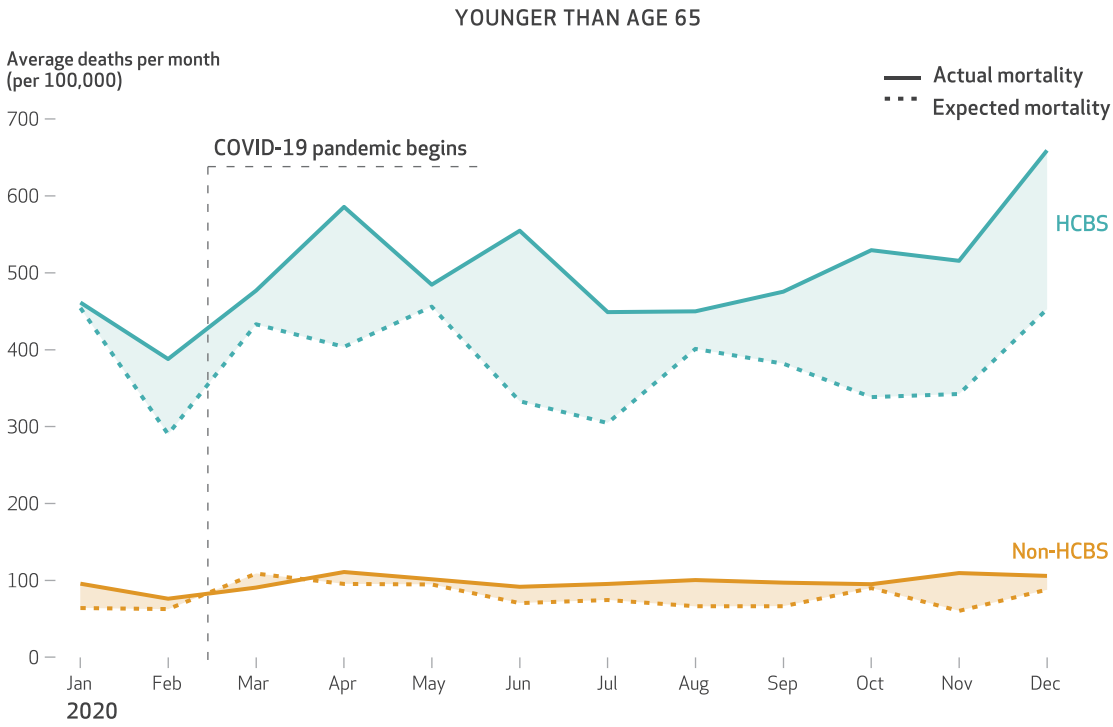
Exhibits 1 and 2 provide average expected and excess monthly mortality rates by LTSS receipt and setting during the period March–December 2020 for younger (exhibit 1) and older (exhibit 2) adults, respectively. (Please note the difference in scale between the two exhibits.) Compared with the differences in excess mortality rates between younger HCBS recipients and their age peers in the non-HCBS Medicaid and general populations, noted above, the differences between older HCBS recipients and their age peers in the non-HCBS Medicaid and general populations were less dramatic but nevertheless pronounced: 3.5 times as great as for their non-HCBS peers and 5.7 times as great as for their peers in the general population.

In addition, the expected mortality rate for nursing home residents was more than three times as great as for HCBS recipients in both age groups. Yet, as noted earlier, the increase in the average monthly mortality rate of younger HCBS recipients approximately equaled that of their nursing home–age peers, and average monthly excess mortality, expressed as a percentage increase over expected mortality, was more than three times as great in the former versus the latter group.

Average expected and actual mortality rates for each month of 2020 are shown in exhibits 3 and 4, by HCBS receipt, for younger and older adults, respectively. (Again, please note the difference in scale between the two exhibits.) Regardless of age group, both expected and actual mortality rates were much greater for HCBS recipients than for non-HCBS Medicaid beneficiaries in the community (not including residents of long-term care facilities) in the initial pandemic months. The two exhibits also show simi-

EXHIBIT 3

Monthly average mortality, actual and expected, among Medicaid beneficiaries younger than age 65, by home and community-based services (HCBS) receipt, 2020



SOURCE Authors' analyses of data provided by health plans. **NOTES** The lines labeled "HCBS" report findings for people receiving Medicaid HCBS. The lines labeled "Non-HCBS" report findings for community-dwelling Medicaid beneficiaries not receiving HCBS and not residing in nursing homes or other institutional long-term services and supports settings. Calculation of expected monthly mortality is explained in the exhibit 1 notes.

lar patterns of increased mortality in the spring, summer, and fall/winter of 2020, corresponding to peaks in COVID-19 infection rates mostly in the Northeast (spring), in the South (summer), and across the country (fall/winter).

Discussion

This study was among the first to provide multistate data on mortality among people receiving Medicaid HCBS during the early months of the COVID-19 pandemic. We found high excess mortality rates for Medicaid beneficiaries receiving HCBS compared with other community-dwelling Medicaid beneficiaries not receiving HCBS and the general population, particularly for younger adults (younger than age sixty-five). As a proportion of expected mortality, excess mortality for older HCBS recipients (ages sixty-five and older) was slightly higher but was comparable to that of older nursing home residents.

