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# Impact of the COVID-19 Outbreak on Long-Term Care in the United States

**Courtney Harold Van Houtven, Nathan A. Boucher, Walter D. Dawson**

Last updated 24 April 2020

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## **Itccovid.org**

This document is available through the website [Itccovid.org](#), which was set up in March 2020 as a rapidly shared collection of resources for community and institution-based long-term care responses to Covid-19. The website is hosted by CPEC at the London School of Economics and Political Science and draws on the resources of the International Long Term Care Policy Network.

Corrections and comments are welcome at [info@itccovid.org](mailto:info@itccovid.org). This document was last updated on 24 April 2020 and may be subject to revision.

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## 1. Key findings

- The US currently has the largest number of confirmed cases of COVID-19 of any country; a lack of widespread testing remains an issue.
- Historical challenges within the US long term care (LTC) system that disproportionality impact individuals of low-socioeconomic status (SES) and certain racial and ethnic communities have been greatly exacerbated by the crisis.
- The US federal political system ensures that individual states and the federal government have joint and overlapping responsibility for responding to the COVID-19 outbreak.
- Significant regional differences in the impact of COVID-19 on health and social systems including LTC as well as on the response.
- Near-term and long-term strategies for change in LTC policy are needed to adapt and respond to COVID-19.

## 2. Introduction

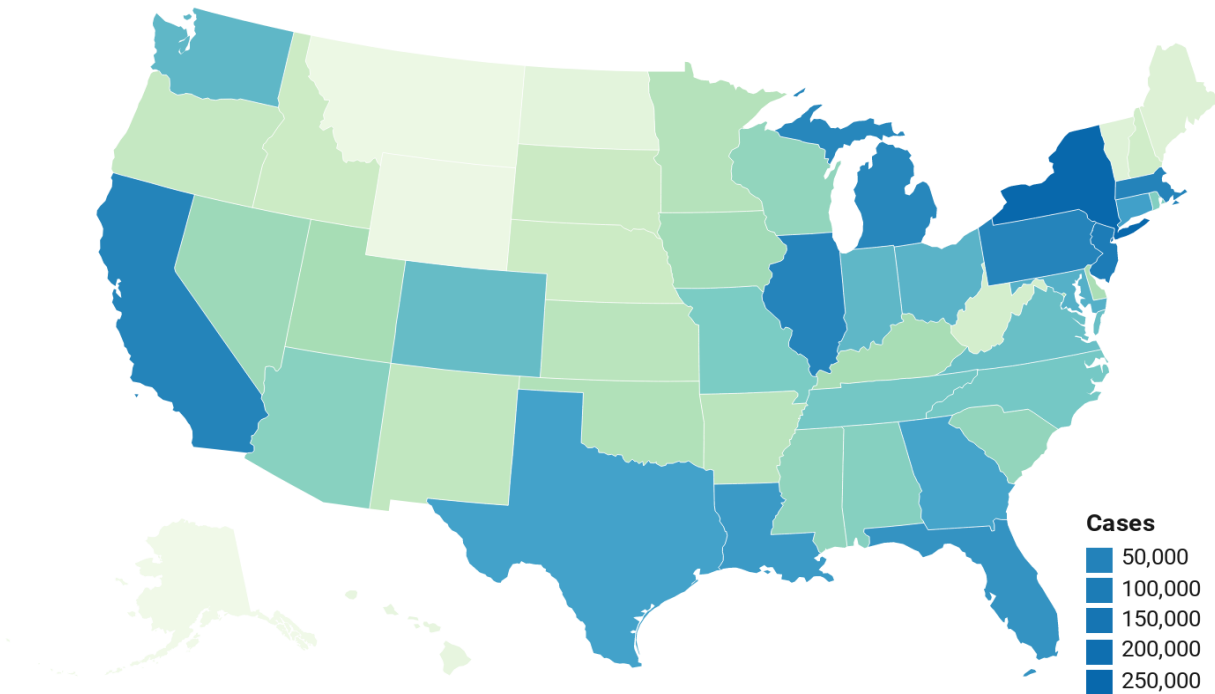
The United States (US) currently has the most confirmed cases of COVID-19 of any country. Yet, adequate testing for the virus remains a major issue. Approximately 51.6 million Americans are over the age of 65 and 56 percent of adults over 65 are living with two or more chronic conditions (23 percent have 3 or more).<sup>1, 2</sup> Given the higher risk of death and complications associated with advanced age and underlying health conditions, COVID-19 has had an immense impact upon LTC in the United States.<sup>3</sup> Yet, the level and intensity of impact has been sporadic in application. This is due in part to a highly disparate and fractured long-term care system and perennial systemic challenges that have been exacerbated by the pandemic. In terms of financing care, the US relies on a mix of public and private funding sources. Further, individual states and the federal government have overlapping responsibility for funding and regulation of care. Meanwhile, fragmentation between financing and ownership of health care entities versus long-term care entities hinders coordinated delivery of care across sectors; and social sectors and health care sectors are also not integrated. The challenges of the system's design suggest that both a near-term and long-term response is needed to mitigate the impact of COVID-19 on the approximately 13 million Americans who require long-term care.<sup>4</sup> This report provides an overview of the current challenges facing LTC and outlines several potential policy responses to the pandemic as well as for life post-pandemic.

