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RAISE ACT REPORT, CONGRESS, AND COVID-19

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RAISE Act Council delivers major caregiving report

The first fruits of the RAISE Act have appeared in the form of a [136-page report](#) by the Family Caregiving Advisory Council. The product of many months of deliberation and drafting by the 15 public member body, the report offers a wide-ranging set of recommendations and analysis backed up by vignettes of individual and family caregiving experiences that underscore the need for the supportive measures the report envisions. The report's 26 recommendations, as summarized by the Administration for Community Living (ACL), fall within five goals:

- Increasing awareness of family caregivers to increase public understanding of the contributions caregivers make, including helping individuals self-identify as caregivers so that they can get the support they need.
- Engaging family caregivers as partners in healthcare and long-term services and supports to better integrate family caregivers into healthcare processes and systems.
- Improving access to services and supports for family caregivers including counseling, respite care, peer support, training on common in-home medical tasks, practical assistance like transportation, and strengthening the paid caregiver workforce.
- Financial and workplace security for family caregivers to decrease the impact family caregiving can have on the financial well-being and professional lives of caregivers.
- Generating Research, Data, and Evidence-Informed Practices to help create policies and interventions that meaningfully help family caregivers.

Each of the 26 recommendations is supported by a 100-250 word rationale statement that explains why the council believes the recommendation, if implemented widely, can positively impact family caregivers. These statements were developed by members of the council during a series of sub-committee meetings. The council agreed that the recommendations should be further illustrated with the voices and stories of real caregivers. Their voices are featured throughout the report as a series of section dividers.



Congress weighs paid family leave options

As the Biden domestic legislative battle grinds on, the focus centers on finding a meeting point between the president's expansive vision and the strictures sought by Senators Joe Manchin III and Kyrsten Sinema. Among the many safety net programs hanging in the balance that would greatly impact family caregivers: a paid family leave payment plan. As The New York Times Claire Cain Miller [writes](#) "Paid family leave could become law in the United States, if Democrats succeed in pushing through their large social safety net spending plan. But lawmakers are still debating the details of the policy. Policy design matters a lot, experts say, because depending on the choices made, paid leave could be inaccessible to those who need it, or even end up backfiring by penalizing people who take it. Also, lawmakers may not get a second chance anytime soon. When Congress passed 12 weeks of unpaid leave in 1993, proponents hoped it was a first step toward a paid benefit. But little has changed in 28 years." Miller explores six elements of paid leave policy: who qualifies, how long is the leave period, will leave takers jobs be protected, how much does it pay, who pays for it, and how will people find out about it. The proposal under consideration, Miller observes, "would include a wider range of circumstances than those covered by even the most generous state policies, including domestic violence; a spouse's military deployment; bereavement; and caregiving for extended family, in-laws, domestic partners, and people who are the 'equivalent' of family. Most of the international research on paid leave is about new parents, but studies in the states that offer leave have shown that broadening the definition increases uptake. The main challenge for employers has been difficulty covering for absent employees, especially at small firms. But a majority of firms were still supportive of it, according to a study this year of paid leave's effect on employers in New York."

Job protection and payment methods loom as paid leave challenges

"The [Biden plan](#), as of now, would not provide job protection. Some workers would still have job protection, under the Family and Medical Leave Act, but that excludes nearly half of workers,

including those at businesses with fewer than 50 employees and those who have been employed less than a year. When paid leave doesn't include job protection, a significant share of workers are unlikely to take it even if they're eligible — particularly Hispanic workers, low earners, those who work at small businesses and those who work part time or frequently switch jobs. 'My view is if leaves aren't job-protected, it's barely leave,' said Christopher Ruhm, professor of public policy and economics at the University of Virginia. 'You're going to have lots of people being very hesitant to use it, so it loses a lot of the benefit.' How to pay for it remains one of the more disputed issues, even among voters who support paid leave. An idea generally supported by Democrats — which is how it works in the nine states (and D.C.) that have passed paid leave — is to fund it through a small payroll tax that goes into a paid leave fund, similar to the way disability works. Here's the catch: President Biden pledged not to raise taxes on anyone but the rich. Instead, federal paid leave would be an entitlement for all workers (as it already is for federal workers), paid for by tax increases on corporations and rich Americans."

Biden seeks Medicare drug price bargaining power

While the paid leave debate proceeds somewhat under the radar, a much more conspicuous, in fact all out lobbying battle, has erupted over the future of prescription drug prices, particularly over whether Medicare will be allowed to negotiate drug costs with pharmaceutical companies. TV airwaves are increasingly filling with pro and con ads. "The [Biden plan](#)," [writes](#) The Wall Street Journal's Stephanie Armour, "empowers the federal government to negotiate for drug prices in Medicare and pass those lower costs along to the private sector. The road map goes further, however, by outlining administrative actions by agencies and departments that could come in concert with possible legislative changes. Administrative measures include testing reimbursement for drugs in Medicare based on the clinical value they provide to patients and offering federal funding for research into new treatments. 'The Biden administration is trying to thread a political needle here by going aggressively after high drug prices while promoting research to blunt the pharmaceutical industry's argument that innovation will be harmed,' said Larry Levitt, executive vice president for health policy at the Kaiser Family Foundation. But PhRMA, a trade group for drug manufacturers, said the Administration's plan would hamper the industry's ability to develop new treatments as it combats the COVID-19 pandemic, while also hurting consumers. 'What was released today is a laundry list of old partisan ideas and not a serious plan to address what patients pay out of pocket for prescription drugs,' said PhRMA President and CEO Steve Uhl. Adds the Associated Press's Ricardo Alonso-Zaldivar: 'When lawmakers created Medicare's Part D drug program, they barred Medicare from negotiating prices. Drugs costing tens of thousands of dollars a month were rare when the prescription benefit was enacted nearly 20 years ago. Now they have become more common. And, amid a furious lobbying and advertising campaign, AARP, consumer groups, and health insurers are pressing for Medicare negotiations to get underway.'"

