

How President Trump Put People With Disabilities At Risk Ahead Of The Pandemic

People With Intellectual and Developmental Disabilities
Are Seeing Alarming Rates of Infections and Deaths
From Coronavirus

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People With Intellectual and Developmental Disabilities Are Seeing Higher Rates of Infections and Deaths From Coronavirus

There are [61 million adults](#) with a disability in the United States. According to the Centers for Disease Control and Prevention (CDC), adults with disabilities are [three times more likely](#) to have chronic conditions, like heart disease, diabetes, and cancer, that put them at higher risk for severe illness if they contract the coronavirus.

While more research is needed to assess the disproportionate impact of the virus on people with disabilities broadly, early data has revealed that people with intellectual/developmental disabilities (I/DD) are seeing higher rates of infections and deaths from the virus. Many of these individuals live in group settings or rely on direct care workers to meet their daily needs, increasing their likelihood of exposure to the virus. Individuals residing in congregate settings are particularly at risk: a growing body of research has shown that individuals residing in facilities are [more likely to die](#) from the virus. A New York Times analysis [revealed](#) that there is a racial disparity in nursing homes that have experienced outbreaks, but more research is needed to show the intersection between race, disabilities and the toll of the coronavirus. Access to health care has always been essential for people with disabilities, but during the pandemic, the stakes have never been higher.

BY THE NUMBERS:

- **[61 million U.S adults have a disability](#)**. Thanks to the Affordable Care Act, insurance companies can no longer deny them coverage, drop their coverage for no reason, or charge them more because of a pre-existing condition.
- **More than [seven million](#) people live with intellectual disability in the United States.**
- **[One in six](#) U.S. children has a developmental disability**. According to the CDC, roughly 17 percent of children aged 3 through 17 years have one or more developmental disabilities, including ADHD, intellectual disability, and autism.
- **8.7 million nonelderly adults with disabilities depend on Medicaid for care**. Nearly [8.7 million adults](#) enrolled in Medicaid have a disability. Of this group, only 43 percent qualify for supplemental security income (SSI). The remaining [5 million](#) beneficiaries do not receive SSI and therefore do not qualify for coverage based on their disability status alone, meaning they rely on the ACA's Medicaid expansion or eligibility as low-income parents.
- **More than [1 in 3 adults](#) under age 65 enrolled in Medicaid lives with at least one disability.**
- **Nearly 45 percent of adults with disabilities have Medicaid coverage**. Medicaid covers [45 percent](#) of nonelderly adults with disabilities, including adults with physical disabilities, developmental disabilities, brain injuries, and mental illnesses.
- **More than half of adults with disabilities covered through Medicaid earn less than 100 percent of the federal poverty line (FPL)**. A majority, [52 percent](#), of adults with disabilities who have Medicaid coverage earn annual incomes of less than 100 percent of the FPL, \$12,060 for an individual, and could not afford needed care without the program.
- **Medicaid helps people who need long-term supports and services to stay in their communities**. Of nonelderly people with disabilities who rely on Medicaid for long-term supports and services, [80 percent](#) receive community-based services, while only 20 percent receive institutional services.

People With I/DD Are At Higher Risk Of Infection And Death From Coronavirus

June 2020 Associated Press Analysis: At Least 5,800 Residents Living in Congregate Settings Have Tested Positive For Coronavirus, And More Than 680 Have Died. “While nursing homes have come under the spotlight, little attention has gone toward facilities nationwide that experts have estimated house more than 275,000 people with conditions such as Down syndrome, cerebral palsy and autism. Many residents have severe underlying medical issues that leave them vulnerable to the coronavirus. At least 5,800 residents in such facilities nationwide have already contracted COVID-19, and more than 680 have died, The Associated Press found in a survey of every state. The true number is almost certainly much higher because about a dozen states did not respond or disclose comprehensive information, including two of the biggest, California and Texas.” [Associated Press, [6/10/20](#)]