### 3. Impact of the COVID19 outbreak so far and population level measures

#### 3.1. Number of positive cases in population and deaths

As of April 23, the US had 880,112 cases, 50,111 deaths and 80,937 recovered persons. These numbers are changing rapidly and reflect a moment in time.<sup>5</sup>

#### Confirmed COVID-19 Cases by US State



*These data represent a snapshot in time (April 23). The number of news cases is rapidly changing.*  
Source: Johns Hopkins University CSSE • Created with Datawrapper

In the US, COVID-19 is disproportionately affecting African American and Latino populations as these groups are experiencing very high coronavirus infection rates and deaths.<sup>6</sup> Underlying contributors are thought to include: 1) poorer overall health (i.e., diabetes, heart disease, hyper-tension); 2) some members' status as "essential" workers required to continue to commute and work; 3) long-standing community distrust of authorities and recommendations. Many argue it comes down to equally long-standing historical, systematic, structural and individual racism in US society which has contributed to denigrated health of these populations for many decades before the present pandemic.<sup>7</sup> Additionally, 4) high rate of poverty are thought to be major contributors to this rate, given that African Americans, Latinos, and Native Americans experience poverty disproportionality compared to rest of US population.<sup>8</sup> Native Americans as a group have not received much news coverage, and yet recent reports show

death rates are strikingly high for residents of the Navajo Tribe reservation, with over 1000 cases and 44 deaths.<sup>9</sup> Finally, there will likely be disproportionately negative impacts on African American, Latino, and Native American populations in areas where there has been disinvestment in public health and Medicaid. Specifically, for residents of states that did not expand Medicaid as a part of US health care reform in 2010, there could be differential negative effects on at-risk populations. Future research will need to disentangle the multiple reasons for the disparities in death rates. In the meantime, efforts are ramping up to try to assist these communities and mitigate risks of spread and death.

New York City continues to be a hot spot although reports are that they are past their peak.<sup>10</sup> Attention towards Boston, Detroit, New Orleans and Philadelphia is growing as numbers rise in these localities.<sup>11</sup> Rural populations, and, subsequently, rural hospital capacity are also growing concerns.<sup>12</sup>

Like other countries, congregant living arrangements are leading to considerable infection spread and death. Later in the report we will discuss long-term care facilities, but we would like to briefly draw attention to another congregant living situation that poses multiple risks: prisons and jails.

#### *Prisons and Jails.*

State and federal prisons are seeing disturbing infection rates in the context of close quarters and often substandard conditions that existed prior to the pandemic. The US imprisons a larger proportion of its population than any other country with 1,291,000 in state prisons, 631,000 in local jails, and 226,000 in federal prisons and jails amounting to approximately 655 imprisoned per 100,000 in the US population.<sup>13</sup> Infection control is a challenge in these settings. Contrary to our thinking of prisons and jails as enclosed spaces, staff, contractors, and visitors can introduce the virus to inmates. Additionally, inmates themselves often travel to and from these institutions for medical and legal activities. Viral exchange between inmates and community is possible. Responses to mitigate this such as confining inmates to their cells – often shared – is not necessarily the solution either as this could amount to solitary confinement, a cruel approach that goes above and beyond the original legal sentence. Early release is another approach but is controversial and not happening quickly enough to have an effect, according to some.

Older inmates and those with multiple chronic illnesses are at particular risk. In fact, many people in prisons and jails are in relatively poor health which existed prior to their sentencing due to poverty and continued due to sometimes substandard prison health services. Harsher sentencing in recent decades has led to an aging prison population in poor health – a constellation of vulnerability in the context of COVID-19.<sup>14</sup>

To our knowledge, early releases are being decided at the state level and there is still no systematic testing of prison staff, even though there have been reports of infection of staff in multiple states, such as New York, North Carolina and Oklahoma. These reports are increasing, and with no systematic testing of wardens, staff, or prisoners, it is unclear how risk will be mitigated in coming weeks.

### *Place of death.*

Another important population health measure is where people are dying. For the first time in 2019 more people were dying at home than in the hospital in the US.<sup>15</sup> Most Americans state they prefer to die at home, 80 percent, but far fewer ultimately do. With support, such as hospice, dying at home can be considered a 'good death'.<sup>16</sup>

However, COVID-19 is changing this picture. There are an increasing number of people dying at home (part of the so-called overall burden of the pandemic). In part this is a problem of testing and access to care directly associated with COVID-19. But individuals may not seek care for other ailments due to fear of contracting COVID-19 from engagement with health system or they may not want to use scarce health resources they see as needed for the pandemic.<sup>17</sup> Or they may not recognize when it is important to seek care, given so little is still known about the virus, and die at home from COVID-19.

Future work will be needed to understand the consequences of these increasing deaths at home, including causes of death, receipt of support near the time of death (e.g., hospice, palliative care) and the spill over effects on family members' emotional wellbeing.

## **3.2. Population-level measures to contain spread of COVID-19**

The Federalism model of governance in the US results in 50 different states' governors making their own decision regarding issuing stay at home orders. The US federal government does not have this jurisdiction. The majority of states are under stay at home orders and social distancing guidelines amounting to 97 percent of Americans subject to these orders. However, seven states still do not have a stay at home order, all of which have Republican Party governors signalling that decisions around the pandemic response are possibly being politicized.<sup>18</sup>

There is variability in success for stay at home orders. Possible reasons across states could include some businesses remaining open or essential businesses choosing to close, the number of essential workers in the state, or the populations' willingness to practice shelter at home. Mixed messages from federal government and state governments add to the confusion. Unfortunately, it has become a politicized issue, rather than one based on public health recommendations. For a list of states and their measures can be [found here](#).<sup>19</sup>

With most of the country living under shelter in place orders, the US is experiencing major lags – even decreases in some areas -- in testing the population and implementing contact tracing of infected individuals. Yet, experts agree that massive increases in testing and contact tracing is necessary to ensure a safe re-opening of society (e.g., discontinuing stay at home orders or lightening social distancing procedures).

