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Elevated COVID-19 Mortality Risk Among Recipients of Home and Community-Based Services: A case for prioritizing vaccination for this population

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Under Federal guidance, states have developed plans to vaccinate residents for COVID-19 in tiers. Nursing home residents and older adults have been prioritized across the board, but as state plans evolve over time, it has become clear that non-elderly community residents with disabilities, as a group, are not being afforded high priority for vaccination. Several states target segments of the disability population, such as those with specified chronic health conditions confirmed to increase the risk of COVID-related mortality, leaving many others at high risk for COVID exposure, severe disease, and mortality to wait for a later phase.¹ This analysis focuses on people with disabilities who need and receive long-term services and supports (LTSS) in their homes and other community settings, a largely overlooked population at high risk for both exposure to the virus, because they typically get daily help and other services from people entering their living quarters, and for mortality, because of health conditions and impairments that increase their likelihood of severe disease.

In this brief, I present evidence that states should be targeting participants in Medicaid Home and Community-Based Services (HCBS) programs as high priority vaccine recipients:

- HCBS recipients with intellectual and developmental disabilities (I/DD) have between 3.6 and 4.8 times the mortality risk from COVID-19 as people in the same age group without I/DD.
- Other HCBS recipients without I/DD, who have about 4 chronic health conditions on average, have 3 to 6 times the mortality risk from COVID-19 as people in the same age group without chronic conditions.
- This increased risk for mortality puts many non-elderly HCBS recipients in a risk category equivalent to people over 65 without LTSS needs. In particular, HCBS recipients between 45 and 64 years of age appear to be at greater mortality risk than the general community-resident population between 65 and 74 years of age.
- As a consequence of this elevated mortality risk, states would be more than justified in increasing the vaccination priority for HCBS recipients under age 65 to equal that of the general population age 65 and older.

¹ Johns Hopkins University Disability Health Research Center. (2021, 6 February). COVID-19 Vaccine Prioritization Dashboard Retrieved 10 February, 2021, from <https://disabilityhealth.jhu.edu/vaccine/>

HCBS recipients with I/DD

Of a total of about 4.2 million Medicaid HCBS recipients nationally,² just under 800,000 are enrolled in I/DD-specific 1915(c) Waivers. Between 85 and 90% of participants, or roughly 700,000 people, are under 65 years of age.³ The vast majority have a diagnosis of intellectual disability (89%), and 29% have epilepsy or another seizure disorder, 20% have autism, and 15% have cerebral palsy. Nearly one-quarter (23%) use a mobility device or need mobility assistance. About one-third live in group homes, congregate living arrangements that increase their risk of exposure to the virus but whose residents have not yet been vaccinated in many states. About half live in private homes, meaning that priorities that target congregate living arrangements would not reach them.

Increased COVID mortality risk among I/DD HCBS recipients

In an analysis published in November 2020, FAIR Health and collaborators undertook a statistical analysis of a claims database containing private insurance claims for nearly one-third of the U.S. population.⁴ For the 467,773 individuals with claims indicating a COVID-19 infection between April and August 2020, the authors searched their claims database for comorbidities (chronic health conditions and other risk factors) reported over the prior three years, and then performed regression analysis to assess which comorbidities increased the likelihood of death, controlling for demographic factors and other co-occurring conditions. For this brief, I focus on a model in which the authors limited the analysis to COVID-diagnosed individuals below 70 years of age. This group comprises 95.2% of all people contracting the virus but only 56.2% of all COVID-attributed deaths.

Figure 1 shows the extent to which each of the risk factors predicts mortality from COVID-19. The length of the bars represents the odds ratio, which is approximately⁵ equivalent to the multiplier by which a person's likelihood of death increases if they have the specified risk factor, compared to someone without that risk factor, all other variables being equal. Most notably, **a person with an intellectual disability has 3.6**

² Includes participants in 1915(c) Waivers, 1915(i) and (k) programs, state plan personal care services programs, and 1115 Waiver HCBS programs, but excludes home health recipients. Watts, M. O. M., Musumeci, M., & Chidambaram, P. (2020). Medicaid Home and Community-Based Services Enrollment and Spending. San Francisco, CA: Henry J. Kaiser Family Foundation.