Ongoing COVID-19 hospitalizations raise rationing spector

The ripple effects of the resurgent COVID-19 pandemic are being felt across the entire spectrum of the nation's healthcare facilities. In the wake of COVID-19's lingering presence, a frightening prospect has penetrated emergency rooms, operating rooms, and intensive care units: resource rationing, or, as it is coming to be known, "crisis standards of care." "Our Lady of the Lake Regional Medical Center in Baton Rouge, Louisiana," [reports](#) the AP's Amy Forliti and Carla K. Johnson "began seeing a surge of COVID-19 hospitalizations in mid-July, and by the first week of August, the place was beyond capacity. It stopped elective surgeries and brought in military doctors and nurses to help care for patients. With cases now down, the military team is scheduled to leave at the end of October. Still, the hospital's chief medical officer, Dr. Catherine O'Neal, said the rate of hospitalizations isn't decreasing as quickly as cases in the community because the delta variant is affecting more young people who are otherwise healthy and are living much longer in the intensive care unit on ventilators. One influential model, from the University of Washington, projects new cases will bump up again this fall, but vaccine protection and infection-induced immunity will prevent the virus from taking as many lives as it did last winter. Still, the model predicts about 90,000 more Americans will die by Jan. 1 for an overall death toll of 788,000 by that date. The model calculates that about half of those deaths could be averted if almost everyone wore masks in public. 'Mask wearing is already heading in the wrong direction,' said Ali Mokdad, a professor of health metrics sciences at the university. 'We need to make sure we are ready for winter because our hospitals are exhausted.'"

States contemplate 'crisis standards of care'

The Washington Post's Ariana Eunjung Cha and Meryl Kornfield [describe](#) some emerging examples

of COVID-19 rationing. “In mid-Sept. Idaho officials announced the state was taking the extraordinary step of activating crisis standards of care statewide, giving hospitals the power to allocate — and potentially even deny — care based on the goal of who could benefit the most when faced with a shortage of resources such as ventilators, medications or staff. The decision will affect both COVID and non-COVID patients in a healthcare system that is fraying. In Montana, St. Peter’s Health in Helena moved into crisis standards, and Billings Clinic, the largest hospital system in the state, warned it could be next. Hawaii’s governor on Sept. 1 signed an order releasing health-care facilities and health-care workers from liability if they have to ration healthcare. ‘I’m scared,’ Steven Nemerson, chief clinical officer of Saint Alphonsus Health System in Boise, which has run out of ICU beds, said at a news conference. ‘I’m scared for all of us.’ Jim Souza, chief physician executive at Idaho’s largest health system, St. Luke’s, described having to squeeze bags for up to hours at a time to provide oxygen for patients while awaiting a mechanical ventilator to become available; having to leave patients on oxygen treatments in unmonitored areas where staffers might not be able to hear alarms; and stopping all surgical procedures, including those they know may result in ‘permanent disability or pathology,’ such as those for breast or endometrial cancer. ‘The net is gone,’ Souza said, ‘and people will fall from the wire.’ Idaho is one of the least vaccinated states, with about 40 percent of residents fully immunized. A doctor who called coronavirus vaccines ‘fake’ was recently selected for a regional health board.”

Triage criteria pose dilemmas

“Some states,” The Washington Post’s Hannah Knowles [reports](#), “have no crisis standards of care plans, while others just created them during the pandemic. The common goal: give healthcare workers last-resort guidance to make potentially wrenching decisions. But people disagree on the best calculus. ‘We only end up needing crisis standards of care when our other systems have utterly failed,’ said Emily Cleveland Manchanda, an assistant professor of emergency medicine at Boston University School of Medicine. Hospitals typically operate on a first come, first served basis. In a crisis — a hurricane, mass shooting or multitar crash, for example, as well as a pandemic surge — they must triage by prioritizing some patients over others to save the most lives. Different plans take different approaches, but there are common themes. Most typically start by scoring the health of major organs such as the brain, heart, kidney and liver. They may take into account people’s chances of recovery, their life expectancy and even their ‘essential worker’ status. ‘Exclusion criteria’ can instruct healthcare workers to withhold care from certain groups — patients in cardiac arrest, for instance, or those with severe dementia. Then others are ranked with scoring systems and sometimes a series of ‘tiebreakers.’ Doctors ask: How badly are patients’ organs failing? Do they have other diseases such as cancer, Alzheimer’s, or kidney damage requiring dialysis? Some plans also give priority to those who are pregnant, younger people or badly needed healthcare staff. Patients are typically evaluated throughout their stay in the hospital to check if their priority should change.”