As of April 21, 3.35 million Americans have been tested for COVID-19. Daily updates are provided by the COVID Tracking Project. This amounts to approximately one percent of the U.S. population.<sup>20</sup>

Testing of health care workers continues to lag in the US.<sup>21</sup> According to the Centres for Disease Control (CDC), 9,282 US health care workers have tested positive for COVID-19. However, this number is likely a major undercount. The data report of 27 deaths is also a major under count.<sup>22</sup>

Key policy leaders are proposing plans to thoughtfully and safely re-open society including 1) better data identifying areas of spread and rates of exposure and immunity; 2) improvements in state/local healthcare system capabilities, public-health infrastructure, case containment, and adequate medical supplies; and 3) therapeutic, prophylactic, and preventive treatments including targeting the most vulnerable.<sup>23</sup>

State governors have also begun to make plans to open their states. On the west coast, Washington, Oregon and California jointly released their plan to re-open.<sup>24</sup> Six states on the East Coast including New York, New Jersey, Connecticut, Pennsylvania, Rhode Island and Delaware, also jointly released their plan for re-opening.<sup>25</sup> Several Midwestern states have also agreed to a joint re-opening process: Wisconsin, Michigan, Ohio, Illinois, Indiana, and Kentucky.<sup>26</sup>

Again, reflecting the politically polarized regard for shelter in place orders, there are increasing protests at state capitols around the country by citizens demanding the economy be re-opened. These protesters tend to identify as pro-Trump supporters.<sup>27</sup> The economic pain people are experiencing is real. Unlike some European countries who incentivized firms to not to lay off workers, the pandemic has devastated the US economy since policies have been adopted to flatten the curve. As of April 24, 26 million workers were unemployed due to the pandemic.

And yet, most health experts agree that much more testing is needed before states can re-open. Some argue three million tests need to be administered per day, others claim 30 million<sup>28</sup>, before we can loosen shelter in place orders and resume economic activities beyond essential workers.<sup>29</sup>

### **3.3. Numbers of residents in care homes infected and deceased, impact on community-based care users, impact on unpaid carers, impact on care staff**

“Nobody has ever wanted to think about the state of nursing homes in this country. Now is no different” – Personal communication with Rachel Werner, Director, Leonard Davis Institute, University of Pennsylvania

*Care homes/nursing homes.*

There is an important distinction in the US of what is a nursing home or skilled nursing facility (e.g. facilities that accept Medicare and/or Medicaid patients or Veterans Affairs patients) versus other types of care homes that are more likely to be privately funded including assisted living facilities, independent living facilities, and memory care homes. Some states allow

payment for care in assisted living and memory care homes through Medicaid. The generic term for care homes in the US is “long-term care facility.”

Due to the high fragility (e.g., multiple co-occurring chronic conditions) and advanced age of the population served in long-term care settings, these settings appear to account for a disproportionate share of US deaths from COVID-19. By April 22 there were over 10,000 deaths reported from nursing and other long-term care facilities, with reporting in from only 35 states.<sup>30</sup> Not all states are reporting statistics on deaths, however, and they are not yet required to. However, the US Centers for Medicare and Medicaid Services (CMS) has proposed that all nursing homes report to the CDC infections and deaths in the weeks ahead. Even as reporting becomes required, this will not capture all possible long-term care deaths because regulations are different for assisted living facilities, independent living facilities, and memory care units, when they are not a part of the Medicare or Medicaid program. Variable reporting by state and by type of facility, compounded by death certificates listing dementia or the underlying non-COVID-19 health condition(s) as the cause of death, suggest that the infection rates and deaths in long-term care facilities are likely underestimated.

There is also limited data available on the number of LTC workers who have died as a result of COVID-19. According to the Centres for Disease Control and Prevention (CDC), 9,282 US health care workers have tested positive for COVID-19. However, this number is likely a major undercount.<sup>31</sup> The data also reports 27 health care worker deaths, but this also a major undercount.<sup>31</sup> No data on employment setting of healthcare workers (e.g. hospital or nursing home) is provided in the CDC report.

#### *Community-based care and unpaid carers.*

Very little systematic information exists on the impacts of Covid-19 on community-based care users or unpaid carers. We know that there are similarly felt shortages of PPE and of screening and tests, although home care agencies have implemented employee screening procedures. There are also reports that many families have discontinued their home health aide during the pandemic, which undoubtedly places more strain on unpaid carers. Although the use of these services is not high, families are likely reducing the use of adult day care services and respite services for their care recipients in light of the pandemic. Expansion of home-based tele-health is being used by home health agencies, which is discussed in further detail below.

#### *Impact on workers.*

The structure of the US LTC workforce is relevant to the current pandemic. US LTC workers are predominantly female, one-third are born outside the US, have high rates of injury, earn low wages (\$18 an hour), have no health insurance through their employment, and often hold multiple jobs. Specifically, a recent profile noted that “70% of LTC facility workers agreed or strongly agreed with the following statement: “When you are sick, you still feel obligated to come into work.” One-sixth had a second job, where they worked an average of 20 hours per week, and over 60% held double- or triple-duty caregiving roles.” Given that their unpaid



caregiving duties often occurred outside the home, workers are particularly at-risk themselves, and pose risks to residents, their families and their care recipients.<sup>32</sup> Beyond pre-shift screening and testing, immediately extending sick leave and offering substantial hazard pay could reduce risks to all, especially by having these essential workers visit only one job location without prohibitive financial penalties.

