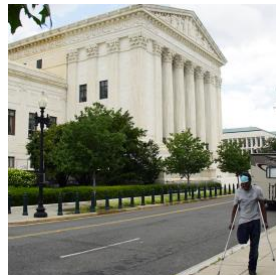


The Changing Reality of Disability in America: 2020



Allan R. Meyers Memorial Project



The Changing Reality of Disability in America: Allan R. Meyers Memorial Project, a report prepared by the Institute for Human Centered Design, September 2020

Changing Reality of Disability in America 2020 | Dr. Allen R. Meyers Memorial Project

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This IHCD initiative has had a consistent core project team from inception and their biosketches are at the back of the document: Valerie Fletcher, Team Leader, Writer, and Researcher; Matthew Brault, Demographic and Statistical Research Consultant; P.J. Moynihan, Producer Director, and Cinematographer; and Erica Walker, Public Health Specialist, Writer, and Researcher. Additional IHCD staff and interns added expertise and pertinent talents to the film and the report. They are: Meghan Dufresne, Oce Harrison, Jennifer Kalashian, Janice Majewski, Vay Orstadt, Gabriela Sims, Rachel Wang, David West.

This is a working paper and Phase I of an ongoing project. It represents research in progress. This paper represents the opinions of the authors, and is the product of professional research. Any errors are the fault of the authors.

Acknowledgement

Dr. Allan R. Meyers was Professor of Public Health, Boston University School of Public Health, Research Professor of Physical Medicine and Rehabilitation, Boston University School of Medicine, and Professor of Anthropology, Boston University College of Arts and Sciences Graduate School.

He had a keen commitment to work related to disability and human rights. He conducted research and authored many publications related to disability, spinal cord injury, access to care, managed care, and substance abuse. In addition, he mentored students with disabilities in careers in public health. He saw a clear opportunity in the burgeoning universal design movement to benefit people with disabilities and collaborated with IHCD (then Adaptive Environments) to analyze the physical environmental context. After his death in May of 2000, the American Public Health Association created the APHA Disability Section Allen Meyers Award for Research, Teaching and Advocacy which continues still.

This memorial project builds from our colleague Allen Meyers' fearless pursuit of accuracy and rigor, and the vital importance of environments that minimize disability and facilitate the opportunity for everyone to live fully. Funding for this first phase of the Changing Reality of Disability in America 2020 was from the Allen Meyers' Memorial Foundation through his wife Anne and sons David and Jon.

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Attachments

The Changing Reality of Disability in America: From Legal Coverage to the Big Tent
Timeline from the Passage of the ADA to the Present Noting Pertinent Additional
Milestones from the Passage of the ADA to the Present

**NOTE: Wherever possible we have included tables alongside charts to ensure
accessibility to content and data for assistive technology users.**

Foreword

This project started in January of 2020 when the world, and most especially the United States, was different. Our priority to analyze the changing reality of disability was born of a growing sense of concern that much of what people knew of disability in 1990 had not evolved or not evolved enough. Unless we know who's being left out we cannot create a world that minimizes the rising volume of functional limitation and support everyone to live self-directed lives.

The Institute for Human Centered Design (IHCD), founded in 1978 as Adaptive Environments, is an international design and education not-for-profit whose mission focuses on the role of design in social justice for people at the edges of the social and economic spectrum. That includes people with disabilities, older people, and people racially, culturally or economically who live, often imposed by social norms, on the margins.

IHCD is fortunate to do this work globally and has had a window into other ways of thinking and counting people with disabilities. Data varies wildly from nation to nation. Some countries do not count brain-based conditions at all. Some cease to count people who are over 60 or 65 as disabled. Internationally there is a priority on improving both accuracy and comparability through the *UN Convention on the Human Right of People with Disabilities* (CRPD), the *World Health Organization's Global Disability Action Plan 2014-2021*, and the UN Statistics body, The Washington Group, for internationally comparable disability statistics. (<https://www.washingtongroup-disability.com>)

Even in the US, which has the most accurate information on disability in the world, it is never simple. Data collection methods vary substantially and are inherently imprecise. The International Committee on Disability Research estimated that there are sixty-seven (67) definitions of disability in the federal government codes alone. In a majority of cases, the motivation for definition of disability is to determine individual eligibility for services. The small number of objective national data sources on disability each have inherent limitations but are invaluable for a longitudinal understanding of what changes.

In addition to the national big data sources, we have sought out population-level data that offer evidence of issues commonly absent from our understanding of disability. For many of these stories, defined by shared experience of a particular physical or mental health impairment, the link to disability is unexpressed. Across the board, research is limited, particularly for Black Americans and people of color in relation to disability. We need to

know who's included - and who's left out - in order to assess the multiple contexts of American life so central to reducing the creation of impairment and to minimizing the negative aspects of a functional limitation.

This report uses data from a variety of sources and care should be taken when making comparisons between estimates.

The demographic data are not perfect and research on all US minority communities is especially thin. Today, US Census data informs us that 60.1 percent of the US population is white, 18.3 percent Hispanic/Latino, 13.4 percent Black, 5.9 percent Asian and just over 1 percent Native American. Twenty-six percent of adults have a disability but it does not fall equally.

The World Health Organization's International Classification of Function, Disability, and Health (WHO ICF) of 2001 is the current gold standard for framing disability in the US and globally. It starts with the foundational premise that impairment alone tells us too little. Diagnosis is not destiny. It tells us little about what might be possible for someone with even very significant limitations. The experience of the last fifty years of the disability rights movement has made that clear. Impairment at the individual level must be understood in terms of functioning and participation in social roles. Environmental factors, including physical and social contexts, establish the barriers or facilitators that determine meaningful participation.

COVID 19 laid bare the inequity that has been a constant throughout the nation's history from the first days of colonization and slavery. This public health emergency delivered daily evidence of an alarming racial disparity in illness and deaths. Three times more Black Americans became ill and two and a half times as many Blacks as whites died. Americans suspended from their busy lives registered an entrenched reality as news.

The US, the richest nation on earth, spends nearly twice as much as other developed nations on health care but has tolerated persistent and now undeniable disparity. But little of that money is spent on addressing population health, the means by which so much infectious disease was eliminated in the 20th century. That investment transformed life in the 20th Century by eliminating deadly contagion from tuberculosis, diphtheria, smallpox, tetanus, and polio. Today, just 2.5 percent of the \$3.5 trillion in US spending on healthcare goes to public health. The US delivers healthcare to individuals or at least to individuals with health insurance. In America today, responsibility for health is not a shared responsibility but a private one.

This project, both report and accompanying documentary film, is intended to spur conversation that needs to happen now. It is not intended as an iteration of all of the facets of the disability experience. That's impossible. We have abundant individual stories that prove that personal and environmental factors can minimize limitations and support being fully engaged societal actors. Too often that experience remains an exception. The necessary quest for the opportunity for full participation continues to apply to all people with lived experience of impairment.

Our goal is to spotlight issues for people too seldom considered as central to understanding disability in America. We want to summon awareness that can help to inform policy as we act to rebuild from the 2020 COVID 19 pandemic and the Black Lives Matter protests. We seek to stimulate research with neglected populations. We need to end doing harm and learn what works if we are to measure progress.

The crisis of the pandemic and all it reveals about entrenched habits of inequity and racism is the best opportunity of several lifetimes to act. A still fragile awareness of our interdependence can guide us to tackle a social and environmental context that fails too many of us and puts all of us in jeopardy of an unsustainable society and economy. We need to rebuild our identity on the global stage as a place that strives always for equity and human rights.

The ADA gave us a primer on equity for people with disabilities by affirming clear rights and responsibilities. Paired with the WHO ICF and its focus on context and participation, they open a path forward. But we need to own where functional limitation intersects with inequity to inform priorities.

***Not everything that is faced can be changed, but
nothing can be changed until it is faced.***

— James Baldwin

Please join us in this necessary conversation.

Sincerely,

A handwritten signature in black ink, appearing to read 'Valerie Fletcher', with a stylized, flowing script.