- **40 Percent Of Intermediate Care Facilities Failed To Meet Safety Standards For Preventing And Controlling The Spread Of Infections And Communicable Diseases Before The Pandemic.**

“Perhaps the best-known government-funded homes for the disabled are called Intermediate Care Facilities, which range from large state-run institutions to homes for a handful of people. Before the coronavirus hit, regulators concluded that about 40 percent of these facilities — at least 2,300 — had failed to meet safety standards for preventing and controlling the spread of infections and communicable diseases, according to inspection reports obtained by AP. The failures, from 2013 to early 2019, ranged from not taking precautionary steps to limit the spread of infections to unsanitary conditions and missed signs that illnesses were passing between residents and employees.” [Associated Press, [6/10/20](#)]

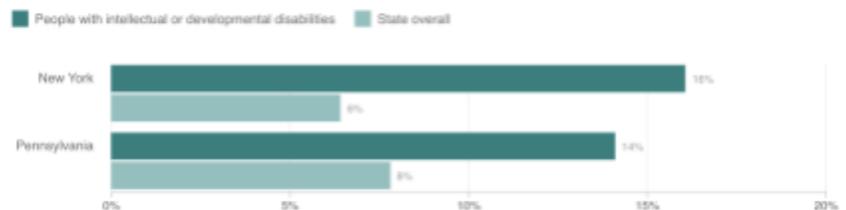
- **AP Survey Found That At Least 2,100 Congregate Settings Have Experienced Coronavirus Outbreaks, But The Federal Government Is Not Tracking This Data.** “No such data exists for thousands of other group homes for the disabled because they are less regulated. But AP found those homes have also been hit hard by the virus...More than 2,100 homes for the disabled have seen COVID-19 infections among residents or staff, according to the AP survey — an undercount because not all states provided specific information.” [Associated Press, [6/10/20](#)]

June 2020 NPR Analysis: People With Intellectual Disabilities And Autism In Pennsylvania And New York Who Test Positive For Coronavirus Are Dying At About Twice The Rate Of The General Public. “In Pennsylvania, numbers obtained by NPR show that people with intellectual disabilities and autism who test positive for COVID-19 die at a rate about twice as high as other Pennsylvania residents who contract the illness. In New York, the state with the most deaths from COVID-19, people with developmental disabilities die at a rate 2.5 times the rate of others who contract the virus.” [NPR, [6/9/20](#)]

- **As Of June 2, There Were 801 Confirmed Cases And 113 Deaths Among People With Intellectual Disabilities And Autism In Pennsylvania.** “The numbers in Pennsylvania are compiled by the Office of Developmental Programs of the Pennsylvania Department of Human Services and count people who get state services while living in group homes, state institutions or in their own homes. As of June 2,

People With Intellectual Disabilities And Autism Die Of COVID-19 At A Higher Rate

In New York and Pennsylvania, COVID-19 case-fatality rates for people with intellectual and developmental disabilities are higher than the states' overall rates. (Case-fatality rates are deaths as a percentage of total confirmed cases within the population.)



Notes

Data as of June 3. Numbers for people with intellectual disabilities reflect those who get services from the state.

Source: NPR, 6/9/20

there were 801 confirmed cases and 113 deaths among people with intellectual disabilities and autism.” [NPR, [6/9/20](#)]

- **At Least 2,289 People With Developmental Disabilities In New York Have Tested Positive For Coronavirus, And 368 Have Died.** “In New York, NPR calculated data obtained from the New York State Office for People with Developmental Disabilities. Of people who get state services from that office, 2,289 have tested positive for COVID-19 and 368 have died.” [NPR, [6/9/20](#)]

The Covid-19 Fatality Rate For Children With Intellectual/Developmental Disabilities Is 1.6 Percent, Compared To Less Than 0.1 Percent For Children Without I/DD. “The researchers analyzed data from TriNetX — an electronic medical record database that includes information from 42 health care organizations — on 30,282 test-confirmed coronavirus patients: 474 with IDD and 29,808 without. The patients received their positive diagnosis between Jan. 20 and May 14, the study said...For patients between 0 and 17 years of age, those with IDD had a fatality rate of 1.6%, while those without IDD had a fatality rate of less than 0.1%, the study revealed.” [Miami Herald, [6/11/20](#)]