## 4. Background to the long-term care system

Approximately 13 million Americans require some form of LTC.<sup>4</sup> The US LTSS system is primarily based on informal caregiving, with 75% of older persons with at least 2 or more functional limitations receiving informal care, 36% or so receiving formal home health care, and about.<sup>33</sup> The majority of Americans who need LTSS are 65 + but 40 percent are under 65.

The US has a highly fragmented LTSS financing system, with no public long-term care insurance program other than for individuals with limited financial resources or those who spend down their assets (e.g., Medicaid). Yet, the bulk of all LTSS public financing takes place through public programs such as Medicaid, Medicare, and the Veterans Administration. The annual costs of LTSS were officially estimated at \$366 billion in 2016.<sup>34</sup> The true costs of LTSS are almost certainly much higher as most care is provided informally by family caregivers. The cost of unpaid family care is estimated as high as \$470 billion annually with over 41 million Americans acting as caregivers.<sup>35</sup> These costs are disproportionately experienced by women, individuals of low socio-economic status, and racial and ethnic populations, who more often rely on as well as provide unpaid care.<sup>36</sup>

An estimated 7.4 million Americans own a private long-term care (LTC) insurance policy, or around 15% of persons 65 and over.<sup>37</sup> A multitude of arguments exist for why private LTC insurance is not more widely utilized, but a major limiting factor is cost, with premiums upwards of \$6,000-\$8,000 a year.<sup>38</sup> Publicly funded care, mostly provided through the Medicaid program, generally pays for LTSS only if an individual's income falls below the federal poverty level (FPL) (\$12,760 or less in 2020), although state Medicaid programs have flexibility to establish eligibility thresholds above the FPL.<sup>39</sup> Under US federal law, Medicaid is only required to cover care in institutional settings, while home and community-based care is largely optional.

Major state variation in funding for home and community-based services (HCBS) at a state-level, including variation in state funding for Medicaid home and community-based waivers, which cover custodial care in the home for older adults with disabilities and other special populations (fragile children, etc.). Some states allow for self-directed Medicaid funds to be used to pay family caregivers.<sup>40</sup> Many states have strongly embraced HCBS through the use of Medicaid waivers and provisions within the Affordable Care Act (the major health care reform in the US from 2010), or ACA, that prioritize rebalancing Medicaid LTSS away from institutional settings. Yet, while an overall majority of Medicaid LTSS funding (57% as of 2016) is now spent on HCBS, several states continue to spend the majority of their Medicaid LTSS dollars on institutional care.<sup>41</sup>

Despite attempts to address LTC financing as part of the ACA (e.g., the CLASS Act), LTC was ultimately largely omitted from US health care reform efforts. At a systems level, little has changed in the way LTC is delivered over the past decade. Twenty-seven states now use managed care for Medicaid LTC. Further, expansion of LTC covered services under Medicare Advantage (MA) is occurring (e.g. pilot tests of Meals on Wheels, coverage of assisted living under some MA plans, and transportation costs).<sup>42</sup> However, the exact benefits remain at the discretion of individual insurers.

Medicaid expansion under the ACA does directly affect LTC, although the ACA contained measures to support increased access to HCBS. For example, states that adopt the K-Plan Waiver receive an additional six percent Medicaid match (CMS). Medicaid expansion shown to increase access to LTC at home and nursing home for non-elderly adults who gained coverage through health reform.

Overall, however, given the lack of a comprehensive public LTC financing structure in the US, LTC costs comprise a large proportion of total out of pocket costs for Medicare beneficiaries (e.g. usually those 65 and older). Facility-based LTC services remain the largest proportion of out of pocket expenditures for Medicare beneficiaries nationally, 32% of total out of pocket costs, of an annual total amount of ~\$3,600.<sup>43</sup> This fragmented and prohibitively expensive LTC system explains why informal caregivers are the main suppliers of LTC in the US.

With a concern that informal caregiver supply may not keep pace with demand with aging of the population, policy attention in the US has turned to caregiver support policies in recent years. Specifically, The National Academy of Sciences, Engineering and Medicine urged building a national caregiver policy after recommendations from NASEM to do so.<sup>44</sup> In 2018, the RAISE Family Care Act was signed into law, requiring the convening of a Family Caregiving Advisory Council to advise, provide recommendations, and identify best practices on recognizing and supporting family caregivers.<sup>45</sup>

The development and implementation of caregiver supports remain largely up to state policymakers. Several state-level policies and programs have been initiated to support family caregivers.<sup>46</sup> Some states have additional (non-Medicaid) caregiver financial support programs (e.g. Hawaii).<sup>47</sup> A handful of states now offer tax credits for caregivers and up to 9 are implementing paid family leave in the near future which can cover family caregiving duties for up to a 12 week period and some in population are eligible for unpaid family leave.<sup>48</sup> Other state-level supports include family caregiver training and respite services.