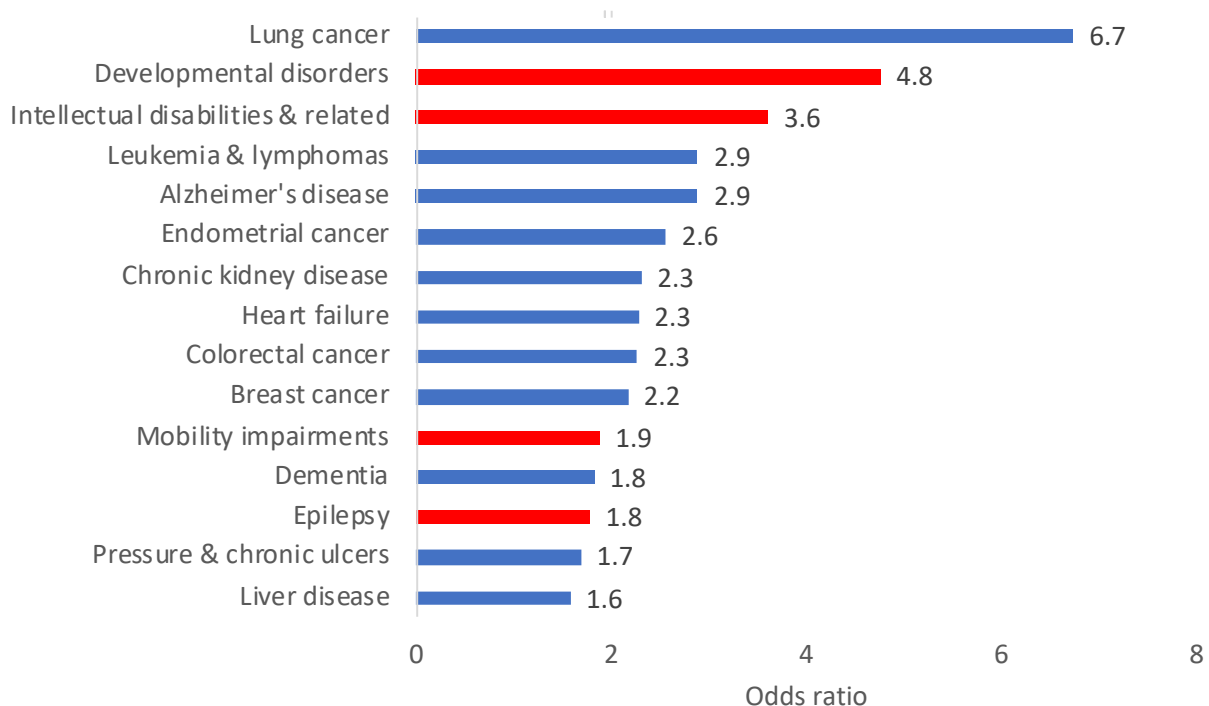
³ Human Services Research Institute & National Association of State Directors of Developmental Disabilities Services. (2020). National Core Indicators 2018-19 In-Person Survey Report. Cambridge, MA: Human Services Research Institute.

⁴ FAIR Health, West Health Institute, & Makary, M. (2020). Risk Factors for COVID-19 Mortality among Privately Insured Patients: A Claims Data Analysis. New York: FAIR Health, Inc. Because the data are for people with private insurance, the findings likely underestimate risks for poorer Medicaid recipients.

⁵ Technically, 'odds' and 'risk' are different concepts, but in this instance of relatively low likelihood of death, the odds ratio is nearly equal to the relative risk.

times the risk of dying of COVID-19 as a person of the same age with none of the risk factors, and a person with some other developmental disability has an even greater risk of 4.8 times that of someone without the listed risk factors. Note also the other relevant risk factors in the Figure, indicated with red bars. Mobility impairment and epilepsy/seizure disorder, both prevalent among HCBS users with I/DD, each increases risk of death by nearly a factor of 2. A person with, for example, both an intellectual disability and a mobility impairment would in principle have a mortality risk about 6.8 (=1.9*3.6) times that of a similar person without those disabilities.