- **The Chances Of Contracting Covid-19 Were “Remarkably Higher” For Children With I/DD Than Children Without Them.** “At the same time, the chances of contracting COVID-19 were about the same for people with and without IDD, but it was ‘remarkably higher’ for those with the disabilities (26%) versus those without them (3%) at 17 years old and younger.” [Miami Herald, [6/11/20](#)]

The Death Rate For Coronavirus Among People In Virginia With Intellectual-Development Disorders Is Three Times Higher Than For The General Population. “People with developmental issues are more likely to die from Covid-19, the disease caused by the new virus, than the general population, according to data from Maryland and Virginia. People with autism, for instance, suffer greater incidences of obesity, immune disorders and diabetes, according to research by Kaiser Permanente Northern California—conditions that have led to higher death rates during the pandemic. The rate of death for people in Virginia with intellectual-development disorders is three times higher than that of the general population, according to the Virginia Department of Behavioral Health & Developmental Services.” [Wall Street Journal, [6/11/20](#)]

By May, More Than One In Five Illinoisans Living In State Homes For Adults With Disabilities Had Tested Positive For Coronavirus. “As of Thursday, more than 1 in 5 people living in these developmental centers had tested positive for the novel coronavirus, state data shows. That’s more than double the infection rate seen in nursing homes and other long-term care facilities, where confirmed cases account for about 7% of residents, according to the Illinois Department of Public Health. Of about 1,650 people who live in the seven developmental centers, which are scattered throughout the state, at least 355 have tested positive, or 21.5%. Eight residents have died, as have four workers.” [ProPublica, [5/22/20](#)]

Kaiser Health News: In Wisconsin, The Coronavirus Pandemic Has “Exposed Vulnerabilities In The State’s Health Care Programs, Including Those Designed To Serve Older Residents And Those With Disabilities.” “The novel coronavirus, which has infected nearly 13,000 Wisconsinites, has exposed vulnerabilities in the state’s health care programs, including those designed to serve older residents and those with disabilities. Before the pandemic, Gov. Tony Evers in 2019 created a state task force to address a chronic shortage of caregivers. A report released in February described a ‘crisis’ in the direct care workforce, with 20,655 vacant positions in Wisconsin’s long-term care facilities and residential settings, and an average workforce vacancy rate of nearly 26%. For residents with disabilities who need caregivers in order to live and work independently, the pandemic is adding hurdles. These visiting aides take on demanding duties and are typically paid about \$12 an hour in Wisconsin.” [Kaiser Health News, [6/17/20](#)]

Every Respondent To An April Survey Of Nearly 500 Wisconsinites With Disabilities And Older Adults Reported That The Pandemic Disrupted Their Caregiving Services. "Every respondent to an April survey of nearly 500 Wisconsinites with disabilities and older adults said the pandemic had disrupted their caregiving service. Wisconsin Watch conducted a dozen interviews with people with disabilities, their family members and caregivers across Wisconsin, revealing how the crisis has transformed each life in unique ways." [Kaiser Health News, [6/17/20](#)]