Valerie Fletcher
IHCD Executive Director

Introduction

Introduction

Disability is not special. Not so long ago, and true when the Americans with Disabilities Act (ADA) was passed in 1990, the focus was on “impairment.” Some people were already in the ADA’s newly legally “protected class” but anyone might acquire an impairment and join. Thirty years later, after dozens of nations have created civil and human rights protections for people with disabilities, the ADA remains the global standard for ensuring rights and clarifying responsibilities. No other nation has the infrastructure of technical assistance, enforcement and research with a nationwide network of ADA Centers to support voluntary compliance. No other place has such high expectations of equity as a civil right for people with disabilities nor so large a proportion of people with disabilities able to live lives that they choose.

Unsurprisingly, there are prevalent and often wrong assumptions about disability. Those habits of thought tend to reinforce notions of people with disabilities as “special,” as “other,” and as readily identifiable by appearance or by use of wheeled mobility, or white canes, or American Sign Language. It tends to minimize a sense of shared experience.

Dr. Irving Kenneth Zola, a founding member of the Society for Disability Studies and professor of Sociology at Brandeis University, argued in 1989 that a focus on the individual with an impairment and the language of “special” powerfully depoliticizes all of the external factors that shape an individual’s experience. He stressed the critical need for attention to the environment and to policy. Eleven years before the World Health Organization published the International Classification of Function, Disability and Health (WHO ICF) with its *contextual* definition of disability Dr. Zola made the case that “recognizing each person’s uniqueness also acknowledges their interdependence and promulgates a concept of special needs which is not based on breaking the rules of order for the few but on designing a flexible world for the many.” (Zola, 1989. 21)

The World Health Organization International Classification of Function, Disability and Health (WHO ICF) and its contextual definition in 2001 offered a framework for thinking about impairment as part of a continuum of health that happened within a context of personal and environmental factors. Its key features included:

- Functional limitation is a universal human experience if one lives a typical lifespan.
- There is parity between mental and physical reasons for impairment.

- Most importantly, the goal was clear that people with functional limitations should be able to become fully engaged members of society. In the WHO ICF, it was no longer about cause of the limitation but about its impact. It was a radical shift to an emphasis on health at both the personal and the population levels. The model summoned attention to creative intervention. Redesign the context and you minimize the limitation.

The ICF focuses on the context, on the dynamic interaction of a person with a functional limitation and physical and social environments. That interaction is the point at which disability is amplified or minimized. The model invites awareness that environments are not fixed but mutable and inevitably powerful either negatively or positively. The contextual definition offers a tool for dramatically modifying the outcomes of a functional limitation if we choose to use it.

If we take the opportunity to focus on creating environments - including policies and attitudes - that minimize limitations and support people, we minimize negative outcomes. This bio-psycho-social model became the global gold standard for understanding and measuring disability at the population level. The WHO recommended Universal Design in 2001 as the most promising framework for creating *facilitating* environments that would go well beyond narrow concepts of barrier removal.

Chapter 1: Patterns

Chapter Sections:

- Aging and Chronic Health Conditions
- The Rise in Prevalence of Brain Function as Reason for Impairment
- Stress, Trauma, and Health for Black Americans
- General Characteristics about Disability in America in 2020

Patterns

According to the CDC, 90 percent of the \$3.5 trillion in annual US healthcare spending are expenditures for chronic and mental health conditions. It is a partial reflection of the changing reasons for disability in America.

In the US, the definition of disability under the ADA has gone from expansive to diminished by court decisions and back to expansive with the 2008 ADA Amendments Act. At the time of the passage of the ADA in 1990, the statute stated that ‘43 million Americans have one or more physical or mental disabilities.’ The Centers for Disease Control (CDC) finds 61 million adults with a disability in 2020, 26 percent of the adult population.

A sharp shift has occurred since 1990 in reasons for disability. Mobility limitations remain the most prevalent reason for disability among adults. Difficulty walking and climbing stairs predominate rather than the use of wheeled mobility. Even with the highest proportion of people over 65 in our history, just 1.4% of people outside of institutional care use wheeled mobility. The high prevalence of difficulty walking results from chronic health conditions such as arthritis, heart disease, stroke and diabetes. The majority of people with mobility limitations don’t use any assistive technology including canes, crutches, or walkers.

Aging and Chronic Health Conditions

Medicare reports that Americans 65 and over numbered 30 million in 1990 and are now 56.1 million in 2020. But a transformation of aging has occurred since 1990. With prevention through healthy habits to avoid smoking and obesity and increase exercise, paired with a boon in surgical and pharmacological innovation, there is a growing pattern of “compression of morbidity” that shrinks serious limitations and trouble caring for oneself to an ever-shorter period at the end of life. James Fries’ original hypothesis of healthy aging dates to 1980 and described “healthy aging” as the alternative to the assumption of disability as inherent to aging. The projected demographics of an aging society had generated fears of a “pandemic of disability.” It has not materialized.

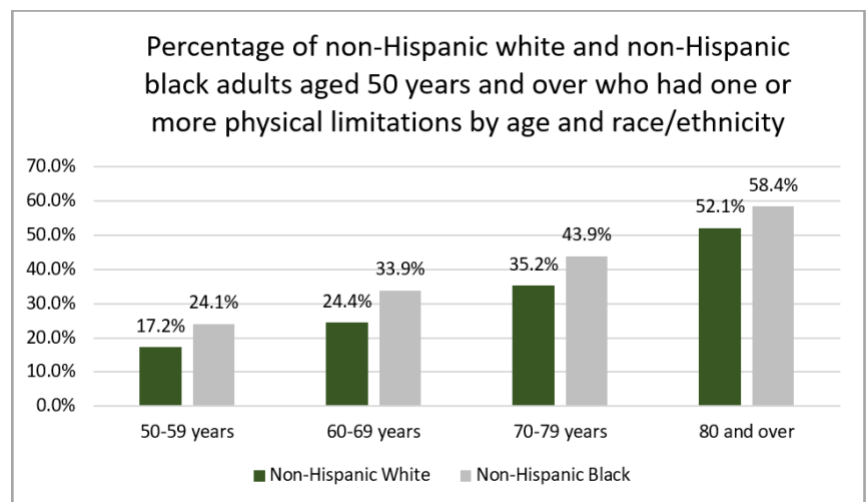
But compression of morbidity doesn’t apply equally. Black Americans and people who are poor report limitations at earlier ages than people who are more advantaged. Data from the National Health Interview Survey report that acquired physical limitations of Blacks between

age 50 and 59 are one in four. Reliable data for the mental spectrum of functional limitations is limited.

Chronic conditions are commonly the “pre-existing conditions” that condemned so many Black and Hispanic/Latino Americans to the highest infection and death rates from COVID 19. In addition to high rates of high blood pressure, diabetes, and stroke, a new study by the Center for Environmental Medicine and Informatics at State University of New York (SUNY) at Syracuse offers an early analysis about the role of the environment in creating chronic conditions. Hazardous air pollutants are culprits in creating chronic respiratory conditions that have increased vulnerability to infection and death from COVID 19. Low income Black residential neighborhoods sited along industrial corridors have become “asthma and cancer alleys”, most acute in parts of Louisiana, Alabama, and New York.

The whole notion of the presumed dichotomy between healthy aging with compressed morbidity and extended periods of disability was born in 1980. In this model, disability was not a complex and mutable part of human experience but rather a medical model assumption of a fixed condition of limitation. “Healthy Aging” was a radical notion of interrupting a process in order to drive preferred outcomes. It worked. But it only worked for some. Unsurprisingly it worked for white Americans with middle and higher incomes. Black adults generally have rates of physical limitations similar to whites a decade older.

| Percentage of non-Hispanic white and non-Hispanic black adults aged 50 years and over who had one or more physical limitations by age and race/ethnicity | | |
|--|--------------------|--------------------|
| Age | Non-Hispanic White | Non-Hispanic Black |
| 50-59 years | 17.2% | 24.1% |
| 60-69 years | 24.4% | 33.9% |
| 70-79 years | 35.2% | 43.9% |
| 80 and over | 52.1% | 58.4% |
| Source: CDC/NCHS, National Health Interview Survey, US, 2001-2007. | | |



“Healthy Aging” shares a belief in mutability with the 2001 WHO reframing of disability as a contextual phenomenon. Limitation does not occur in a vacuum. One can change the outcome with a near guaranteed bonus of greater and longer opportunities for social participation.