Bioethicists debate saving lives versus saving life-years

The onset of rationing measures is not occurring without pushback as various stakeholders question the criteria being applied in the process. Weighing in on the debate concerning crisis standards of care, the Hastings Center has [published](#) a number of articles addressing the bioethical dimensions of the controversy. “Language about saving more life-years and criteria operationalizing this concept,” the authors of the [lead article](#) write, “were quickly incorporated into numerous state-level pandemic resource allocation plans for dealing with COVID-19. Yet the term ‘life-years’ is not univocal, and the ethical justification for using a principle of maximizing life-years as a means of rationing medical resources has not been adequately investigated. The first duty, of course, is to do all that one can to avoid rationing in the first place. This might require resource sharing between services and institutions, transferring patients, or employing comparably effective alternative treatments. It might require even ingenuity, such as sharing ventilators between patients or fashioning ventilators out of other equipment. Should rationing prove necessary, adherence to the standard duties of beneficence, respect for persons, and justice would entail: valuing each person equally, regardless of age or disability, and on the basis of a duty of equal beneficence toward all, deciding which treatments are potentially beneficial (and ordinarily indicated) for each patient. We endorse an aim to save the most lives while we reject an aim to save the most life-years. While not perfect, physicians are experts in judging the expected effectiveness of medical interventions for particular patients and in judging who is most likely to survive to hospital discharge, whether by a clinical scoring system or clinical assessment. Clinical determinations to withhold or withdraw ineffective care are ethically justified on the grounds that there can be no moral duty to do what will not work. It also would be ethically justifiable, in the circumstances of acute scarcity and overwhelming need, on the basis of practical

wisdom and respect for the equal dignity of all patients, to exclude anyone with any condition from which they are likely to die within one year. On the chance that two patients have the same expected benefit, one might allocate by lottery rather than some discriminatory criterion such as age or expected life-years or social worth or race or gender or any other characteristic of the person as a 'tiebreaker.' This approach seems most just and fair, respectful of the equality of all, basing decisions not on personal characteristics of the patient, such as age, disability, or social worth, but on basic medical criteria. The acute limitation of resources would dictate maximizing the number of lives saved, but it would not permit deciding which lives will be saved on the basis of other criteria such as expected life-years. It can be ethically defensible to decide that a treatment is not worthwhile, but it is never justifiable to judge that a patient is not worthy of treatment."

Staff shortages threaten nursing home care

While the front end of the healthcare system — ERs and hospitals — contends with the delta variant pressure on resources, the nursing home industry, the epicenter of the initial wave of COVID-19 deaths, is facing its own set of ongoing challenges. As AARP's Emily Paulin [writes](#), "after months of low COVID-19 cases following last winter's high peaks, infections in nursing homes are rising again. In the week ending Aug. 22, cases among residents and staff were at their highest since February. Residents died with COVID-19 at a rate three times higher than that of mid-July. On top of the highly contagious delta variant, vaccine hesitancy among nursing home workers is an ongoing threat, with only 65 percent of the workforce fully vaccinated. In some states, just over half of workers have been vaccinated. 'It's not exactly safe at this time,' says Charlene Harrington, a nursing home researcher at the University of California, San Francisco (UCSF). Vaccine mandates for nursing home workers — which have recently been handed down from long-term care companies, some state governments and now the federal government for nursing homes participating in Medicare and Medicaid — 'are a huge step in the right direction,' she says. 'But right now, as we wait for many of the mandates' deadlines to come to pass, unvaccinated workers are still a safety problem.' Staffing shortages, which have long plagued nursing homes and were exacerbated during the pandemic, are also contributing to empty beds. Every month since summer 2020, at least a fifth of nursing homes nationwide have reported a shortage of direct care workers. In some states, as many as 60 percent of homes reported such shortages during COVID-19 surges. There are signs that nursing home care is diminishing along with their revenues. Staff cuts often come first, since wages are a huge expense. Telemedicine can provide some degree of care, but most of what residents need is hands-on help: bathing, feeding, lifting and changing. Staff that survive cuts are often suffering, too. More qualified staff are often cut first to save money, leaving lower-paid staff — mainly certified nursing assistants (CNAs) — to tend to more residents than usual. CNAs are mostly women, generally make less than \$15 per hour and often lack health insurance and benefits. 'How am I supposed to be kind and compassionate and person-centered in my care if I have 30 [residents to look after]?' asks Lori Porter, cofounder and CEO of the National Association of Health Care Assistants. 'It's like an assembly line: I start at one end of the hall and I go like lightning, yanking people out of bed, dropping them in their wheelchairs, driving as fast as I can to the dining room, so no one's late for supper. Even on [a nursing home's] best day, if you're fully staffed, things can still go wrong. But things will definitely go wrong if you're staffed at a third of what you need.' More delta variant lockdowns may add to the stress. In low-occupancy facilities, where staff are overburdened, family members often help out with their loved one's care, from feeding and grooming to entertaining. But federal guidance recommends locking down an entire unit for at least two weeks after a positive test, which means putting family visits on hold."