Figure 1. Risk factors for mortality among people under 70 with a COVID-19



Adapted from FAIR Health, West Health Institute, & Makary, M. (2020), Figure 8.

HCBS recipients with physical and other disabilities (non-I/DD)

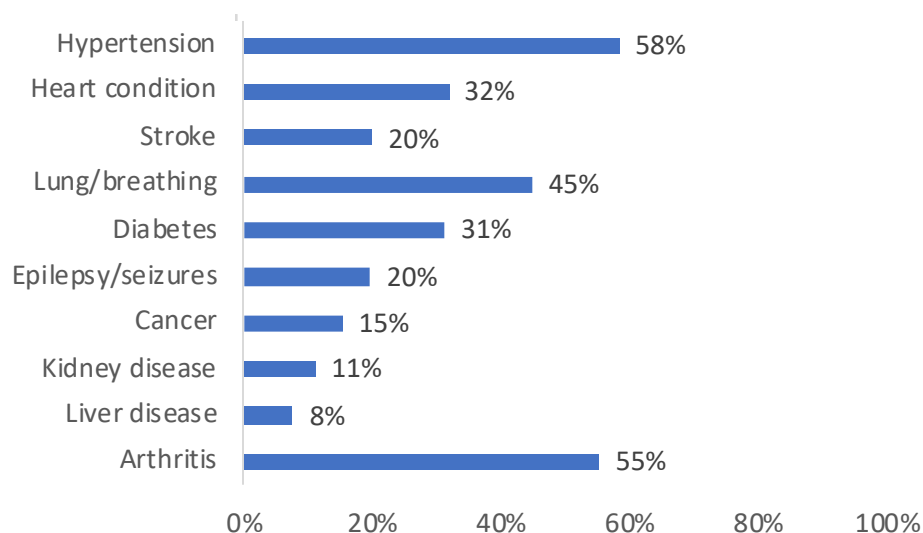
Roughly 3.4 million Americans receive Medicaid-funded HCBS through programs other than those targeted toward the I/DD population. Some 44% are under 65, or about 1.5 million people. Based on data from a 2017-18 survey of HCBS program participants in 14 states, 82% of those under 65 have at least one chronic health condition and 78% either use mobility devices or get assistance walking. Healthcare utilization is high, with 33% having been hospitalized and 50% visiting an Emergency Room at least once over the prior year.⁶ Although family members can sometimes be paid to provide daily assistance (24% report having a paid family member as their primary HCBS provider), most program participants get help from workers who enter the homes and potentially

⁶ Community Living Policy Center analysis of 2017–18 data from the National Core Indicators–Aging and Disability (NCI-AD) Adult Consumer Survey, conducted by Health Services Research Institute (HSRI) and AdvancingStates.

expose them to COVID risks. Such workers have not necessarily been vaccinated, and vaccination might not prevent transmission of the virus.

There are remarkably few data sources on chronic health conditions and impairments among HCBS recipients nationally. In lieu of such data, I conducted an analysis of 2016–18 data from the National Health Interview Survey (NHIS). Although HCBS recipients are not specifically identified in the survey, I used a proxy measure of likely HCBS users, namely Medicaid recipients under 65 needing help in at least 2 activities of daily living (ADLs such as dressing, bathing, and getting to the toilet). The sample size for likely HCBS users is 381. Actual HCBS program eligibility is generally somewhat more restrictive, meaning that the findings from this analysis are conservative (i.e., HCBS users probably have higher rates chronic conditions and impairments than the NHIS population I selected).

Figure 2. Chronic health conditions among likely HCBS recipients



Source: Author’s analysis of 2016–18 data from the National Health Interview Survey

Key findings for likely HCBS recipients under age 65:

- **Recipients have, on average, 4.8 chronic health conditions** out of a list of 16 conditions asked about.⁷ The median number of conditions among likely HCBS recipients is 4.

⁷ Hypertension, coronary heart disease, angina, heart attack, any other heart condition, stroke, ongoing asthma, chronic obstructive pulmonary disease, emphysema, chronic bronchitis, cancer (active or survivor), diabetes, “weak or failing kidneys,” liver disease, arthritis/joint pain, and epilepsy/seizure condition. The reported mean is for 2017, the only year when epilepsy is asked about; for the full three-year period, excluding epilepsy, the mean is 4.3 conditions, with the median unchanged at 4.

