



## **CT residents with developmental disabilities get less primary care, with costly consequences**

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### **Research reports**

#### [‘I Am Not The Doctor For You’: Physicians’ Attitudes About Caring For People With Disabilities](#)

T Lagu et al, Health Affairs 41: 1387-1395, October 2022

In focus groups with physicians, researchers found structural and financial barriers, as well as poor information and attitudes, that affected their willingness to care for patients with disabilities. Physicians are overwhelmed, both in general and by ADA requirements. They often lack knowledge and feel unqualified to care for patients with disabilities. One noted that the usual fifteen-minute visit is “absolutely ridiculous”. They reported needing help with care coordination, more space in facilities, and more reimbursement to overcome the barriers.

#### [Physicians’ Perceptions of People with Disability And Their Health Care](#), L Iezzoni, et. al., Health Affairs 40: 297-306, February 2021

In addition to health problems related to their disabilities, patients also face challenges because of physicians’ biased and stigmatized perceptions. In a national physician survey, 82% believe that people with disabilities have a worse quality of life than people without disabilities, despite the fact that over half of people with disabilities report an excellent or good quality of life. Almost 60% agree that people with disabilities are often treated unfairly in the health care system, 59% are not very confident of their ability to care for people with disabilities, and only 57% strongly agree that they welcome people with disabilities into their practice. These reported physician biases are higher than for other underserved populations. The rates of biases was not lower for physicians who have practiced over twenty years, suggesting that the biases persist even after experience treating patients with disabilities.

#### [“He only takes those type of patients on certain days”: Specialty care access for children with special health care needs](#)

RF Winizker, et al, Disability and Health Journal, 5: 26-33, 2012

The authors found disparities in access to care for children with special healthcare needs.

#### [National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities](#)

S Havercamp and H Scott, Disability and Health Journal 8:165-172, 2015

Compared to Americans without disabilities, adults with intellectual and developmental disabilities were five times more likely to be in poor health and half as likely to get a check-up. They have lower rates of blood pressure checks, flu shots, or screens for cancer, cholesterol, vision, or hearing. They are also four times less likely to get physical activity and more likely to be obese. The authors state these risks lead to a “thinner margin of health” for people with disabilities.

#### [Social determinants of health, emergency department utilization, and people with intellectual and developmental disabilities](#)

C Friedman, Disability and Health Journal, 6/8/2020

Researchers found a strong relationship between social determinants of health and emergency department visits for people with intellectual and developmental disabilities. The authors note “despite the fact that people with IDD face many health disparities, these disparities are not necessarily due to people with IDD’s health behaviors or impairments alone. Instead, people with IDD’s social circumstances, access to healthcare services, high rates of poverty, environments, social seclusion, and ableism - social determinants of health - all contribute to people with IDD’s health.”

#### [Indicators of poor mental health and stressors during the COVID-19 pandemic, by disability status: A cross-sectional analysis](#)

C Okoro et al, Disability and Health Journal, 4: 101110, 2021

During the first year of COVID, people with disabilities were more likely to suffer depression, abuse, suicidal ideation, substance use than other Americans. They had worse access to healthcare, more difficulty caring for themselves or others, and more difficulty accessing food.

#### [Effects of the Medicaid expansion under the Affordable Care Act on health insurance coverage, health care access, and use for people with disabilities](#)

X Dong et al, Disability and Health Journal, January (15) 2022

While the Affordable Care Act expanded healthcare coverage to many more Americans, including people with disabilities, this study found no improvement in access to care or health outcomes for people with disabilities. They measured having a usual source of care, unmet medical care needs, and unmet prescription medicine needs. People with disabilities face serious healthcare delivery challenges in addition to coverage.

#### [Disparities in patient-physician communication for persons with a disability from the 2006 Medical Expenditure Panel Survey \(MEPS\)](#)

D Smith, Disability and Health Journal, 2009 2 (2009) pp 206-215

People with disabilities are 1.36 to 1.78 times more likely to report inadequate patient-physician communication. They are significantly more likely to feel that their physician does not listen to them, does not explain treatment so that they understand, does not treat them with respect, does not spend enough time with them, and does not involve them in treatment decisions.

[Disability-competence training influences health care providers' conceptualizations of disability: An evaluation study](#)

K Phillips et al, Disability and Health Journal, 14(4) October 2021

Health care provider training on the needs of patients with disabilities improves their knowledge, outlook, and approach to caring for people with disabilities.

[Dental access and expenditures for adults with intellectual and other disabilities,](#)

C Fosse, et al, Journal of Public Health Dentistry, 81(4):299-307, December 2021

American adults with intellectual disabilities are 2.7 times less likely to get dental care and 2.88 times more likely to delay needed dental care than other adults. They are more likely to be covered by Medicaid.

[Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies,](#) BMC Women's Health, January 30, 2021

Women with disabilities face different barriers to accessing healthcare than men, including "sociocultural (erroneous assumptions, negative attitudes, being ignored, being judged, violence, abuse, insult, impoliteness, and low health literacy), financial (poverty, unemployment, high transportation costs) and structural (lack of insurance coverage, inaccessible equipment and transportation facilities, lack of knowledge, lack of information, lack of transparency, and communicative problems)."

[Perinatal Health Risks And Outcomes Among US Women With Self-Reported Disability, 2011–19](#)

W Horner-Johnson et al, Health Affairs, 41: 1477-1385, October 2022

Using an improved data source, the authors find that pregnant disabled women are at higher risk for poor birth outcomes than women who are not disabled. Their babies are at 24% and 29% higher risks of preterm and low birth weight, respectively.

## Data

[Definition and demographics of developmental disabilities,](#) CT Council on Developmental Disabilities

There are about 43,000 Connecticut residents with developmental disabilities. Many state residents have intellectual, mobility, or psychiatric disabilities, substance use disorder, autism, epilepsy, hearing or vision loss, often with a developmental disability.

[Disability & Health U.S. State Profile Data for Connecticut \(Adults 18+ years of age\),](#) CDC

One in ten Connecticut adults have a cognitive disability, the most common type of disability among adults in our state. They are more likely to be depressed, smoke tobacco, be obese, have diabetes and heart disease than other state residents.

[Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States,](#) MMWR, August 17, 2018

Among adult Americans with cognitive disabilities in 2016, access to care was most challenging for young adults (ages 18 to 44). One in five did not have insurance coverage (21.5%), 34.0 %

did not have a usual healthcare provider, 33.4% had an unmet healthcare need due to cost, and 38.6% did not get a check-up in the last year. Access to care is somewhat better for older Americans with cognitive disabilities, although 86.4% of seniors had a cost-related unmet healthcare need. The article also includes the prevalence of disabilities and access by type of disability, age, gender, race/ethnicity, socioeconomic status, and geographic region.

[Health Care, Family, and Community Factors Associated with Mental, Behavioral, and Developmental Disorders and Poverty Among Children Aged 2–8 Years — United States, 2016](#), MMWR, 2018

In 2016, children ages 2 to 8 years with any mental, behavioral, or developmental disorder were 4.2 times less likely to receive needed care than children without those disorders. They were more likely to be on public insurance (likely Medicaid) or have no coverage. They were also more likely to be Black, live in poverty, and live in unsafe, unsupportive neighborhoods.

## **Policy**

[Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care?](#)

Lisa Iezzoni, et. al., Health Affairs, 41: 1371-1378, October 2022

Despite years of advocacy under the Americans with Disabilities Act and its Amendments, there are still wide disparities in access to care for people with disabilities. However, things are getting better. The article outlines six areas of barriers with potential remedies.

[Advancing Health Equity And Reducing Health Disparities For People With Disabilities In The United States](#)

M Mitra, et al., Health Affairs 41: 1379-1386, October 2022

The authors give the prevalence of disability in the US based on race, ethnicity, and sexual orientation and how disability intersects with other forms of marginalization.

[Health care under the ADA: A vision or a mirage?](#)

N Mudrick, et al, Disability and Health Journal, (2010) 3: 233-239

And

[Achieving accessible health care for people with disabilities: Why the ADA is only part of the solution](#)

S Yee, Disability and Health Journal 3: 253, 2010

The Americans with Disabilities Act has been a critical tool to address physical barriers to services for people with disabilities, but for a variety of reasons it has not had a significant impact on access to healthcare. Access to care is a challenge for many Americans. Healthcare access and quality are complex, as are the solutions. Litigation is difficult and there are few tools to change the attitudes and knowledge gaps of providers.

[Persons With Disabilities as an Unrecognized Health Disparity Population](#), Am J Public Health, 105(Suppl 2): S198–S206, April 2015

Adults with disabilities are four times more likely to be in fair or poor health. There is a long history of discrimination and exclusion of people with disabilities that impacts their health.

Addressing the inequities as a public health issue would bring attention and resources to bear by increasing access to care, expanding healthcare workforce capacity for people with disabilities, and inclusion in public programs.

## **Resources**

[What Do Primary Health Care Providers Need to Know? A guide for health care providers of young adults with and without disabilities, Connecticut Edition, 2012](#), CT-KASA, CT DPH Family Health Section

Almost half (45%) of youth with disabilities lack access to a doctor who is familiar with their diagnosis and are far more likely to use the Emergency Department than other youth (45% vs. 25%). Written by youth with disabilities, this resource provides actionable assistance for healthcare providers in caring for Connecticut youth with disabilities.

[Healthcare for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Care Providers](#), Vanderbilt University Medical Center

The site provides best-practice tools and information on specific medical and behavioral concerns for primary care providers caring for adults with IDD. The Toolkit also includes resources for patients and families.

[Doctors Are Failing Patients With Disabilities](#), Atlantic Monthly

A very readable description of the challenges facing patients with disabilities, including real world challenges, the causes, a synthesis of the research, and potential solutions.