Home health aides become scarce

And then there is home care. A third pillar of caregiver support — home care aides — has not been spared by COVID-19. The New York Times' Sharon Otterman [reports](#) that "New York State's pioneering mandate for health care workers is moving into a second and likely more difficult phase: requiring at least 250,000 home health care workers to get at least one dose of the vaccine by mid-October or face the threat of losing their jobs. While the first phase of the mandate was widely viewed as successful in pressuring thousands of nurses, doctors, technicians and orderlies to get the vaccine, many industry officials say they fear this second phase will result in thousands of workers simply quitting their jobs and finding new work in restaurants, retail or other industries. Most home health care aides, many of them immigrants, are paid about minimum wage and could find jobs paying similar wages elsewhere. Without enough workers to go around, patients recovering from stints in the hospital or elderly New Yorkers who rely on long-term aides for assistance with everything from grocery shopping to bathing could find their care reduced or ended. The shortage could also exacerbate patient backlogs at hospitals, which often discharge patients with the support

of in-home care. Already facing an industry-wide staffing crunch, agencies have begun to implement emergency staffing plans, which include limiting new admissions, asking family members of home care recipients to shoulder more of the burden, and authorizing overtime. The Visiting Nurse Service is asking to have until the end of the year to comply with the mandate. 'Home care is a different situation for workers and patients,' said Assemblyman Richard Gottfried. 'If a hospital has 95 percent of its staff, you can move people around and survive. But if a home care patient's home health aide doesn't show up, it's a 100 percent shortage for that patient.'"

Families face interminable wait for Medicaid home-based care

"In Maryland," The Washington Post's Rebecca Tan [writes](#), "Tiffanie Rivers was running out of time. Over the past year, as the coronavirus swept through nursing homes across the country and as dementia deepened its hold on her mother, she had promised herself that she would do everything possible to keep Gayle Love, 75, at home with her in Hyattsville, Md. She had pestered state employees about her paperwork for a Medicaid waiver, filed two years ago, that would help her afford home-based care. She had hired a consultant, who told her that the waiver that she was applying for in Maryland has a wait list of 21,000 names — one of the longest in the country — and that the vast majority of families see their loved ones check into nursing homes or die before they hear back. 'The wait list [in Maryland] is essentially meaningless at this point,' said Elena Sallitto, president of the Maryland/DC Chapter of the National Academy of Elder Law Attorneys. 'People die, people move, people have dementia and don't open their mail. By the time they're at the front of the line . . . it's too late.' One woman helped her elderly mother apply for a waiver in 2014, only to receive approval five years later, at which point, both she and her mother were in nursing homes. A couple joined a waiver wait list when their disabled son was 5 and heard back when he was 14. Part of the challenge in scaling up home care is resistance from nursing home lobbies, which worry competing models of long-term care could threaten their profits. But the more significant issue, said Harvard University researcher David Grabowski, is that state governments are often too financially strapped to invest in any social services that aren't mandatory, especially since states have to match federal funding with their own dollars. So even though researchers have shown for years that caring for someone in their home costs the government less in the long run than placing them in an institution, many states like Maryland have held back funding for home-based care. This still, however, doesn't have the effect of driving people to skilled-nursing facilities. In Maryland, the number of nursing home beds for long-term care had been declining for more than a decade before the pandemic. Rather than admit their loved ones into an institution, some families empty their savings to pay for a professional caregiver or have a relative, often a woman, cut down on work to provide care herself. 'To say that, well, this care is unpaid, doesn't mean it's free,' Grabowski said. 'It's hugely inefficient to put this burden on families.'"

Justice in Aging urges retroactive Medicaid home care payments

Eric Carlson, directing attorney of Justice and Aging, [calls attention](#) to a legal impediment that is further complicating access to home and community-based services (HCBS). "As a practical matter, federal policy allows Medicaid coverage to start from the first day for nursing facility care, but not for Home and Community-Based Services (HCBS). As a result, persons needing immediate help often have no choice but to move into a nursing facility. The underlying problem is federal policy that prohibits Medicaid programs from covering HCBS provided prior to the approval date of an HCBS service plan. This counterproductive policy could be addressed legislatively. A small change to federal law could allow HCBS services to be covered retroactively — the same way that coverage for many types of health care is approved after care has been provided. With this change, a person needing immediate assistance would be able to fairly choose between HCBS and nursing facility care, rather than being forced into a nursing facility by lack of an alternative. As a practical matter, healthcare providers routinely treat the patient first and then submit a claim for reimbursement. The insurer — whether a private insurer, Medicare, or Medicaid — provides payment as long as the treatment meets pre-existing standards. And, because providers become familiar with those standards, they are willing to provide care prior to receiving payment.

With long-term care and family caregiving needs so pressing, the Biden domestic agenda's many legislative pieces assume ever more significance. The **National Consumer Voice for Quality Long Term Care** has offered a comprehensive review of the current status of the various measures vying for congressional action. Its legislative update webinar and accompanying slides are available [here](#).

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Researchers propose expansive use of ARPA funds for older adults

The American Rescue Plan Act of 2021 pumped \$1.9 trillion into the ravaged COVID-19 economy, addressing the health, social and economic fallout of the pandemic. [Writing](#) in a Milbank Memorial Fund Issue Brief, Madeleine Shea and Aaron Tripp offer an array of proposals to put the resources to use in support of older adults. “With a tremendous amount of ARPA money now available for state and local governments to implement pandemic recovery plans, and still more forthcoming, states are well positioned to ‘build back stronger’ for all Americans, including older adults. While many provisions come with restrictions specific to existing programs, we believe that strategic and cross-sector use of funds can provide lasting improvements in the systems and infrastructure to support older adults to live longer in their own homes and communities. Based on early feedback from state officials and subject matter experts, we encourage states to think strategically about the use of ARPA funds, whether in combination or alongside each other, to address key themes that can deliver on the promise of community transformation to support older adults and their ability to age in homes and communities. Realizing the full opportunities that the ARPA funding provides to deliver coordinated services will require partnerships across state executive agencies, state legislatures, and governor’s offices and supports for older adults. Although the focus on Medicaid-funded HCBS is evident, several non-Medicaid funding opportunities can also be aligned and braided together to increase the reach of the dollars beyond the population eligible for Medicaid services. Combining enhanced service funding with improved supportive services such as assistance with housing, child care support for direct service workers, and integrated data systems across federal- and state-funded programs can allow the one-time ARPA funds to have a more lasting impact. Additionally, with the required quarterly updates to the HCBS spending plans and narratives, states have a real opportunity to engage in strategic planning and engagement with older adult stakeholders. ARPA offers the chance to build sustainable infrastructure and systems to support older adults to live longer in their own homes and communities. State Medicaid, aging, and housing and community development officials, state legislators, and gubernatorial advisors can come together to invest in state-tailored approaches to align and integrate Medicaid and non-Medicaid funding streams to expand supports for older adults in home and community settings that will pay dividends in the future.”