- **Stacy Ellingen, A 34-Year-Old Wisconsinite Living With Cerebral Palsy, Was Forced To Move Back In With Her Parents After The Pandemic Disrupted Her Home Care.** "When the COVID-19 pandemic hit, Stacy Ellingen, 34, of Oshkosh, Wisconsin, lost two of the three caregivers she depends on to dress, shower, eat and use the bathroom. The caregivers — both University of Wisconsin-Oshkosh students — returned to their parents' homes when the university canceled in-person classes. Ellingen, who lives with complications from cerebral palsy, had little choice but to do the same — moving back to her parents' home in Fond du Lac." [Kaiser Health News, [6/17/20](#)]
- **Jason Endres, Wisconsinite With Spina Bifida-Linked Scoliosis, Chose To Go Without Needed Home Care, Fearing Risks Of Exposure To Coronavirus Without Adequate PPE.** "Jason Endres asked his care workers to stay away from the home he shares with his wife Julie in Eau Claire. With masks hard to come by, Endres feared the caregivers could inadvertently spread the virus, possibly ravaging his lungs, which have been weakened by spina bifida... 'It's really one of the big reasons why we haven't had anyone come into the home,' Endres said. Without a ready supply of masks, the couple feels uncomfortable inviting even familiar workers into their home, considering that many of them visit multiple clients or other work sites." [Kaiser Health News, [6/17/20](#)]

Scott Landes, Associate Professor Of Sociology At Syracuse University's Maxwell School Of Citizenship And Public Affairs, Said His Research Shows That People With Developmental Disabilities Who Live In Group Homes Are Four Times More Likely To Contract Coronavirus. "'They're more likely — four times more likely, we're showing — to actually contract COVID-19 than the general population,' he says. 'And then if they do contract COVID-19, what we're seeing is they're about two times more likely to die from it.'" [NPR, [6/9/20](#)]

- **Up To 20 Percent Of People With Developmental Disabilities Live In Group Homes, Compared To 6 Percent Of People Over The Age Of 65.** "They're much more likely, than even elderly people, to live in a setting with roommates and staff like group homes where two or four or 10 or more people live together. About 13% to 20% of people with developmental disabilities live in such settings, Landes notes, compared with only about 6% of people over age 65." [NPR, [6/9/20](#)]

Disability Activist Alice Wong Called For Investigations Into Outbreaks At All Congregate Care Settings.

"Governors need to launch investigations into outbreaks at all congregate settings, mandate reporting of infections and deaths, enact universal testing for all workers and residents, provide adequate personal protective equipment, increase wages and protections for workers, and deny the nursing home industry the legal immunity it is demanding." [Disability Visibility Project, [June 2020](#)]

Tom McAlvanah, President Of New York Disability Advocates, Said That Low Wages Have Contributed To Shortages Of Direct Care Workers During The Pandemic. "In New York, a direct service professional working in a group home makes little money — 'at or below the poverty line,' in the mid \$20,000s a year, says Tom McAlvanah, president of New York Disability Advocates, a coalition of service providers. He says it has been hard to keep workers healthy and on the job. They're vulnerable not only because of where they work, but because they often rely on public transportation. McAlvanah says New York's Medicaid program, the main source of payment for group home providers, has failed to increase reimbursements even before the coronavirus pandemic. Now, he says, group home residents have

stopped going to work and group home providers have had to pay staff — without government reimbursement — to work more hours and overtime to run the group homes where residents now spend their full days.” [NPR, [6/9/20](#)]

David Ervin, Chief Executive Of Jewish Foundation For Group Homes Inc., Said Group Homes Were Low Priority For Obtaining Personal Protective Equipment At The Beginning Of The Pandemic: “We Scoured The Earth To Get Access To Equipment.” “Most care homes are nonprofits, funded through Medicaid and charitable donations. David Ervin, chief executive of Jewish Foundation for Group Homes Inc., which runs 27 homes in Maryland and Virginia and is Mr. Stewart’s employer, said homes were a low priority when state and county authorities were doling out personal protection equipment and testing supplies, despite direct-support professionals being designated as essential health-care workers. “‘We scoured the earth to get access to equipment,’ he said.” [Wall Street Journal, [6/11/20](#)]