- Obesity, a known risk factor for adverse outcomes of COVID-19,⁸ is highly prevalent, at 49%. An additional 17% fall into the overweight category.
- Three-quarters (76%) report a mobility impairment, confirming the finding from the HCBS participant survey. More than half (55%) report arthritis or joint pain. The FAIR Health study identified mobility impairment as a mortality risk factor (odds ratio 1.9).⁹
- **Nearly all of the reported chronic conditions (shown in Figure 2) are listed by the Centers for Disease Control and Prevention (CDC) as either confirmed or possible risk factors for severe COVID-19 illness:** hypertension (58% of non-elderly HCBS recipients, possible), heart disease (32%, confirmed), stroke (20%, possible), lung/breathing problems (45% overall; COPD confirmed; asthma, cystic fibrosis, and pulmonary fibrosis are possible), diabetes (31%, possible), epilepsy (20%, possible as a neurological condition), cancer (15%, confirmed), kidney disease (11%, confirmed), and liver disease (8%, possible).¹⁰ Cancers, heart disease, kidney disease, and liver disease are also listed as risk factors in the FAIR Health study, with odds ratios ranging from 1.6 to 6.7.¹¹

The authors of the FAIR study analyzed not only the impact of specific comorbidities, but also the increased risk of having multiple comorbidities (Figure 3). For example, once the virus is contracted, a person with 4 chronic health conditions (comorbidities) would have approximately 6.1 times the risk of dying as a person without any comorbidities.¹² The NHIS analysis tells us that likely HCBS recipients have a median of 4 chronic health conditions, and a mean of somewhat more than that. The list of conditions from my analysis of NHIS data is not the same as that used in the FAIR Health analysis,¹³ but the FAIR findings clearly illustrate that people with multiple chronic conditions are at especially elevated risk of death from COVID-19. Even if the HCBS recipients had only two comorbidities, on average, their risk would be 2.8 times as high as similar people without comorbidities.

⁸ Center for Disease Control and Prevention. (2021, 8 January). Obesity, Race/Ethnicity, and COVID-19. Retrieved 10 February, 2021, from <https://www.cdc.gov/obesity/data/obesity-and-covid-19.html>

⁹ FAIR Health, West Health Institute, & Makary, M. (2020).

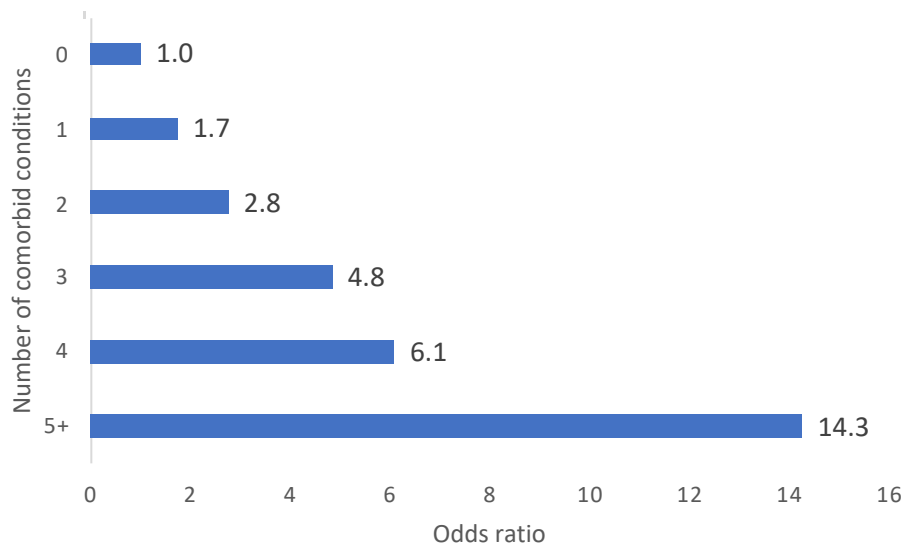
¹⁰ Center for Disease Control and Prevention. (2021, 3 February). People with Certain Medical Conditions Retrieved 10 February, 2021, from <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

¹¹ FAIR Health, West Health Institute, & Makary, M. (2020).