AARP: Support for working family caregivers yields substantial economic returns

In collaboration with the Economist’s Intelligence Unit, AARP has delved into the [Economic Impact of Supporting Working Family Caregivers](#); preventing these caregivers from dropping out of the labor force gives the biggest potential to boost the economy. “Keeping family caregivers ages 50 and older in the workforce,” [writes](#) AARP’s Jean Accius, Ph.D., “could generate an additional \$1.7 trillion in GDP in 2030, a figure equivalent to New York’s total economy and larger than Florida’s. In addition, improving assistance for ages 50 and older working caregivers could support 10.7 million jobs — a 5.2 percent increase in total jobs — for the entire U.S. working population in 2030, as well as boosting wages and salaries by \$1.1 trillion! Key supports from governments and employers would help caregivers of all ages remain engaged in the workforce rather than having to consider early retirement. Research shows that more than 75 percent of family caregivers ages 50 and older who retired early because of family caregiving responsibilities would have remained in the workforce longer if they had access to financial supports such as paid family/sick leave, FMLA eligibility, respite services, long-term care insurance, and care subsidies or nonfinancial supports such as employee assistance programs, flexible hours/shifts, compressed schedules, telecommuting, and phased retirement. There is no one-size-fits-all approach or policy to creating a caregiving-friendly workplace. Nevertheless, there’s a compelling business case for increasing family caregiver supports and

inclusion in the workplace.”

NAC spotlights caregivers’ need for workplace flexibility

From the experiences of some of the nation’s 23 million working caregivers, the National Alliance for Caregiving has drawn some [lessons](#) illustrating “many of the issues that have generally stood between caregivers and the support they need so they can earn a living: the mismatch between the benefits that employers offer and what caregivers truly want; the communication and confidence gap between human resources and employees; the reality that, even with a deep-pocketed employer providing robust benefits, work-life-friendly offerings can be all but unusable without a shift in workplace culture; and, crucially, the fact that Americans too often must rely on employers to provide social safety nets and services that are a matter of public policy in other wealthy economies. ‘A company’s primary concern is the bottom line, that’s just the nature of business,’ says Ariane Ollier-Malaterre, professor of management at the Université du Québec at Montréal. ‘So, it will always be problematic when critical work-life protections come from an employer and are framed in economic terms, as they are in the United States.’ For a caregiver, workplace flexibility can make the difference between shifting one’s schedule by an hour because an aide shows up late, and having to take an entire day off. It makes it possible and acceptable to join a meeting remotely from a hospital waiting area or nursing home instead of missing out. The United States is the only country among 41 developed economies where paid time off of any kind is not guaranteed to all workers. This state of affairs is particularly harmful to women, people of color and low-wage earners, who comprise a disproportionate share of this country’s working caregivers.”

Researchers highlight benefits of support for caregiving children and adolescents

“The United States should recognize and support caregiving youth.” So [argue](#) a quartet of writers who observe that “more than 5.4 million American children and adolescents under age 18 provide care for family members who are aging or have chronic illness, disability, or other health conditions that require assistance. As the numbers of caregiving youth grow, so should advocacy for legislation and supportive policy on their behalf. In the U.S., children and adolescents are largely unrecognized participants in the informal, unwaged family caregiving that millions of U.S. residents undertake to sustain their family members daily. While a growing number of European, Asian, and African countries recognize that the concerns and experiences of caregiving youth are distinct from both older caregivers and their non-caregiving peers, the U.S. has been comparatively slow in moving from identification to further research or action. Despite these challenges, there are success stories of supporting caregiving youth in the U.S. One key example is the American Association of Caregiving Youth, the only organization in the U.S. dedicated to providing support to all caregiving youth regardless of the condition of the care recipient or financial status. In response to the challenges caregiving youth face, the Association established the first U.S. Caregiving Youth Project in partnership with The School District of Palm Beach County, Florida, in 2006, to identify and support caregiving youth. The Caregiving Youth Project launched its first program in Boca Raton Community Middle School and has expanded regionally. Since its inception, the Project has provided support services for nearly 1,800 youth and their families from 6th grade through 12th grade graduation. Even though these children juggle school work and significant responsibilities at home — combined with structural inequalities of coming from primarily minority and low-income homes — their average high school graduation rate during the past six years is 98%. More than 90% of these students go on to post-secondary education, and many seek a career in healthcare, a needed labor force as the U.S. population ages.”