Veterans Affairs (VA), the largest comprehensive system of care in the US caring for former military service members, is a leader in systematic supports to caregivers including direct stipends. More than 40,000 caregivers have received a stipend and direct supports in past 10 years and there are social workers / caregiver support coordinators at all 150+ medical centers dedicated to supporting family carers.<sup>49, 50</sup>

At a community-level or an individual health system level, there are also many small scale caregiver support programs that are adapting during the pandemic, moving services to virtual support calls, reaching out to caregivers, and trying to help caregivers of institutionalized loved ones connect with their family members through video calls such as FaceTime. It is unclear how these voluntary and community-programs are faring during the pandemic since they are often not implemented on a large scale. Our expectation is that, given that only a small fraction of the some 18 million unpaid informal caregivers in the US receive support from policies or programs, there is increased unmet caused by the pandemic that are likely to increase stress and strain.<sup>51</sup>

## 5. Long-Term Care policy and practice measures

Much of the direct efforts to address COVID-19 in LTC settings have come from regulatory agencies at the state-level. Minimal response have been felt from the Centers for Medicare and Medicaid Services (CMS) – the largest payor of both health and LTSS in the US) to the LTC sector specifically. The move to expand telehealth services viewed to be a large potential benefit to providers and patients alike. Some of the direct CMS measures to Address COVID-19 Impact include reducing or waiving regulatory requirements for providers including enrolment as a Medicare eligible provider.

### *Expansion of Telehealth.*

Sweeping expanded access to telehealth services for older adults through Medicare have been in effect since March 2020.<sup>52, 53</sup> Not only for primary care, but also behavioural health and substance use disorder treatment, which have lagged behind in accessing telehealth reimbursement. Private insurers are following suit.<sup>54</sup> Specific to post-acute care needs for those with severe cases of COVID-19, telehealth visits are now at home and in nursing homes and/or skilled nursing facilities. These allow licensed clinical social workers, clinical psychologists, physical therapists, occupational therapists, and speech-language pathologists to conduct virtual check-ins and remote evaluations allowed for occupational therapy, respiratory therapy.<sup>55</sup>

Remote patient monitoring has also been approved for reimbursement. This is critical to minimize spread between providers and recovering and still positive patients (Hoffman, 2020). To more fully support recovery from COVID-19 at home, home health agencies should also be allowed to reimburse for remote patient monitoring. Making the home health benefit more robust in general could greatly enable progress in recovering patients.<sup>56</sup>

### 5.1. Whole sector measures

#### *Funding to LTC Sector*

The CARES Act, the \$3 trillion COVID-19 stimulus package passed in late March 2020, appears to provide fewer financial benefits to the long-term care sector than to hospitals and other health providers. Of the \$100 billion CARES Act funds earmarked for health care providers, \$30 billion are now being disbursed to hospitals and long-term care providers including home health. All facilities and providers that received Medicare fee-for-service (FFS) reimbursements in 2019 are eligible for these funds. These funds will be disbursed proportional to the amount providers billed Medicare FFS in 2019 and irrespective of other factors (e.g., COVID-19 impact or population served). The remaining \$70 billion CARE Act dollars are earmarked for providers in areas particularly impacted by COVID-19, as well as rural providers, providers with lower shares of Medicare reimbursement (e.g. those who predominantly serve Medicaid beneficiaries and the uninsured).<sup>39</sup>

Furthermore, The Families First Coronavirus Response Act from March earmarked 10 million for meal support to older Native Americans and the stimulus bill earmarked \$40 million for the Indian Health Service.<sup>57</sup> There have been no reports that we have identified about how COVID-19 has affected persons with LTC needs in native populations.

Nursing facilities are eligible to receive accelerated Medicare Payments. Three months advance payment for Medicare services to SNFs who have been impact by COVID-19. There is funding from CMS to convert SNFs to COVID-only as well. Thus far only Connecticut and Indiana have announced they will pay a premium (~\$600 per diem) higher than usual rate if SNFs convert to COVID-only and pay for deep cleaning.<sup>58</sup>

Regulatory relaxation – Routine inspections of nursing homes has been suspended by CMS. However, facilities already found not in compliance will continue to be inspected.<sup>59</sup>

## 5.2. Care coordination issues

We have heard news reports of families removing residents from care homes, but we have no solid data on the rate this may be occurring. Additionally, the use of telehealth is expected to increase the ability to coordinate care across sectors. There are major barriers to smooth discharge and transition from hospitals when post-acute care is needed.

### *Post-acute care needs and strategies.*

Beside dedicating facilities to COVID-19 patients, which is happening in some states (e.g., in Austin, TX one wing of an under occupied NH has been retrofitted for Covid-19 patients, other proposals have been to accept recovering patients at COVID-19 negative facilities and move out long-term residents. This approach is not gaining a lot of traction. Other proposals have been to discharge patients to under occupied rural hospitals who are financially on the verge of collapse given reduced usual care utilization. This may be faster than retrofitting nursing homes, but there is lack of integration between acute care and long-term care sectors that may make this difficult. One concern is that if existing facilities do not feel they can safely accept discharged patients, these patients will be discharged from hospitals to home with no services

and not obtain the rehabilitation services that they need to fully recover from the virus. We will continue to monitor data in this area and update as appropriate.

### **5.3. Care homes (long-term care facilities)**

#### **5.3.1. Prevention of COVID-19 infections**

The CDC has published guidelines on preparing and continues to update guidance now that there are cases in nursing homes in all 50 states.<sup>60</sup> This interim guidance focuses on the following priorities:

- Keep unrecognized COVID-19 from entering the facility
- Identify infections early and take actions to prevent spread
- Assess current supply of PPE and initiate measures to optimize supply
- Quickly recognize and manage severe illness”

#### **5.3.2. Controlling spread once infection has entered a facility**

The Centers for Disease Control and Prevention (CDC) provides infection control guidelines to long-term care providers.