¹² Note discussion of odds ratio versus risk in Footnote 4.

¹³ It is not clear to me whether the FAIR multiple comorbidity analysis was limited to those conditions listed in their Figure 8 (my Figure 1) or included additional conditions.

Figure 3. Increased mortality risk by number of comorbidities among people under 70 with COVID-19



Adapted from FAIR Health, West Health Institute, & Makary, M. (2020), Figure 15.

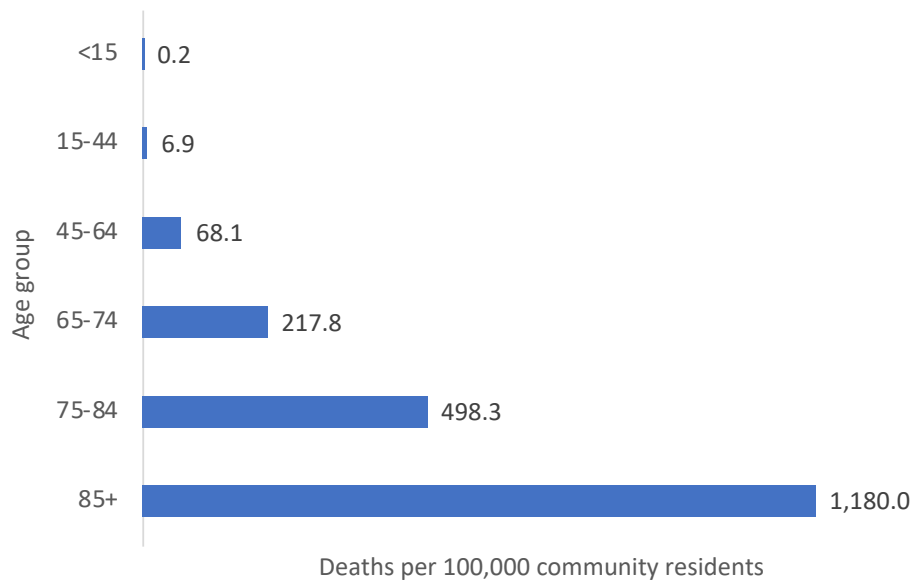
How does the increased risk for HCBS beneficiaries compare to that of older age?

Using CDC-compiled data on COVID-19 mortality by age and place of death¹⁴ and excluding deaths occurring in nursing homes, I calculated the mortality rate by age for people living in community settings.¹⁵ As illustrated in Figure 4, each age group shows a substantial increase in mortality over the next-younger age group. In particular, the non-institutional mortality rate for 65- to 74-year-olds was 217.8 per 100,000 people over the first 11 months of the pandemic, or 3.2 times the 68.1 per 100,000 mortality rate of 45- to 64-year-olds.

¹⁴ Center for Disease Control and Prevention. (2021, 23 January). NVSS Provisional COVID-19 Deaths by Place of Death and Age Retrieved 27 January, 2021, from <https://data.cdc.gov/dataset/NVSS-Provisional-COVID-19-Deaths-by-Place-of-Death/4va6-ph5s>

¹⁵ Deaths in institutional settings other than nursing homes are included in the rates. For the denominator, I used data from the American Community Survey with institutional residents removed.

Figure 4. COVID-19 mortality among U.S. community residents, by age group



Source: CDC data tables by age and place of death. Excludes nursing home deaths.

Because HCBS recipients, both with and without I/DD, appear to have somewhere between 3 and 6 times the risk of dying after they acquire COVID-19 compared to others in the same age group, states would be more than justified in increasing the vaccination priority for HCBS recipients under age 65 to equal that of the general population age 65 and older. Without vaccination, furthermore, HCBS recipients continue to be at higher risk of exposure to the virus, because of the need for frequent contact with people outside of their household. I urge the Federal government and state authorities to act quickly to elevate the vaccination priority of HCBS users.

Acknowledgments

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