FDA advances potential ALS treatment

While possible Alzheimer’s disease prevention and treatment developments understandably garner ongoing news coverage, another intractable illness — amyotrophic lateral sclerosis (ALS) — has recently been the subject of a hopeful sign from the Food and Drug Administration: Cambridge-based Amylyx’s AMX0035 medication can move ahead with a new drug application prior to completion of required phase 3 clinical trials. “Early trial results,” [reports](#) WBUR’s Darryl C. Murphy, “showed that AMX0035 can slow ALS’s progression. The company plans to submit its application in the coming months and will still conduct the final phase of clinical trials. While awaiting FDA review, Amylyx may also create an expanded access program for those who wish to take the drug but do not meet the criteria for the trials.”

Nursing home data base focuses on problem facilities

The Long Term Care Community Coalition has released a new [report](#) containing federal data on nursing home five-star ratings, ownership type, enforcement, and other important information for all 15,000 U.S. facilities. The report features a page dedicated to Problem Facilities: poor performing nursing homes that are in the federal Special Focus Facility (SFF) Program, SFF Candidates, or assigned a one-star overall rating. Some key findings: Key findings: One in six U.S. nursing homes (16.5%) is a Problem Facility, including SFFs (0.6%), SFF Candidates (2.9%), and One-Star nursing homes (13.1%, excluding SFF Candidates); Average overall ratings vary significantly by state, from 2.48 (Louisiana) to 4.02 (Hawaii); and Among Problem Facilities, 86% are for-profit. Access to all the data, searchable by state or more specific location, is available [here](#).

KFF's Kaiser Health News and The John A. Hartford Foundation will hold a 90-minute [interactive web event](#) — **Confronting Ageism in Health Care: A Conversation for Patients, Caregivers and Clinicians** — on Thursday, Oct. 21, beginning at noon (ET). KFF invites registration for a conversation about the pervasive, systemic problem of bias, discrimination or stereotyping based on age. "Ageism," the webinar announcement observes, "is reflected in care strategies that ignore a patient's values and ideas about what constitutes a productive life. Too often, attitudes such as 'these patients are old and near the end anyway' or 'there's not much we can do to help them' prevail."

MEDIA WATCH

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- Alzheimer's patient Tony Bennett and Lady Gaga belt out the American songbook one last time

Aging adults care for frailer parents for longer time spans

"This won't go on for very long Sharon Hall said to herself when she invited her elderly mother, who'd suffered several small strokes, to live with her. That was five years ago," [writes](#) Kaiser Health News' Judith Graham, "just before Hall turned 65 and found herself crossing into older age. In the intervening years, Hall's husband was diagnosed with frontotemporal dementia and forced to retire. Neither he nor Hall's mother, whose memory had deteriorated, could be left alone in the house. Hall had her hands full taking care of both of them, seven days a week. As life spans lengthen, adult children like Hall in their 60s and 70s are increasingly caring for frail, older parents — something few people plan for. 'When we think of an adult child caring for a parent, what comes to mind is a woman in her late 40s or early 50s,' said Lynn Friss Feinberg, senior strategic policy adviser for AARP's Public Policy Institute. 'But it's now common for people 20 years older than that to be caring for a parent in their 90s or older.' The implications of later-life caregiving are considerable. Turning an elderly parent in bed, helping someone get into a car or waking up at night to provide assistance can be demanding on older bodies, which are more vulnerable and less able to recover from physical strain. Socially, older caregivers can be even more isolated than younger caregivers. 'In your 60s and 70s, you may have recently retired and friends and family members are beginning to get sick or pass away,' said Donna Benton, research associate professor of gerontology and director of the Family Caregiver Support Center at the University of Southern California. Caregiving at an older age can put hard-earned savings at risk with no possibility of replacing them by re-entering the workforce. Yvonne Kuo, a family care navigator at USC's Caregiver Support Center, has been helping an 81-year-old woman caring for her 100-year-old mom with vascular dementia in this situation. 'There's no support from family, and she's used up her savings getting some paid help. It's very hard,' Kuo said. As for Sharon Hall, 'I did not expect this kind of life,' she said. Hall has had two knee replacements and a broken femur. 'If someone had told me it would be years caring for my mother and your husband is going to get dementia, I would have said, "No, just no." But you do what you have to do.' Sometimes, caring for a parent can be a decades-long endeavor. In Morehead City, N.C., Elizabeth 'Lark' Fiore,

67, became the primary caregiver for her parents in 1999 when they moved around the corner from her. 'At 90, my mom is healthy as a horse, and I'm glad of that but it's been a long time caring for her,' Fiore said. 'I've changed a lot as a result of caregiving: I'm more loving, more aware of people who are suffering. I've found out that I am willing to go the extra mile. But I have to admit what I feel is tired — just tired.'