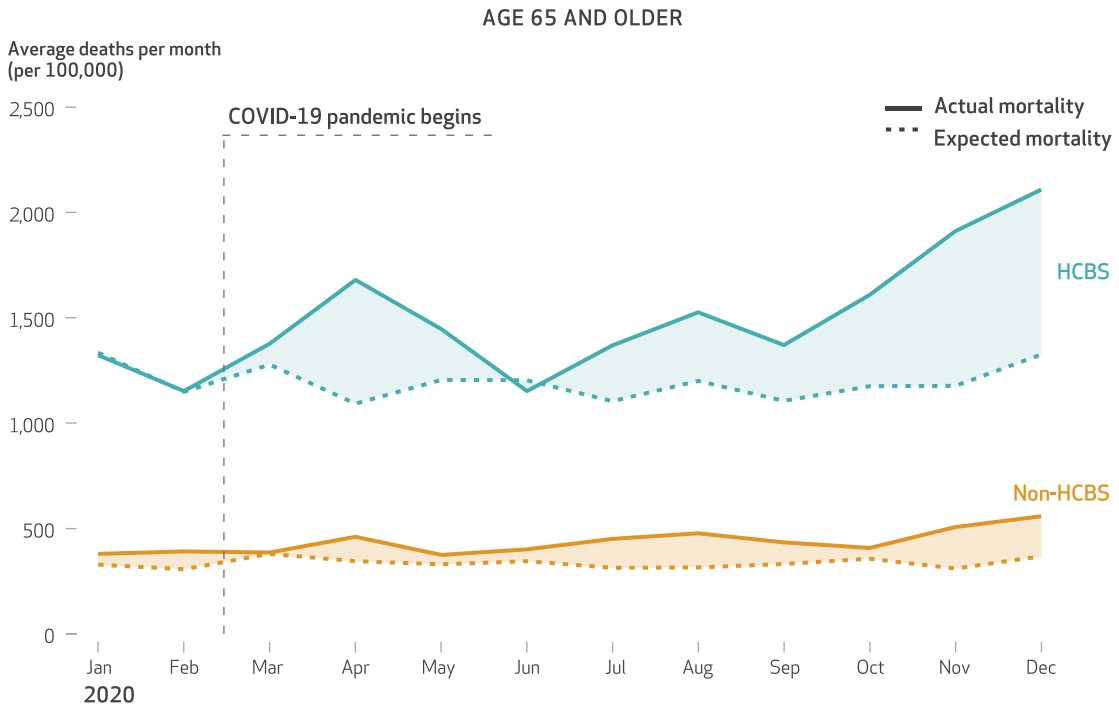
Many factors likely contributed to the high mortality rates of HCBS recipients, including individual risk factors, societal barriers, and indirect impacts. People receiving Medicaid HCBS have high rates of secondary health conditions that contribute to greater risk of contracting COVID-19 and experiencing poorer outcomes. Some people reside in group settings or attend congregate day programs, placing them at greater risk for exposure.[4] In addition, people typically rely on daily in-person supports delivered by unpaid caregivers and direct care workers who routinely enter their homes, which further increases risk for exposure to COVID-19.

People with disabilities, family caregivers, and direct care workers in the community faced significant barriers obtaining personal protective equipment and testing as COVID-19 spread in the US.[5] In addition, long-standing, systemic issues in the availability of direct care workers were exacerbated during COVID-19,[6] which contributed to people going without essential daily supports and services. Although more research is needed, people with disabilities have reported delaying or going without routine preventive and specialty care, which can have dire impacts on this population.[7]

Early in the COVID-19 pandemic, Congress required timely federal reporting on mortality in

EXHIBIT 4

Monthly average mortality, actual and expected, among Medicaid beneficiaries ages 65 and older, by home and community-based services (HCBS) receipt, 2020



SOURCE Authors' analyses of data provided by health plans. **NOTES** The "HCBS" and "Non-HCBS" populations are defined in the exhibit 3 notes. Calculation of expected monthly mortality is explained in the exhibit 1 notes.

nursing homes. Ongoing studies have linked those reports to nursing home staffing,[8] garnered media attention, and helped inform critical policy discussions and responses. Unfortunately, similar reporting was not required for people receiving Medicaid HCBS. Of the approximately fourteen million people with LTSS needs in the US, only a small fraction reside in nursing homes.[9,10] In 2019, approximately 7.5 million Medicaid beneficiaries received HCBS, and 1.6 million resided in nursing homes and other institutions.[11] Our study helps shine a light on a population that has largely been invisible in the public discourse and COVID-19 response. Our findings highlight the vulnerability of the HCBS population during the pandemic.

The COVID-19 pandemic has elevated conversations about the need to reduce states' reliance on nursing home care, expand access to HCBS, and strengthen the direct care workforce. Although states have made significant progress "rebalancing" their LTSS systems during the past several decades, significant gaps remain in access to and availability of HCBS.[12] As aging and disability communities and policy makers work on systems reforms, our findings indicate a need to also address major gaps that exist in access to timely, publicly available data and quality reporting for people receiving HCBS across the age spectrum. ■

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NOTES

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2 To access the appendix, click on the Details tab of the article online.

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