The disparity is a population-level health challenge. It needs to be embraced as an opportunity for an urgent focus on promoting healthy behavior and equally on eliminating environments that create functional limitations. It means expanding a commitment to healthy aging to those currently left out. One facet of that is the exponential rise of chronic conditions. Not everyone who has a chronic condition has a functional limitation that may be a disability. But many do and it's critical to consider the opportunities to modify environments and behavior that could help to stem the rise and make health aging a shared vision.



\$3.5 trillion in US health spending is not delivering longer lives. Today, the CIA Fact Book ranks the US #43 in the world in average lifespan. For the first time in a century, American lifespans have dropped in the last decade and don't keep pace with the rest of the developed nations. Black American lifespans have actually improved in the last two decades. The decrease in average US lifespans is largely attributable to death among blue collar white Americans in middle age because of addiction, alcoholism, and suicide. This mental spectrum of functional limitation are "deaths of despair," occurring at record rates in the US and not occurring in other developed nations. The US has the highest rates of suicide since World War II. Unsurprisingly, chronic physical conditions like high blood pressure, heart disease, diabetes tend to co-occur.

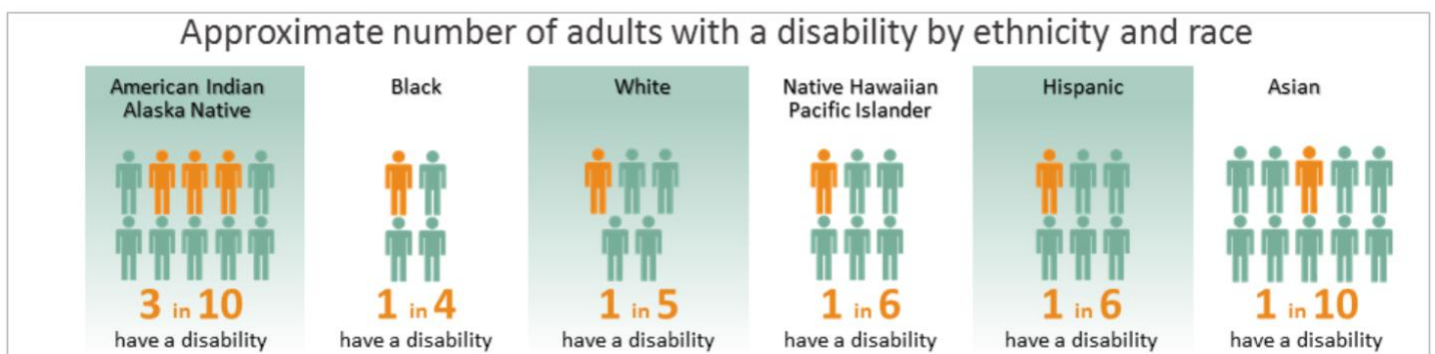
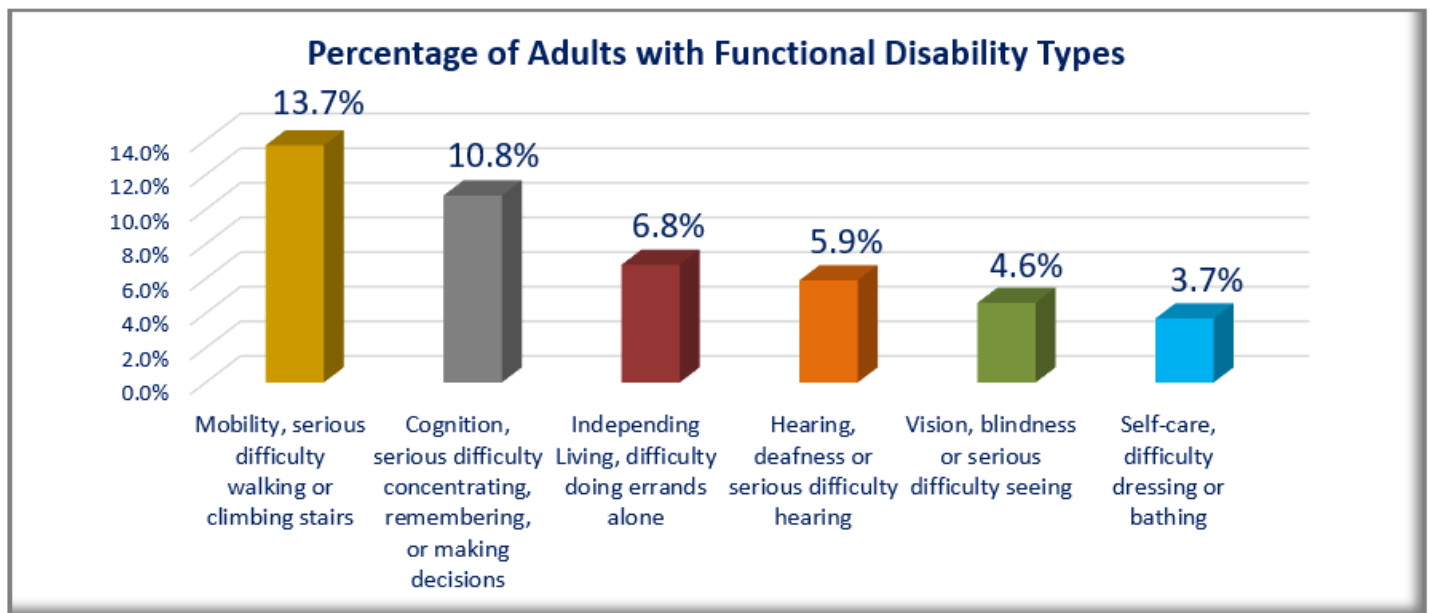
The Rise in Prevalence of Brain Function as Reason for Impairment

Thirty years ago, the constellation of advocates attentive to the “mental” spectrum of disability cheered together that parity between physical and mental reasons for disability was a lynchpin of the ADA. But it was a fragmented group including those concerned with mental health conditions, learning disabilities, substance use, developmental disabilities, intellectual limitations, brain injury, dementias, and neuro-diverse conditions. The stress and trauma related to inequity and racism as the etiology of mental functional limitation were not a part of the mix then.

Today, with clarity born of the 2008 ADA Amendments Act about limitations to “major bodily functions” as equal to limitations of “major life activities” in determining who is in the protected class covered by the ADA, this extraordinary diversity of etiologies all result in limitations to brain function, one of the listed ADAAA “bodily functions.” Among children and youth, emotional, behavioral, and neurological reasons for disability dominate physical reasons. Given the dynamic nature of disability, changing expectations of brain function in a world transformed by technology likely also shift our understanding about what constitutes impairment of necessary functional ability.

Cognition, the mental spectrum of reasons for disability, has become the second most prevalent reason for disability among adults at 10.8 percent of the population. And it is the undeniable leading reason for disability among children and youth. 20 percent of children ages 13-18 currently have and/or previously had a seriously debilitating mental disorder. For children 3-21, 14 percent or 7.1 million who received special education services, 33 percent had specific learning disabilities. An additional 2.3 percent of the school-age population have 504 plans who have conditions like food allergies, diabetes, some anxiety disorders, and mild ADHD.

| Percentage of Adults with Functional Disability Types | |
|---|-------|
| Mobility, serious difficulty walking or climbing stairs | 13.7% |
| Cognition, serious difficulty concentrating, remembering, or making decisions | 10.8% |
| Independent Living, difficulty doing errands alone | 6.8% |
| Hearing, deafness or serious difficulty hearing | 5.9% |
| Vision, blindness or serious difficulty seeing | 4.6% |
| Self-care, difficulty dressing or bathing | 3.7% |
| <i>Provided by "Disabilities impact all of us" from the CDC.</i> | |



Graphics provided by "Disabilities Impact All of Us" from the CDC.