Antipsychotic drugs plague non-psychotic nursing home residents

Over medication of nursing home residents has been the subject of disturbing exposés all too frequently, and the latest one is no less so. "The handwritten doctor's order was just eight words long," [write](#) several New York Times reporters, "but it solved a problem for Dundee Manor, a nursing home in rural South Carolina struggling to handle a new resident with severe dementia. David Blakeney, 63, was restless and agitated. The home's doctor wanted him on an antipsychotic medication called Haldol, a powerful sedative. 'Add Dx of schizophrenia for use of Haldol,' read the doctor's order, using the medical shorthand for 'diagnosis.' But there was no evidence that Mr. Blakeney actually had schizophrenia. A New York Times investigation found a similar pattern of questionable diagnoses nationwide. The result: The government and the industry are obscuring the true rate of antipsychotic drug use on vulnerable residents. Schizophrenia, which often causes delusions, hallucinations and dampened emotions, is almost always diagnosed before the age of 40. 'People don't just wake up with schizophrenia when they are elderly,' said Dr. Michael Wasserman, a geriatrician and former nursing home executive who has become a critic of the industry. 'It's used to skirt the rules.' In the early 2000s, studies found that antipsychotic drugs like Seroquel, Zyprexa and Abilify made older people drowsy and more likely to fall. The drugs were also linked to heart problems in people with dementia. More than a dozen clinical trials concluded that the drugs nearly doubled the risk of death for older dementia patients. In 2005, the Food and Drug Administration required manufacturers to put a label on the drugs warning that they increased the risk of death for patients with dementia. Seven years later, with antipsychotics still widely used, nursing homes were required to report to Medicare how many residents were getting the drugs. That data is posted online and becomes part of a facility's 'quality of resident care' score, one of three major categories that contribute to a home's star rating. The only catch: Antipsychotic prescriptions for residents with any of three uncommon conditions — schizophrenia, Tourette's syndrome, and Huntington's disease — would not be included in a facility's public tally. The theory was that since the drugs were approved to treat patients with those conditions, nursing homes shouldn't be penalized. The loophole was opened. Since 2012, the share of residents classified as having schizophrenia has gone up to 11 percent from less than 7 percent. The diagnoses rose even as nursing homes reported a decline in behaviors associated with the disorder. The number of residents experiencing delusions, for example, fell to 4 percent from 6 percent. False schizophrenia diagnoses are not confined to low-rated homes. In May, the inspector general of the Department of Health and Human Services identified 52 nursing homes where at least 20 percent of all residents had an unsupported diagnosis. Medicare rated more than half of those homes with at least four of the maximum five stars.

Technology fuels emergence of 'virtual assisted living'

Add one more acronym to the list of caregiving options: VAL, which translates into "virtual assisted living." "Virtual assisted living," [writes](#) MIT AgeLab's Joseph F. Coughlin, "may be defined as the integration of the Internet-Of-Things (i.e., all those gadgets and gizmos that somehow 'talk' to each other), with seamless communications, along with the on-demand economy providing a multitude of services from telehealth/therapy, home care and related services, home monitoring, meals, and access to wheels only a finger tap away. The pandemic served as a propellant pushing technology into the lives of adult children and older adults at a velocity far faster than what typical adoption rates might have been before COVID. Suddenly tablets became the new companion enabling friends and family to simply 'drop in,' albeit virtually. Smart speakers became gateways to entertainment, communication, and notifications of deliveries at the door. Webcams, smart doorknobs, medication management devices, and entire monitoring systems ensured that older loved ones were safe in their homes. A tap of an app from miles away brought transportation, hot meals, medication, home care, and groceries to a loved one. Technology and tech-enabled living, once thought to be only the province of connected convenience-hungry Millennials, emerged as a lifeline for otherwise isolated older adults and for the people who care for them. Even if that technology is only a short-term band-aid extending a parent's desire to stay in their home, it can be a way to delay both a challenging family conversation and the move from home. Likewise, cost is always a concern, whether it is the ability to afford senior living or tech-services at home. At least one exploratory study of the Boston area conducted by the MIT AgeLab's CareHive Consortium shows the average cost of assisted living to be more expensive than using on-demand services or VAL at home. Rapidly evolving, competing,

and branded ecosystems of companies, technologies and virtual assisted living services will emerge enabling an entirely new alternative that will be part of an evolving senior living continuum. Virtual assisted living will expand the current continuum of care model — standing in between the low-tech home we knew and the senior living options we know today. In effect, these branded ecosystems of care will become their own senior living asset class — one that does not include real estate. The implications, as well as opportunities, for caregiving, senior housing, and related investment strategies are many.”

Grief ‘triggers’ trigger coping mechanisms

The Washington Post’s Katie C. Riley has some useful advice for those experiencing “grief triggers.” “Weeks after my oldest daughter was born,” Riley [writes](#), “I went on a stroller walk with her around our neighborhood. My mother had died seven years before and my father three years before. So her birth had left me on an emotional high after many years of grieving. At one point on our walk, I heard ‘honks’ of a goose loudly overhead. My dad loved to hunt geese as much for the ritual of explaining and participating in it with other people. The goose sound I heard immediately conjured an image of him. And I suddenly burst into tears as a familiar sadness filled my body. What I experienced, experts say, is a grief trigger. Well after the intense grief of an immediate loss has faded, and you think you’ve moved on, something happens out of the blue to revive it. ‘A lot of people use the metaphor of waves of grief — just when you think you are getting back on your feet, you are knocked over by a wave that you didn’t see coming,’ says Camille Wortman, professor emeritus at Stony Brook University and an expert on grief and bereavement. Some grief activators are more predictable than others, like the ones tied to holidays, anniversaries and birthdays, and events such as a birth, graduation, wedding or retirement. ‘Others are tied to our senses, such as hearing a song on the radio that reminds you of the person you lost or eating a food that reminds you of them or seeing someone who looks like them,’ said Sarah Kroenke, co-founder of the Grief Club of Minnesota.” Riley suggests several actions to provide relief from a triggering event: “Create a plan in advance for the predictable calendar dates that trigger sadness and grief; build up your capacity to deal with these difficult time periods by establishing a tool kit of activities or resources you can turn to when a grief activator occurs; allow self-compassion when a grief activator occurs; and remember that grief activators are a part of the grieving process. ‘In the clinical world of providing grief support, they are not viewed as a step backward, but rather just a natural and normal part of the grieving process,’ Kroenke says. ‘Grief activators,’ adds Jana DeCristofaro, a grief support group facilitator at the Dougy Center in Portland, Ore., ‘remind us of the reality that the people in our life who have died meant something to us. They played a meaningful role in our lives and they continue to play a meaningful role in our life even if they are not here in their physical form.’”