Nursing homes often feel ill equipped and are receiving few resources from the federal government. Yet, they are feeling pressured to accept discharged patients that still test positive for COVID-19.<sup>61</sup>

Isolation has been used to prevent the spread of infection. But isolating residents in facilities is close to impossible. There are also many asymptomatic cases of COVID-19.<sup>62</sup> The proposal to move residents testing positive to new locations has largely been abandoned with the increased spread of the virus. Facilities are working with state and county health departments to obtain more protective equipment (PPE). Some health systems are also working with departments of public health and forming strike forces, ready to reach out to “to assess, educate, test, and support” nursing homes as they fight Covid-19 infection, but this is occurring on an ad hoc basis, from our read of the evidence.<sup>63</sup>

#### **5.3.3. Ensuring access to health care (including palliative care) for residents who have COVID19**

There have been excellent efforts, mostly decentralized, to ensure access to palliative care. Dr. Diane Meier, a national leader in palliative care, offers guidance to help extend palliative care to US patients, given that the palliative care skill set is exactly what is needed to help frightened family members and persons with serious illness navigate anxiety and fear. Key in her recommendations are conversations that contain “listening, curiosity about what people are feeling, support for priority setting, and a calm presence.”<sup>64</sup>

Several resources are also listed (we repeat them here verbatim),

- To help provide reassurance and support to your patients and their families, the CDC has guidance for those living with serious illness, and their caregivers.
- To help clinicians to understand and provide recommended care, the CDC guidance for health professionals is a helpful source.
- Guidance on care settings (home, health care institution, office practices) is also available.

(Additional recommendations for caregivers appears below)

#### **5.3.4. Managing staff availability and wellbeing**

Staff wellbeing is a major concern even without statistics on LTC-specific infection rates. How do we keep staffing with so many ill workers (or not having day care etc.)?

At state level, there are plans for calling in retired and inactive health care providers; calling in healthcare providers from other sectors to help with surges in LTC facility settings. Health systems are helping states Area Health Education Centers (AHEC) create plans for training and deploying additional RN/LPN/CAN staff to nursing homes. Some of these plans are excellent and propose an ideal structure of care delivery with team-based care tenets, recommendations for daily huddles and person-centered care (e.g., goals of care with patient).<sup>65</sup>

Professional organizations are also recommending loosening scope of practice regulations for physician assistants, nurse practitioners, and other providers, to increase ability to perform at top of license and increase efficiencies in health care.<sup>66</sup> This is not being made in the context of LTC-facility surge, but it could help.

### **5.4. Community-based care**

#### **5.4.1. Measures to prevent spread of COVID-19 infection**

Stories of many people dropping their home health aides as well as reports of a lack of PPE. Currently, the National Association of Home Care and Hospice is serving as an information hub for strategies to minimize spread in community-based care settings, including hospice.<sup>67</sup>

#### **5.4.2. Measures to ensure continuity of care and staff wellbeing (including staff retention and recruitment)**

The need to provide care continues regardless of restrictions on movement. The US federal government has listed home care workers as essential in guidance from the federal government, although the areas currently under stay home orders vary by state and locality.<sup>68</sup> Most states have also listed LTC workers as essential service providers. This is an important

albeit basic step in helping ensure continuity of care. We have no other information on this from state or national sources at this time.

## **5.5. Impact on unpaid carers and measures to support them**

First, states and local municipalities should immediately increase funding for area agencies on aging (AAAs) and private organizations that offer caregiver support programs. This will allow moving of more caregiver supports to online/phone based care. There are many evidence-based programs, but they are typically small-scale and have little resources to expand. Investing in caregiver support programs could be a means of supporting caregivers in all types of situations: caring for loved ones for Covid-19 and for other needs. Investing now is an opportunity to support this critical work.

Second, there is no standardized way to identify a patient's primary caregiver in most electronic medical record systems. Thus, to better support family caregivers during COVID-19, a systematic approach to identification is needed. Electronic health record (EHR) systems do not necessarily provide a caregiver field. Since 2013, 42 US states passed the CARE Act, model legislation requiring US hospitals and health systems to document a caregiver within everyone's health record. To what level states have implemented this law remains unknown although early indications are that the IT systems are struggling to add this field. This remains one policy lever to reach caregivers, albeit at a state-level. If Medicare or Medicaid requires it, other systems will follow. This may be important to communicate end of life wishes and have final communications with patients in severe phases of the disease.

Third, with no visiting orders at most health care facilities, concerted effort to keep caregivers and family members informed is required across all settings and phases of disease. This is particularly important in critical care and need for palliative care just published six specific recommendations to better support caregivers in context of palliative and hospice care.<sup>69</sup> Honoring and thanking the caregiver, that their contribution to care is unique and important, is a key recommendation. In addition, they recommend assessing caregiver capacity, discussing about goals of care early, and the better use of telehealth. Being able to be reimbursed for telehealth appointments with family and friend caregivers about a patient's care would incentivize more inclusion of the caregivers in plans of care and increase the ability to deliver preference-centered care.

## **5.6. Impact on people with intellectual disabilities and measures to support them**

There are beginning to be reports of group homes having infection spreading. A general feeling exists that this population, estimated to total approximately 6 million people, has been overlooked during this crisis.<sup>70</sup> Another important point that has not been considered is that intellectually disabled individuals commonly work in jobs with a great level of exposure risk, including grocery store bagging, etc. Thus, congregant living in group homes and exposure of work both need to be addressed.