Stress, Trauma, and Health for Black Americans

The US experience of COVID 19 delivered painful truths about the impact of inequity and racism on health. It demands attention to the context of people's lives as a measure of inequity. We can use the public health language of the "social determinants of health," the conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of-life risks and outcomes. The focus needs to be on addressing the context as both source and amplifier of functional limitations.

The facts are not new. The US has a large population of people with limited education, income, no work or marginal work who are more vulnerable to self-reported poor health and disability. The shared experience of a pandemic exposed the facts. Black Americans are overrepresented in nine of the ten lowest-wage jobs considered "essential." Black Americans are also more likely to live in denser living situations of multi-family and multi-generational households, putting them at greater risk of exposure to COVID.

The added stress of racism adds risk. It's not limited to people who are economically disadvantaged. Public health researcher Arline Geronimus developed a hypothesis of "weathering" originally in 1992 to describe the premature deterioration of health through the wear and tear of the repeated stress of racism. Steady exposure to stress hormones impact the cardiovascular, metabolic, and immune systems, making the body more vulnerable to illness and risking premature death.

The Special Case of Pregnancy for Black Mothers

The weathering hypothesis was about Black women and pregnancy. Nowhere is the phenomenon of racism's harm more sharply etched than in mothers and babies. Evidence of disparities between Black and Native American and white women in reproductive health has been well known for years but was explained away as tied to behavior and/or poverty. An April 2018 feature in the New York Times Magazine, *Why America's Black Mother and Babies are in a Life-or-Death Crisis* shattered those assumptions.

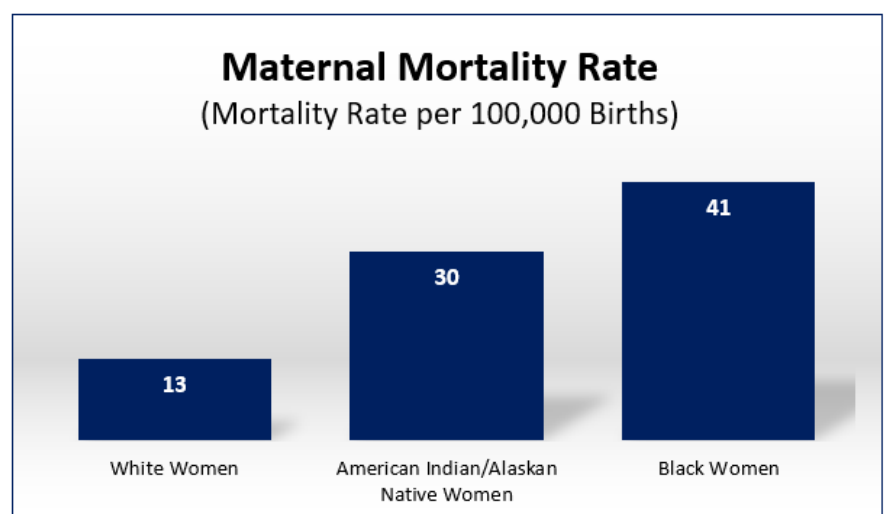
Black mothers have dramatically higher rates of pregnancy-related death. Dramatically more of their babies die in their first year. Black mothers have the highest rates of low birth-weight babies mostly from pre-term births. It is so extreme that it is responsible for the shameful status of the US in the CIA Fact Book rankings of both infant mortality (#174, between Bosnia and the UAE) and maternal mortality (#129, between Russia and Ukraine).

Education, so often the key to improving health status doesn't stem the risk. Nor does age at pregnancy. There is no safe age for a Black woman to have a child. Pregnancy Related Mortality Ratios (PRMR) for Black women with a college education or higher was 5.2 times that of their white counterparts. It gets worse instead of better for the most accomplished Black women. Infant mortality is highest for Black women with a doctorate or a professional degree.

It seems likely that the “weathering” hypothesis is at the heart of this heartbreaking data. But that leaves us with a sense that the transformation of the experience of racism is the only remedy. The health care system itself and its quality share blame for this alarming national disgrace. There are similar rates of pregnancy-related complications among Black and white women but Black women have significantly higher rates of fatality.

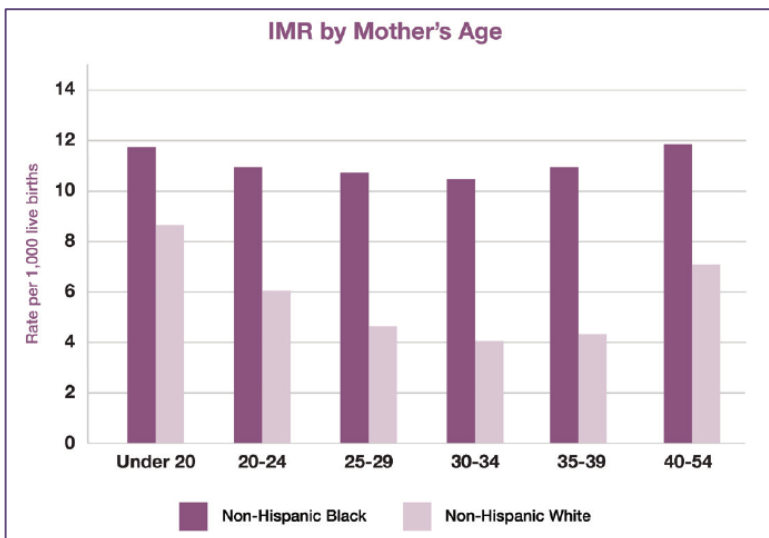
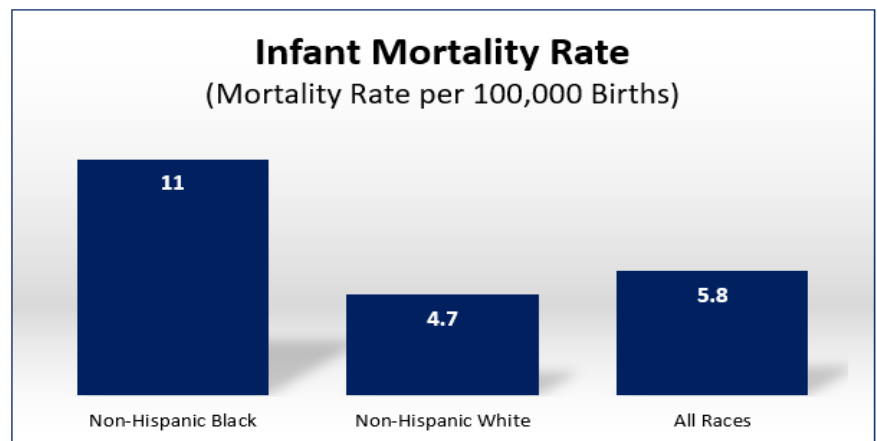
What does this shocking pattern of the vulnerability of pregnancy for Black women in America have to do with disability? One aspect applies to the children, especially the prevalence of low birthweight babies born to Black women. These babies born at who are most at risk for low oxygen levels at birth, trouble staying warm, trouble feeding and gaining weight, infection, nervous system problems, digestive problems, and sudden infant death syndrome (SIDS). Very low-weight babies are at risk for long-term functional limitations including cognitive, motor, sensory, behavioral deficits, poor growth, long-term lung and gastrointestinal conditions.

| Maternal Mortality Rate Mortality Rate per 100,000 Births | |
|---|----|
| White Women | 13 |
| American Indian/Alaskan Native Women | 30 |
| Black Women | 41 |
| Source: Emily E. Petersen et al., "Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007-2016." <i>Morbidity and Mortality Weekly Report</i> 68, no. 35 (September 6, 2019): 762-65. <i>Racism, Inequality, and Health Care for African Americans</i> , December 19, 2019 — Jamila Taylor | |