Patti Davis shares caregiving insights from her father’s battle with Alzheimer’s Disease

Drawing upon her very personal experience, Patti Davis, the daughter of Pres. Ronald Reagan, has written a handbook for Alzheimer’s caregivers. “In 1994,” [reports](#) The Wall Street Journal’s Emily Bobrow, “Ms. Davis learned that her father was about to announce in a public letter that he had Alzheimer’s disease. ‘Something opened up in me,’ she writes in [Floating in the Deep End](#), her new handbook for Alzheimer’s caregivers. Helping her father offered a way out of her ‘dark, little world’ by pushing her to grow up. ‘If he could face the uncertainty of his remaining days with that kind of courage, I could look ahead with courage as well.’ For the six years that she led a twice-weekly caregiver support group, Ms. Davis tried to create a safe space for the inevitable mess of emotions. Yet she pushed back whenever someone said a living patient was ‘gone.’ ‘There’s still a soul in there,’ she insists. Alzheimer’s is an often terrifying foe, but Ms. Davis argues it can be a profound teacher, too. Instead of viewing the disease as a thief, she recommends seeing it as something that ‘peels away the layers of a person’ to reveal the essence underneath. It was also a relief to discover her own strength and capacity for compassion. ‘It helped me realize that we don’t have to be a hostage to our past, to the lives we’ve lived, even to the decisions we have made.’ No one is left unchanged after losing someone to Alzheimer’s. ‘How you will be different, however, is a matter of choice.’”

Alzheimer’s patient Tony Bennett and Lady Gaga belt out the American songbook one last time

The mystery of Alzheimer’s is on full display as CBS 60 Minutes correspondent Anderson Cooper visits with 95-year-old singing legend and Alzheimer’s patient Tony Bennett. Policy Digest has

previously written about Bennett's incredible journey that has now left him still able to sing like his young self but unable to process most aspects of his current life. Cooper's [segment](#) aired in conjunction with Bennett's last public performance in August at Radio City Music Hall. He and Lady Gaga, his multiple album duet partner, sang some very familiar standards before an ecstatic, sold-out audience. Prepare to reach for some Kleenex.

FAMILY CAREGIVER ANNOUNCEMENTS

Innovations in Alzheimer's Caregiving Awards



In partnership with The Rosalinde and Arthur Gilbert Foundation, Bader Philanthropies, Inc., and Family Caregiver Alliance

Applications open!

[The Rosalinde and Arthur Gilbert Foundation](#), the [Bader Philanthropies, Inc.](#), and [Family Caregiver Alliance](#) are pleased to announce that the application period is now open for the [Innovations in Alzheimer's Caregiving Awards 2021](#). The awards highlight organizations that deliver state-of-the-art programs that address the needs of caregivers and those they care for with Alzheimer's disease or a related condition. One award of \$20,000 will be given in each of the following three categories: Creative Expression, Diverse/Multicultural Communities, and Public Policy. **The deadline is October 18, 2021 at 5 p.m. Pacific Time.**

For more information:

Review our [online application form](#).

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See our online [scrapbooks of past recipients 2008–2020](#).

Learn about the [2020 award recipients](#).

Read the [press release about the 2020 awardees](#).



Free online programs for caregivers

The [California Caregiver Resource Centers \(CRCs\)](#) provide regular educational and informative online events open to all family caregivers in California. This is a coordinated effort to offer a wide range of **free programs** in multiple languages and with topics of interest to family caregivers. A downloadable monthly calendar listing of events is available in a [linkable PDF](#). View the PDF on your browser, or download to Adobe reader. You can also view the calendar on the CRC website [here](#).



¿QUÉ PASA?

Cuidadores Familiares del Área de la Bahía de San Francisco

For Spanish-speaking caregivers in the San Francisco Bay Area

[¿Qué Pasa? boletín](#) is a bimonthly newsletter from FCA for Spanish-speaking caregivers. Check out

the September-October 2021 [issue here](#). And click here to [subscribe](#). FCA is unique among national caregiver organizations by providing direct support to family and friend caregivers as the Bay Area Caregiver Resource Center, and is one of 11 caregiver resource centers in California.



Infographic illustrates Best Practice Caregiving program ACTS-2

This recently-produced and downloadable [infographic](#) offers a quick, top-level overview of **ACTS-2: African-American Alzheimer's Caregiving Training and Support Project 2** — one of the 40+ dementia caregiving programs available in [Best Practice Caregiving](#). BPC is a free online database that helps organizations identify, compare, and adopt evidence-based dementia caregiving programs for their clients and community. Every program is proven, vetted, and ready for implementation — plus, many can be delivered remotely and/or are free to adopt. Check out more program downloadable infographics in a recent BPC newsletter [here](#).



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Grab this 1-pg, print-ready infographic on ACTS-2 – one of 44 proven dementia caregiving programs in Best Practice Caregiving – for a quick program snapshot and overview. ow.ly/fWKB50Gia3e



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