## 5.7. Impact on people living with dementia and measures to support them

Approximately 5.8 million Americans are living with some form of dementia, while an additional 15-20 percent of all adults 65 and over are believed to have mild cognitive impairment, a stage of cognitive decline often preceding dementia).<sup>71</sup> People living with dementia face unique challenges as a result of the COVID-19 outbreak. As Wang et al., 2020 note, these individuals may possess limited access to accurate information, they may experience difficulties remembering safeguard measures (e.g. wearing a mask or regular hand washing), or they make face difficulty in understanding public health information.<sup>72</sup> For dementia patients that go to adult day health care centers, this could be another location of risk. As a result, these individuals could be at a higher risk of COVID-19 infection. Further, the 800,000 or more individuals living alone with dementia in the US face additional challenges that this pandemic is exacerbating.<sup>73</sup> Several resources to support people living with dementia during COVID-19 include:

Alzheimer's Association (Family Caregivers)<sup>74</sup>, Alzheimer's Association (LTC settings)<sup>75</sup>, and Alzheimer's Disease International<sup>76</sup>.

Yet, more support is needed for this population including from the federal and state governments alike. For example, enhancement of nutrition support programs such as meals on wheels is particularly important for individuals living alone. This program plays a dual role of addressing isolation.

## 6. Lessons learned so far

### 6.1. Short-term calls for action

*LTC Facilities.*

*Infection control, more resources and new collaborations.*

- Clearly, there is a need to increase testing. Until there is widespread testing available, it will be difficult to address the outbreak.
- Pre-shift screening and testing of staff is also needed, however, pre-shift screening alone is unlikely to be a totally effective measure given the unknown number of asymptomatic cases.
- Increase availability of adequate PPE so that all workers and staff have the PPE they need. This is especially important at other LTC facilities. A survey of 179 assisted living facilities conducted March 6-15 found that two-thirds of them cannot obtain access to necessary supply of N95 masks, face shields, and other PPE.<sup>77</sup>
- Increase the goals of higher care and advance directive completion
- Increase communication between families, residents, and staff using video links.
- Enlist health care systems in this effort - showing link to surge could help. Reducing outbreaks in all congregant living situations can decrease admissions to ICUs, etc.



- Prioritize which nursing homes to help using past reports on quality – try to shift resources towards prevention not reaction – looking for low quality / high risk homes that have not yet had outbreaks. Expand our consideration to all LTC facilities. If we continue to ignore assisted living facilities, which are even further removed from the acute health care system than nursing homes are, we will see increases in deaths and infections. “After all, over one-third of the counties in the 100 most populated MSAs have more units in residential care communities than nursing home beds.”<sup>78</sup>
- Reporting cases to the CDC will help track the spread of infection and intervene. On April 17, CMS announced they will require nursing homes to report to the number of infected residents to the CDC. This requirement will not apply to other settings such as ALFs, ILFs, MC units who do not take Medicare or Medicaid patients. Other strategies are needed to increase transparency in the parts of the market (and states) with fewer regulations. Relying on Freedom of Information Act requests is likely not a fast-enough way to achieve this.<sup>79</sup>
- Vital to avoid blame game of medical directors and facility-owners in order to be able to optimally react and intervene. There is a need to increase trust for information sharing. Families need to know where cases are occurring, but sharing this information introduces a very real litigious component that could block progress.<sup>80</sup>

#### *Intervening to avoid financial collapse of LTC providers*

- Future rounds of the federal stimulus package need to consider potential for collapse in the LTC industry, especially those who have private pay patients exclusively. With halting elective surgeries, for example, post-acute care patients have fallen, already reducing revenue. One option for CMS certified nursing homes is immediate increases in reimbursement for Medicaid (and Medicare patients), will help ensure at-risk LTC facilities continue to operate.<sup>32</sup> This can help the firms and help workers not work in multiple locations (if increased reimbursement is used to fund hazard pay) so would have positive spill over effects on infection spread. Poor Medicaid rate reimbursement is a historical problem. This can be corrected today with more attention to its vital role as the main payor for care in the US. Additional stimulus package support could also directly target LTC workers with hazard pay.
- An especially pronounced issue for Assisted Living Facilities, Independent Living facilities, and Memory Care units that are under-regulated and have even lower profit margins. As Grabowski and Barnett conclude, “Paying a fair price for essential long-term care could increase facilities’ abilities to improve their staffing ratios and encourage better quality of care.” (Washington Post Opinion, April 16, 2020)

For LTC Facilities, ***it is not too late to move now*** with these recommendations and see an impact on reducing infections and saving lives. The Society for Post-Acute and Long-Term Care Medicine (AMDA), an organization representing post-acute care medical providers, has warned nursing homes could lose up to 30 percent of residents due to COVID-19.<sup>81</sup> When possible,

mobilizing volunteer health care workers at all levels who have taken the charge to work in acute care settings, could likely help LTC facilities immensely, locations where at most there is usually one MD-trained individual. Lessons learned on protective equipment and isolation practices and other innovations could be applied to LTC facilities with an increase in cross-sector assistance.

#### *LTC in the community.*

- The same preventive recommendations apply to community based LTC such as increased testing, especially of staff and increased screening and protection with PPE.
- An immediate policy change could be to beef up ability to provide post-acute care at home. This would work best with one dedicated family or friend caregiver able to be a partner in this model. It could be adapted to care for recovering COVID-19 patients without informal caregivers. At a minimum would need to have one dedicated home health aide and telehealth and 24/7 tele-monitoring. This model, proposed by Van Houtven and Werner, also specifically proposes paying one dedicated family member or friend to complement the formal rehabilitation care received, in order to minimize contacts and risk of spread.<sup>56</sup> There would need to be specific measures to ensure safety of the patient at home and this benefit would need to be bolstered considerably from the current Medicare home health aide benefit. RPM and more visits would need to be granted than the typical home health benefit, which is too little to support rehabilitation. The patient would also need to be able to isolate in a separate room until they test negative. The patient and family members will need PPE. The caregivers will need to be trained in minimizing risk and the telehealth benefit needs to reimburse providers and health systems for visits directly with the caregivers, who in this model, is a vital member of the health care team.