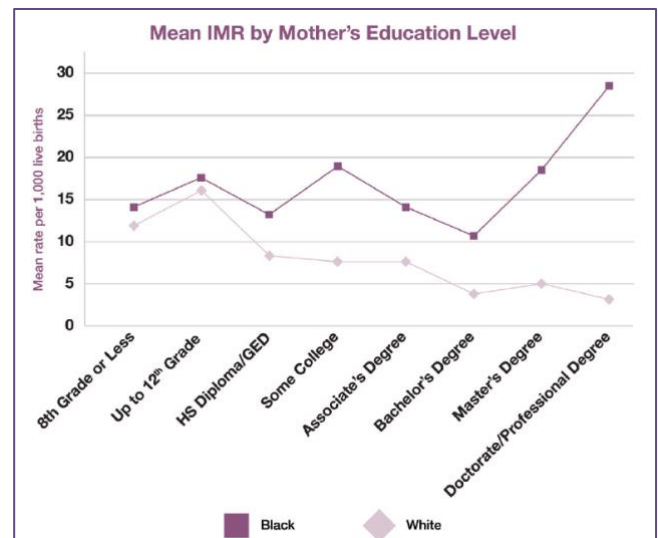


| Infant Mortality Rate Mortality Rate per 1,000 Live Births | |
|---|-----|
| Non-Hispanic Black | 11 |
| Non-Hispanic White | 4.7 |
| All Races | 5.8 |

Source: "Infant Mortality and African Americans." U.S. Department of Health and Human Services, Office of Minority Health. *Racism, Inequality, and Health Care for African Americans*, December 19, 2019 — Jamila Taylor



Source: CDC 2015. Infant Mortality Statistics from the 2013 Period Linked Birth/Infant Death Data Set. National Vital Statistics Reports. Chart obtained from *Fighting at Birth: Eradicating the Black-White Infant Mortality Map*. March 2018



Adapted from source: CDC 2015. Infant Mortality Statistics from the 2013 Period Linked Birth/Infant Death Data Set. National Vital Statistics Reports. Note: This analysis controls for the mother's age and marital status. Chart obtained from *Fighting at Birth: Eradicating the Black-White Infant Mortality Map*. March 2018

Also consider the ADA Amendments Act of 2008 and its clarification that “major life activities” includes “major bodily functions” such as reproductive functions specifically called out in the legislation. We would suggest that the persistent long-term pattern of reproductive inequity and functional limitation for Black women fits that criterion for being covered under the ADA.

There is reason to be hopeful that the impact of stressors can be changed. Evidence comes from observing the most fundamental measures of health among some people with high exposure to the kind of contexts that make most people sick but for whom there is limited

negative impact. They are characterized by high levels of mastery, self-esteem, and/or social support. Unfortunately, those positive contextual qualities seem not to protect Black mothers with significant academic achievement inevitably requiring high levels of mastery and self-esteem, perhaps lacking in social supports.

We should prioritize strategies that generate more of that positive personal context while working simultaneously to prioritize reduction of implicit bias and structural racism in healthcare delivery.

General Characteristics About Disability in America in 2020

Across the spectrum of disability in America there are common characteristics regardless of race or culture, socio-economic status, or reason for a functional impairment.

1. A mental or physical limitation is most commonly along a continuum of severity from mild to significant. It is likely to change over time for each individual and severity on the continuum will vary in response to the personal and social context.
2. Non-apparent conditions are the norm. Assumptions about being able to discern disability by observation were never accurate but are especially wrong today.
3. The overwhelmingly majority of functional limitations are acquired over the course of life. Congenital or gestational conditions occur but their prevalence is not as high.

Chapter 2:

Ethnic/Racial Sub-Populations

Chapter Sections:

- Asian Communities
- Hispanic/Latino Communities
- Native Americans

Ethnic/Racial Sub-Populations

Asian Communities

Asians are the fastest growing racial or ethnic sub-group in the US. Between 2000 and 2019, the population almost doubled from 11.9 million to 22.2 million. Asians are heterogeneous with over twenty (20) distinct nationalities from Chinese to Southeast Asian to Indian and Pakistani. There is scant research to date on prevalence of physical or mental disabilities. Aggregating Asians risks losing the opportunities to understand unique needs and strengths.

Despite the increasing diversity and volume of the Asian community in America, current data on disability is so limited that the default assumption is that disability is quite rare in Asian communities for both children and adults. It is commonly cited as the lowest disability incidence population at about 1 in 10.

No single country-of-origin group dominates the U.S. Asian population. The most recent demographic data indicates that the largest populations are Chinese, Indian, and Filipino with the Chinese the largest at 24 percent, Indian-origin at 20 percent and Filipinos at 19 percent. People of Japanese, Vietnamese, and Korean origin number over 1 million each with 13 additional nations making up the balance. The extraordinary diversity of cultures demands that a new research agenda set a priority on engagement with people with lived experience of disability in the variety of Asian communities. Absent engagement, there is scant hope of moving from our present lack of good data to competence in creating a supportive context for the Asian community with disabilities.

Hispanic/Latino Communities

The Hispanic/Latino population is the largest minority population in the US and a heterogeneous group tied together by a shared language. People of Mexican heritage predominate today with 64 percent of total Hispanic/Latino population in the US though there are sizeable populations from Puerto Rico and Central and South America. The long dominant pattern of Hispanic/Latino concentration in California, Texas, and Florida is shifting to include growing Hispanic/Latino populations in the Midwest, Southeastern and Northeastern states.

The experience of Hispanics/Latinos with disabilities is commonly colored by cultural views on disability that include concealing a person with a disability within the family as a private family issue or shame about the fact of disability and keeping someone entirely at home. Sadly, persistent stereotypes about disability and low expectations of the potential of people with disabilities can limit accurate data reporting and contribute to a lack of community communication and supports.

The disability data reflect trends determined by countries of origin. The data sources are limited though fairly robust in documenting issues of aging with a disability in the Hispanic/Latino community. That applies to most but not all based on socio-economic status and country-of-origin. Older Hispanics/Latinos tend to live a lifespan approximately equivalent to white Americans. But they don't benefit from the progress toward "compressed aging" and tend to experience earlier onset of functional limitations that continue for many for decades.

Native Americans

Native Americans, like Black Americans, were distinguished by having the highest rates of disability in 1990. That remains true today.

**Native Americans
have the highest
rates of disability
in the US**

**2 out of 5
or 40% of adults**

(CDC 2020)

**Native Americans
experience two to three
times more chronic
diseases and earlier
onset of disabilities**

(Moss, Schell, and Goins, 2006)

**In school year 2013–14, the
percentage of children and
youth served under IDEA
was highest for American
Indians/Alaska Natives -
17% percent.** (NCES 2016)

**Most common adult
disabilities:**

- spinal cord injuries
 - complications from diabetes
 - blindness
 - mobility impairments
 - Traumatic Brain Injuries
 - hearing impairments
 - orthopedic impairments
 - joint pain
 - mental health issues
 - learning disabilities
 - alcohol/drug dependency
- (Faircloth, 2006)

Native Americans today are just over 1 percent of the US population. They have a 40 percent disability prevalence rate and the highest rates of disability for school-age children.

There are positive attitudinal assets. Culturally, Native Americans expect each individual to find a meaningful role in the family and the community fitting her or his abilities. The value of balance within the family and community dominate over concerns for autonomy and individualism.

Within the more than 560 Native American nations or tribes, most Native American languages have no equivalent word to 'disability' and no derogatory slang terms for people with disabilities.

57.6 percent of the 65+ Native American population have a disability vs 40 percent of the general 65+ population. Native Americans have the lowest life expectancy of any sub-population.

The environment plays a central role in both creating and magnifying disability among Native Americans. Many tribal lands sit on metal mining waste. There is limited data but it is suspected as a reason for high rates of developmental disabilities and congenital anomalies. Environmental etiology also likely shapes the fact that the Native American rate of tuberculosis is four times higher than the national average.

Accurate estimates of the types and overall prevalence of fetal alcohol spectrum disorders (FASD) among Native Americans and other minority populations in the U.S. are lacking though it is believed that Native Americans have some of the highest rates in the US.

The Substance Abuse and Mental Health Service Administration (SAMHSA) responded to high rates of mental health and substance use disorders among Native Americans with a culturally informed participatory program underway in Native American communities since 1992 called a Gathering for Native Americans (GONA) with a culturally-informed curriculum. The four themes are: belonging, mastery, interdependence, and generosity.