Michelle Phoenix, Assistant Professor School Of Rehabilitation Science At McMaster University And CanChild Scientist, Said Children With Disabilities Are Especially Vulnerable During The Pandemic As They Face Limited Personal Protective Equipment And Personal Support Workforce Shortages. “Many children with disabilities require medication, personal protective equipment (PPE, such as gloves and masks), home care, respite and rehabilitation services. These resources are scarce or unavailable given PPE shortages in communities, delayed or cancelled dispensing of medical equipment, cancellation of respite and group programs and the potential for staffing shortages. Even if PSWs or home nurses are available, families may suspend the service to limit exposure to COVID-19 when staff are providing service in multiple homes.” [The Conversation, [5/11/20](#)]

New York Times: Research Shows People With Intellectual Disabilities At Higher Risk For Death From Pneumonia, Flu. “Studies suggest that death rates from pneumonia — a common Covid-19 complication — were up to 5.8 times higher in 2017 among those with intellectual disabilities. During the 2009 flu pandemic, more than 40 percent of the children who died had neurodevelopmental disorders. The Centers for Disease Control and Prevention has labeled intellectual disability as a high risk condition for flu.” [New York Times, [6/10/20](#)]

How President Trump Made Health Care Worse For People With Disabilities Ahead Of The Pandemic

Medicaid and the Affordable Care Act (ACA) remain lifelines for people with disabilities during this crisis. At a time when millions of people are facing the possibility of coronavirus and devastating health care bills, protecting coverage of our nation’s most vulnerable is more important than ever. The ACA ensures that insurance companies cannot deny coverage, drop coverage for no reason, or charge people more because of a pre-existing condition. Without these protections, people with disabilities could face barriers to accessing coronavirus treatment. Health care coverage not only directly helps individuals who get sick, but it also helps communities slow the spread of the virus by helping detect cases sooner.

Medicaid is a vital source of care for people with disabilities. Research has shown the people with disabilities covered by Medicaid are [more likely](#) to receive comprehensive and consistent care than those who are privately insured. The program also provides half of all long-term care in the United States. Protecting access to Medicaid, particularly during the pandemic, is essential to ensuring people with disabilities continue to get the care they need.

HOW PRESIDENT TRUMP & CONGRESSIONAL REPUBLICANS ARE TRYING TO DISMANTLE THE AFFORDABLE CARE ACT AND MEDICAID:

Trump Wants To Repeal Medicaid Expansion And Protections For Pre-Existing Conditions Through His Lawsuit To Overturn The ACA. The Trump administration is currently backing a lawsuit to overturn the Affordable Care Act and, if they are successful, [23 million](#) people would lose insurance, and protections for pre-existing conditions would be

eliminated overnight. The lawsuit would also terminate Medicaid expansion, threatening to rip away coverage from 17 million, including people with disabilities, and cut key funding for already-struggling rural hospitals during the pandemic.

- **Republican Efforts To Repeal Medicaid Expansion Would Mean 64 Percent Of Medicaid Adults With Disabilities Would Lose Coverage.** Per the [Center on Budget and Policy Priorities](#): “The Affordable Care Act’s Medicaid expansion covers 11 million people. Many of them struggle with a chronic illness or a disability (such as a mental health condition) that wouldn’t, by itself, qualify them for Medicaid. Only 36 percent of non-elderly Medicaid beneficiaries with disabilities receive Supplemental Security Income, which allows them to enroll in Medicaid even without the expansion.”

The Trump Administration Is Encouraging States To Impose Work Requirements And Other Bureaucratic Restrictions On Medicaid Enrollment In Order To Deny Coverage. For years, Trump has empowered states to impose red tape and paperwork requirements as part of his ongoing efforts to dismantle Medicaid. Work requirements have been at the center of these efforts. After Arkansas imposed the nation’s first work requirements program, more than [18,000](#) residents lost Medicaid coverage. While work requirements have been blocked by a federal judge [several times](#), the Trump administration [keeps fighting](#) to impose these onerous rules in Medicaid. In addition to work requirements, the administration has encouraged states to impose other barriers such as [increased eligibility verification](#) as well as premiums and other cost-sharing. All of these efforts amount to blatant attempts to strip health care away from vulnerable Americans.