#### *Unpaid caregiver supports.*

- In addition to the support measures listed above, there should be new policies that immediately allow caregivers of COVID-19 patients to be paid at the rate of home health aides. This approach has been taken at the municipal level in other countries including South Korea.<sup>82</sup> Current efforts to pay family caregivers are generally limited to Medicaid. There is acute economic strain given massive layoffs; also forgoing home health provision in the home. For working caregivers, they need to be paid if they are going to take time off work (especially for low-income caregivers who do not have sick leave, etc.); and for both working and non-working caregivers, being paid will reduce the need for multiple caregivers and will enable them to remain in one place while the care recipient recovers. Adding COVID-19 recovery to one's caregiving role will place added burden on caregivers.

## 6.2. Longer term implications

Crises often make clear the need for reform. The impact of COVID-19 on the US LTC system is that crisis to bring into focus much-needed reforms. Long term, the changes needed to pivot toward shifting society's paradigm of thinking and political will include the following:

### *Mitigating Ageism & Ableism*

Ageism and ableism have driven long term care services and supports into the shadows of healthcare delivery. In general, our society does not value the collective wisdom and continued abilities and contributions of older adults or those with disabilities. Living in the shadows is isolating for members of this community, staff, and patients/residents alike. Staff, because their role in healthcare delivery is seen as being not as important as those of working in hospitals where things "get fixed." Patients/residents, because they need more care than we are willing or able to give them in community. Now social distancing during our pandemic has amplified the isolation that already existed, for patients and residents especially, but also for staff as they struggle to be seen as "essential" workers. The pandemic's impact on LTC facilities can be harnessed to bring to light this overlooked area and the discrimination against aging and disabled communities. The heightened infection rates and deaths observed among Black, Latino, and Native American communities nationally will likely be seen in LTC facilities, and will require another call to action for these particularly disadvantaged groups (older/disabled and minority status).

### *Identifying and Supporting Family Caregivers*

Unpaid carers, often family members and friends are critical to the care needs of those served by long-term care services and supports, much of which in the US is patch-worked together with undue reliance on unpaid carers to provide the necessary cohesion. Even the most integrated and sophisticated health care systems desperately need a way to reliably identify primary carers. While 42 US states have implemented the CARE Act requiring US hospitals and health systems to document a caregiver within everyone's health record, its application is not yet ubiquitous and its impact on long term care unclear. Thinking of carers as part of the team taking care of patients and residents requires a shift in both thinking and in healthcare operations.

### *Improving Interoperability between LTC and Acute Care*

Interoperability between acute care facilities and LTC facilities is lacking and transcends ever-present challenges of shared electronic health records in US healthcare, a challenge across all healthcare settings. There is a persistent organizational and cultural difference between acute care and LTC; one that is compounded by the ageism/ableism note previously. These ways of thinking include the idea that hospitals fix patients and have great value to society while long-term care is where people go when things just are not going to get much better. In the US, disparate ownership of acute care versus long term care facilities complicates hopes of information sharing or collaboration. A complex mix of for-profit, private, and public ownership usually means LTC facilities and nearby hospitals are not part of the same vertically integrated system. Memorandums of understanding or formal contracts reflecting the now popular US

models of “patient-centered medical homes” or “accountable care organizations” may be a philosophical answer to gaps in interoperability and also a practical one.<sup>83</sup>

#### *Reduce Barriers to Telehealth in LTC*

The Centers for Medicare and Medicaid Services has loosened restrictions on the use of telehealth access and privacy in response to the pandemic, including at LTC facilities. Until now, US telehealth expansion has been slow given questions about health care quality and patient privacy and its presumed dramatic shift from traditional, in-person patient care. Now we have a forced natural experiment to see if it works for patients and providers alike. Specific to LTC, US Senators Amy Klobuchar and Bob Casey recently introduced new legislation to enhance telehealth support for older adults and increase access to technology allowing "virtual visits" during this pandemic. The *Advancing Connectivity during the Coronavirus to Ensure Support for Seniors* (ACCESS) Act would help protect vulnerable LTC populations, their providers, and their families. This includes \$50 million to the Department of Health and Human Services' (HHS) Telehealth Resource Center to assist nursing facilities receiving funding through Medicare or Medicaid to expand telehealth offerings.<sup>84</sup> This proposal is additionally supported by the AARP, the Center for Medicare Advocacy, Justice in Aging, the Long Term Care Community Coalition, and the National Consumer Voice for Quality Long-Term Care, yet remains under review in the Senate Finance Committee.

#### *Provide incentives to care for our most vulnerable populations*

Poor programs result in poor outcomes. A more equitable system of providing and paying for care is desperately needed. Right now, there is a need to invest heavily in providers who serve low-income, medically fragile LTC residents. This is a long-standing need, but the current crisis makes this an urgent need. A federal response is needed to ensure and support high quality facility-based care nationally. As seen with the challenges experienced with the roll out of the stimulus packages, the small businesses who need the resources the most are often the ones unable to secure loans or grants that are essential to support their work.<sup>85</sup> This is true for many independent long term care providers and home care providers. These providers often care for the most vulnerable and medically fragile and need resources to provide care that Medicaid reimbursements is unable to fully cover. While increasing Medicaid payments across the board would help, a thorough realignment of the system to better provide and finance care is needed. Without this larger systemic reform of LTC, the challenges that plague the current system will persist and intensify far beyond the current crisis.

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