Chapter 3:

Changing Reality at Life Stages

Chapter Sections:

- Childhood and Youth
- Adulthood
- Elderhood

Changing Reality at Life Stages

Childhood and Youth

In addition to the transformative innovations of the last century that eliminated so many infectious diseases that made childhood a period of intense health risk, there has been more recent progress in increasing survival rates of heart diseases and cancers and other life-threatening diseases in children.

Chronic Conditions

A steady rise in chronic conditions in children that began fifty years ago continues, however, four conditions characterize the trend: asthma, obesity, mental health conditions, and neurodevelopmental disorders. In 2010, eight percent of children had a health condition that interfered with daily activities, a 400 percent increase in fifty years. There are likely intersecting reasons for the dramatic rise that include genetic susceptibility interacting with the environment. And a holistically understood environment includes diet, level of physical activity, and media exposure. There have been dramatic shifts in how children spend their time that are likely to contribute to the rise in chronic conditions.

Racial disparities in patterns for chronic conditions in children vary by disorder. Black children have the highest rates of obesity. Hispanic/Latino children and Hispanic/Latino children have the highest rates of asthma and are more likely to be hospitalized. But gender is the most dramatic indicator of having a chronic health condition. Boys have 50 percent higher rates.

Autism and Autism Spectrum Disorder

Since 1990, Autism and Autism Spectrum Disorder (ASD) prevalence has climbed steadily, presumed due to awareness of the condition and shifts in the diagnosing criteria. Parental interviews report higher rates than do school and medical records. In the case of ASD, racial disparity tilts toward whites with highest rates followed by Blacks and Hispanics/Latinos. Rates appear to be stabilizing at between 2 and 3 percent of children. Beginning in 2017, the CDC released the first estimates of adults 18 and older living with ASD. It aligns with the

child rates and is estimated for adults at 2.21 percent nationally with highs of 2.4 percent in Massachusetts and 1.97 percent in Louisiana.

Fetal Alcohol Spectrum Disorders (FASD)

FASD, is an umbrella term for functional limitations that occur to children with prenatal alcohol exposure. It includes Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorders (ARND), and Alcohol-Related Birth Defects (ARBD). The conditions are irreversible and impairments may cause serious physical, mental, and behavioral limitations. There is little screening for the condition and missed or wrong diagnosis is common. One study of foster and adopted youth found that 86.5 percent with FASD had never been previously diagnosed or had been misdiagnosed. It's estimated that at least 40,000 children are born with FASD every year.

A 2018 National Institutes of Health (NIH) study that looked at four communities in different parts of the country found that the traditional estimated prevalence rates may be much higher than previously thought. Using a "weighted prevalence" approach, their estimated prevalence for FASD ranged from 3.1 to 9.8 percent among the study sites. The study also determined that children with FASD often go undiagnosed or misdiagnosed. It's estimated that 35 percent of people with FASD have been in jail or prison. Average lifetime cost for an individual with FASD is \$1.4M.

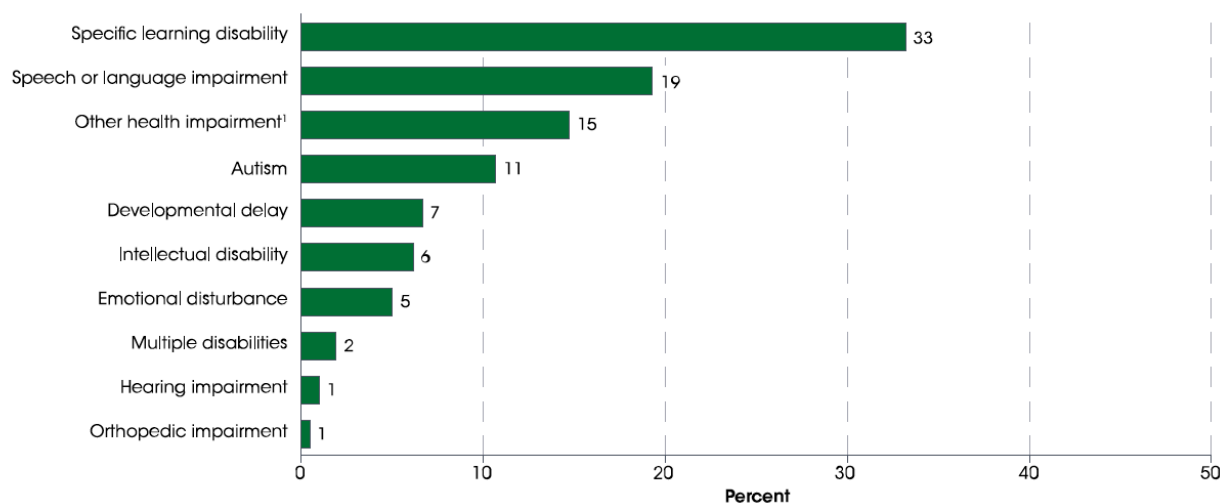
National Data on Children with Disabilities

The Individuals with Disabilities Education Act (IDEA), enacted originally in 1975 mandates free and appropriate public-school education for eligible students 3-21. Data collection began in 1976 and provides some of the most reliable sources of data on disability among children. In the school year 2018-19, students in special education who had an Individual Education Plan (IEP) increased to 7.1 million children or 14 percent of the total school population. The disability type breakdown has been consistent for some time with specific learning disability predominating at 33 percent. These disorders involve one or more processes involved in understanding or using language and can include limitations to listening, thinking, speaking, reading, writing, spelling, or math.

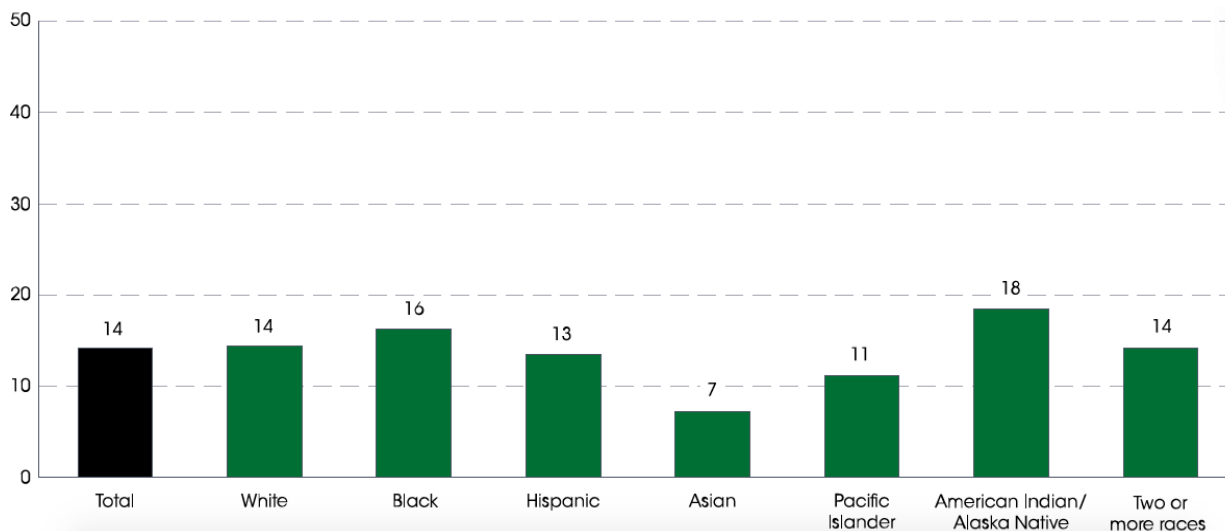
Black children are served in Special Education at 1.4 times higher rates than white students. There has been a debate about whether racial bias is at play and policies requiring analysis of "disproportionality" have been intense. Once again, context must be part of thinking through the level of functional impairment. Almost three quarters of Black children and

three quarters of Hispanic/Latino children attend majority student-of-color schools. Black children are three times more likely to live in poor families as white children. The specter of low expectations regarding Black children’s abilities may also be a factor that can lead some educators to disregard the basis of functional limitation in low academic performance. For example, Black children are more likely to experience symptoms of Attention-Deficit Hyperactivity Disorder (ADHD) but less likely to be given a diagnosis and treated.