- **Requiring People To Work To Maintain Medicaid Coverage Is Particularly Burdensome For People With Disabilities.** Though some states are claiming to exempt people with disabilities from their work requirements, these exemptions are narrow and [leave many behind](#). Among those who should qualify for exemptions, work requirements make it more difficult to keep coverage by requiring enrollees to provide documentation, testimony, and records to prove they have disabilities.

Trump Wants To Gut The Medicaid Budget & Has Encouraged States To Pursue Harmful Block Grants. Trump has repeatedly sought deep health care cuts in his budget proposals, most recently seeking [more than a trillion in cuts](#) to Medicaid and the Affordable Care Act for 2021. This budget essentially ends Medicaid expansion by [eliminating](#) the enhanced federal payment and proposes nationwide work requirements. Under the Trump administration’s recently finalized [block grant](#) proposal, federal funding would no longer necessarily increase in response to a public health emergency like coronavirus. This could lead to people losing coverage and access to care, undermining prevention and treatment of diseases nationwide.

President Trump And His Administration Are Pushing Short-Term Junk Plans That Allow Insurance Companies To Discriminate Against People With Pre-Existing Conditions. The Trump administration is bringing back health plans that are allowed to [discriminate against](#) people with pre-existing conditions and designed to suck health people out of the individual market, thus raising premiums for people who depend on the individual market for comprehensive coverage.

President Trump And His Administration Have Refused To Reauthorize Money Follows the Person (MFP). In the [2019 budget](#), the Trump administration refused to reauthorize the Money Follows the Person program, which allows Medicaid beneficiaries to move from institutional settings into the community. The Administration’s refusal to extend MFP beyond the end of the year 2020, continues to put people with disabilities at risk.

TRUMP WANTS TO “TERMINATE” THE AFFORDABLE CARE ACT, WHICH PROVIDES AFFORDABLE COVERAGE AND HEALTH SECURITY TO PEOPLE WITH DISABILITIES

Without the ACA, protections for [135 million Americans](#) with pre-existing conditions will be eliminated overnight, and the uninsured rate will increase by 65 percent. Making matters worse, if the ACA is struck down, everyone who contracts the coronavirus could be deemed as having a pre-existing condition and be at the mercy of their insurance companies who could refuse to pay for needed care. This is especially important for people with I/DD, who are both more likely to have pre-existing health conditions and contracting the coronavirus at higher rates.

The Affordable Care Act Prevents Insurance Companies From Charging Americans With A Disability More, Or Denying Them Coverage Altogether. Prior to the ACA, insurance companies were allowed to charge people more or deny coverage simply because they had a pre-existing condition. The ACA banned this practice, requiring that insurance companies offer people coverage regardless of their health status.

Thanks To The Affordable Care Act, Insurance Companies Can No Longer Impose Annual And Lifetime Limits On Coverage. Before the ACA, insurance companies could restrict the dollar amount of benefits someone could use per year or over a lifetime. At the time the ACA was passed, [91 million](#) Americans had health care through their employers that imposed lifetime limits. Many such plans capped benefits at \$1 million annually, functionally locking people with complex medical needs out of coverage.

Insurance Companies Can No Longer Practice Medical Underwriting, A Process That Let Insurers Make It Harder For People With Disabilities To Get The Coverage They Needed. Before the ACA, insurance companies could screen applicants for any conditions that might be costly to the company. If someone had condition that was predicted to cost the insurance company more, the insurance company would follow a practice called "[medical underwriting](#)" that allowed them to charge the applicant a higher premium, specifically exclude coverage for the condition that was expected to be costly, charge the applicant a higher deductible, or limit the applicant's benefits (for instance, offer a policy that did not cover prescription drugs).

The ACA Requires Insurance Companies To Cover Basic Health Services. The Affordable Care Act established the ten [essential health benefits](#), requiring insurance companies to cover rehabilitative or habilitative services, hospitalization, maternity care, prescription drugs, maternity care, and mental health services.