Percentage Distribution of Students Ages 3-21 Served Under the Individuals with Disabilities Education Act (IDEA), by Disability Type: School Year 2018–19.



Percentage of Students Ages 3-21 Served Under the Individuals with Disabilities Education Act (IDEA), by Race/Ethnicity: School Year 2018–19.



Source (applies to both charts): U.S. Department of Education, Office of Special Education Programs, Individuals with Disabilities Education Act (IDEA) database, retrieved February 20, 2020, from <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>; and National Center for Education Statistics, National Elementary and Secondary Enrollment Projection Model, 1972 through 2029.

Adulthood

Black Americans and Extended Morbidity Starting in Middle Age

Over the last thirty years, worsening social, economic, and environmental contexts have fallen hardest on people already living with health inequity. Black Americans are demonstrating that reality in the pattern of pre-mature illness and functional limitation in middle age. Rather than the “compression of morbidity,” the shrinking of time that one suffers significant functional limitation before the end of life, Black Americans are more likely to experience functional limitations from conditions like high blood pressure, diabetes, and stroke starting in early and middle years of adulthood. There are higher rates of dying but also much more extended periods of living with functional limitations.

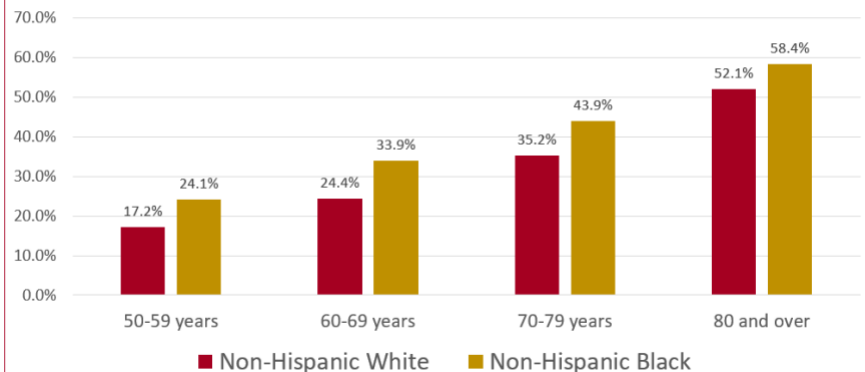
Health equity is a major factor. Black Americans are three times more likely to have amputations related to diabetes, most of them avoidable. Black Americans pay twice as much for health care though they make half as much as white Americans. A new initiative of the American Diabetes Association calls for a Health Equity Bill of Rights.

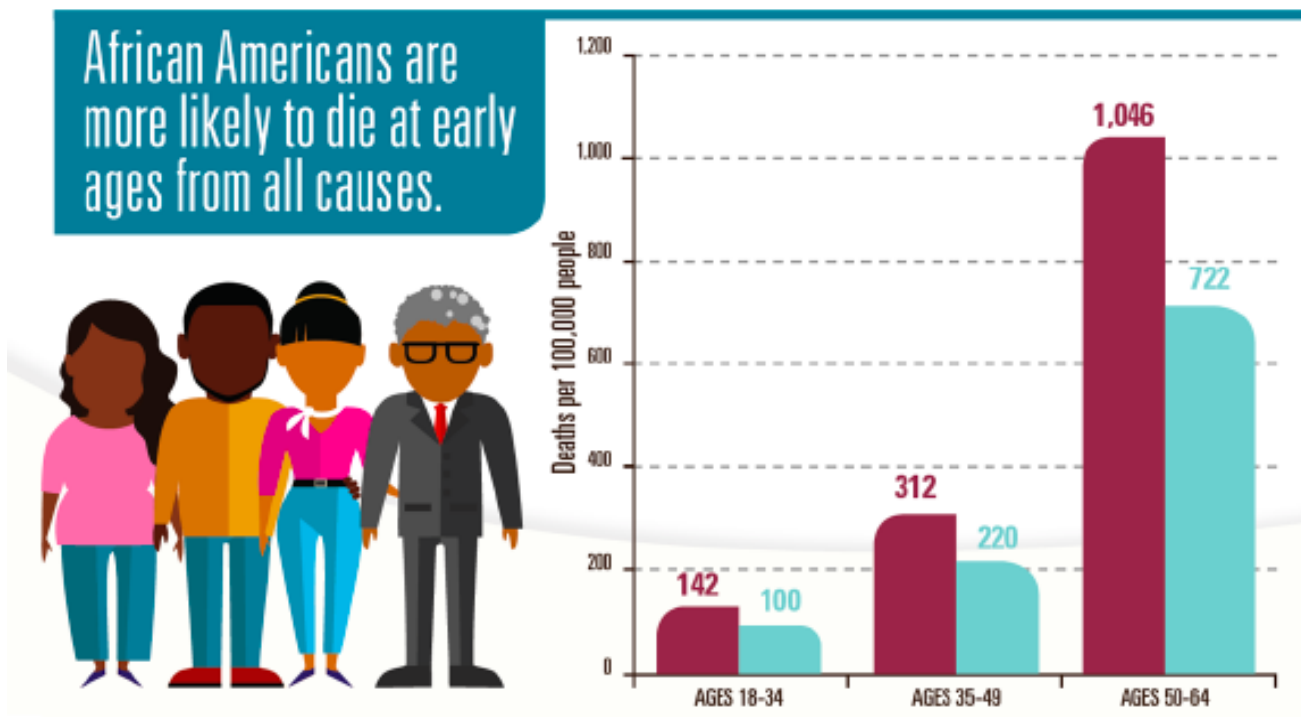
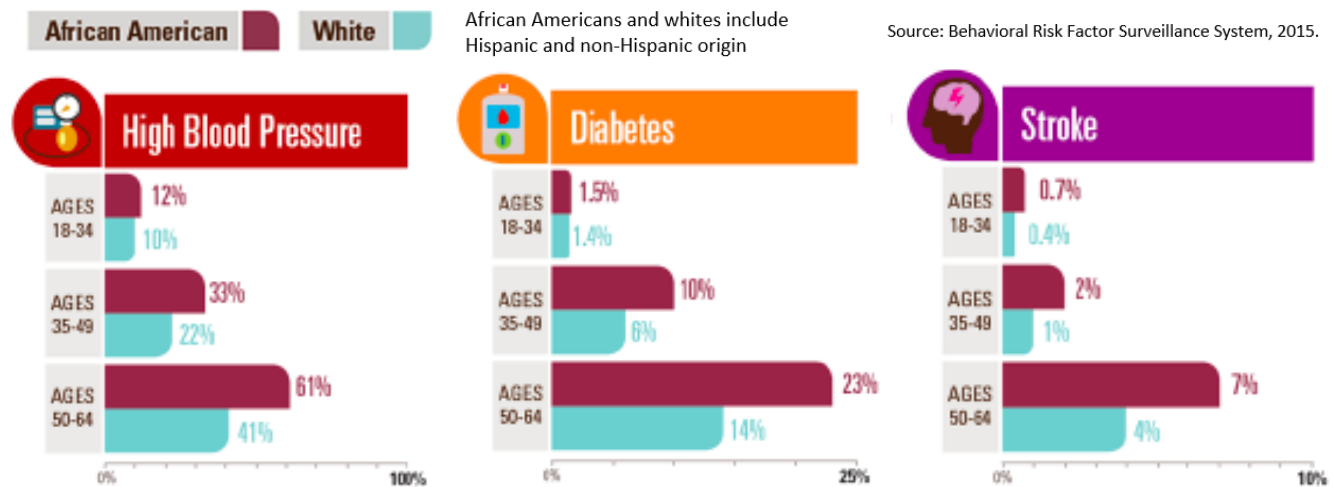
Percentage of non-Hispanic white and non-Hispanic black adults aged 50 years and over who had one or more physical limitations by age and race/ethnicity

| Age | Non-Hispanic White | Non-Hispanic Black |
|-------------|--------------------|--------------------|
| 50-59 years | 17.2% | 24.1% |
| 60-69 years | 24.4% | 33.9% |
| 70-79 years | 35.2% | 43.9% |
| 80 and over | 52.1% | 58.4% |

Source: CDC/NCHS, National Health Interview Survey, US, 2001-2007.

Percentage of non-Hispanic white and non-Hispanic black adults aged 50 years and over who had one or more physical limitations by age and race/ethnicity



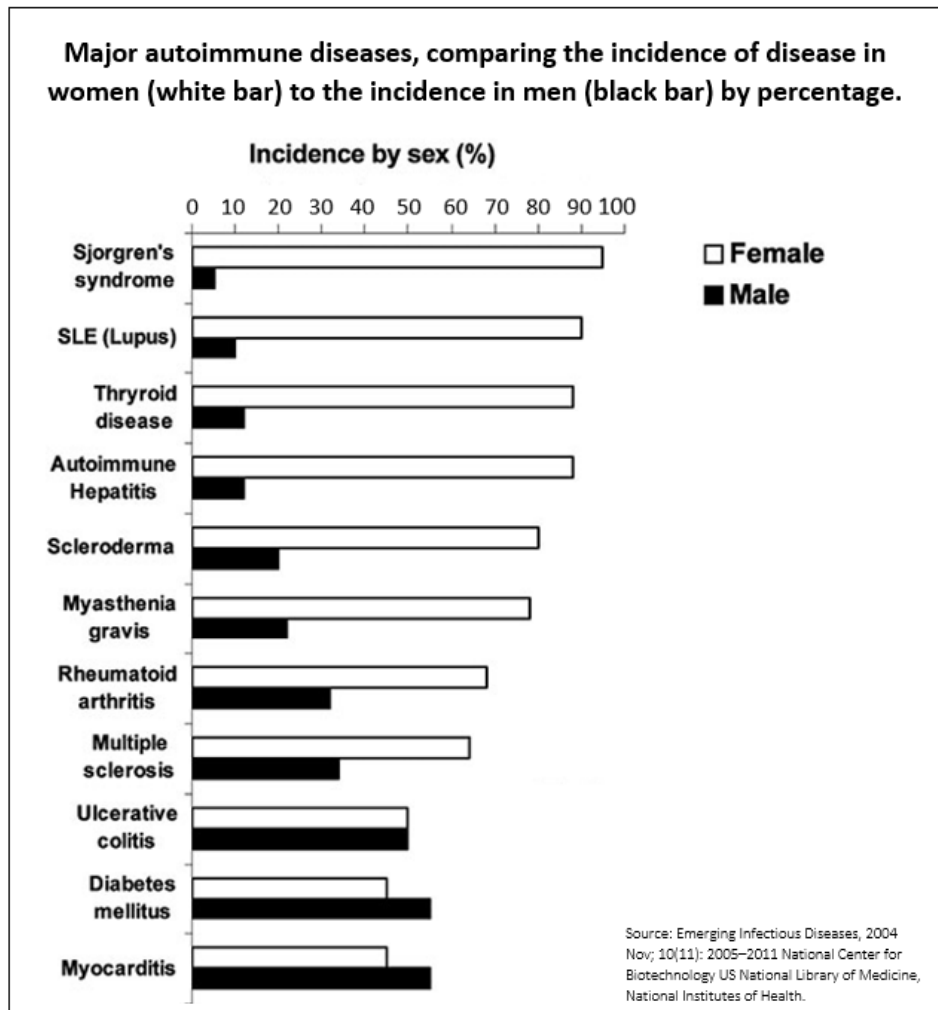


Source: US Vital Statistics, 2015.

Rising Rates of Autoimmune Disorders Especially for Women

The human immune system is our body's defense against disease and infection. When the system malfunctions, the body attacks healthy cells, tissues, and organs. The phenomenon is called autoimmune disease and there are believed to be over 100 autoimmune diseases. The most common are familiar: Type I diabetes, multiple sclerosis, lupus, and rheumatoid

arthritis. Many are rare, hard to diagnose, and often difficult to treat. Autoimmune conditions are among the leading causes of death for young and middle-aged adult women.



Autoimmune disorders are increasing around the world. The prevalence of antinuclear antibodies in the blood are a primary biomarker for vulnerability to autoimmune conditions. They've increased substantially over the last 25 years and are worryingly and increasingly common in adolescence.

Prevalence of autoimmune diseases has risen to affect between 14.7 and 23.5 million Americans, more than 7 percent of the overall population and, at 80 percent, disproportionately women. Extensive research is underway to study genetic predisposition and the patterns of autoimmune conditions of different types occurring in a single family. Environmental risks are assumed to interact with genetic predisposition and are believed to include exposure to solvents, to silica, and to agricultural chemicals. High ultraviolet index in

places with increasingly extreme intensity of sunlight also appears to be an environmental risk. But there is also evidence from animal models that viral exposure may be a catalyst to autoimmune conditions.

Autoimmune conditions closely align with the ADA Amendments Act of 2008 clarification of inclusion in the protected class of people who have impairments of ‘major bodily functions’ and are a significant reason for disability. Given rising prevalence and the significant severity of so many autoimmune conditions, research on environmental causes as well as the potential causal impact of infection needs to be an urgent priority.

Deaths of Despair

America’s decreasing average lifespans and its shocking rating as #43 in the world for human longevity is not borne of a predictable shortening of life caused by racism and inequity for Black Americans and people of color. The Washington Post reported in 2017 that the racial gap in life expectancy is closing with the mortality gap between Blacks and whites cut in half since 1999.

Rather, it’s another tragic public health breakdown born of inequity that results in deaths from suicide and fatal overdoses, especially from opioids. Rates of suicide are highest in the nation’s most rural counties and overwhelmingly a blue-collar white population. Between 2006 and 2014, emergency room visits for mental health and substance abuse treatment expanded 44.1 percent overall and for suicidal ideation 414.6 percent.

And places with high rates of chronic pain - an estimated one hundred million Americans suffer it - also had high rates of suicide. Again, this is especially true for white Americans though not for Black or Hispanic/Latino Americans. Princeton economists Anne Case and Angus Deaton coined the term “deaths of despair” first in a paper in 2015 and then more fully in the book, *Deaths of Despair*, published in 2020 in which they explore the economic, social, and psychological causes. They learned that not only suicide and addiction deaths were rising for middle-aged white Americans but all deaths. Between 1999 and 2017, there were over 600,000 deaths beyond projected norms to people forty-five to fifty-four. Case and Deaton include alcoholic liver disease, typically accompanied by a range of additional functional impairments, to drug overdoses and suicide.

The last thirty years have devastated the life prospects of Americans without a four-year college degree, the case for almost two-thirds of the US population. For generations, decent respectable jobs paid a living wage with good benefits allowed working class Americans to

buy homes, have reliable health care, and have expectations that their children would do better. No longer. As has been exposed so vividly by COVID 19, the US economy serves the educated classes well and penalizes those who are not. Globalization plays a key role in the demise of so many opportunities for good jobs in American manufacturing.

But every other developed nation has watched industry shift to lower wage global economies. None of the other Organization for Economic Co-operation and Development (OECD) nations have had so sharp a decline in good jobs among blue-collar workers. Other developed nations have responded to globalization through increases in minimum wage, initiatives to retrain workers, and more reliable social safety nets such as healthcare not tied to employment. The US seems to demonstrate a presumption that the economic forces that created the new reality were the responsibility of the its victims to fix.

Only the US has the pernicious tie of healthcare to a job, so thin a social safety net, and a minimum wage of \$7.25 an hour that would be \$22 an hour today if it had kept up with cost of living and productivity. Only in the last year have alarm bells sounded in media attention to “deaths of despair.” None of the measurable by-products of this reality bode well for a healthy society. The rates of impairment and death among the middle-aged adults may be the most undeniable measure of the problem but it is not the only impact. The split between the more and less educated can be measured not just in marginal work or no work but in low rates of marriage, childbirth outside of marriage, falling church attendance, diminished community participation. The US now ranks a dismal #30 globally even in high-school enrollment.

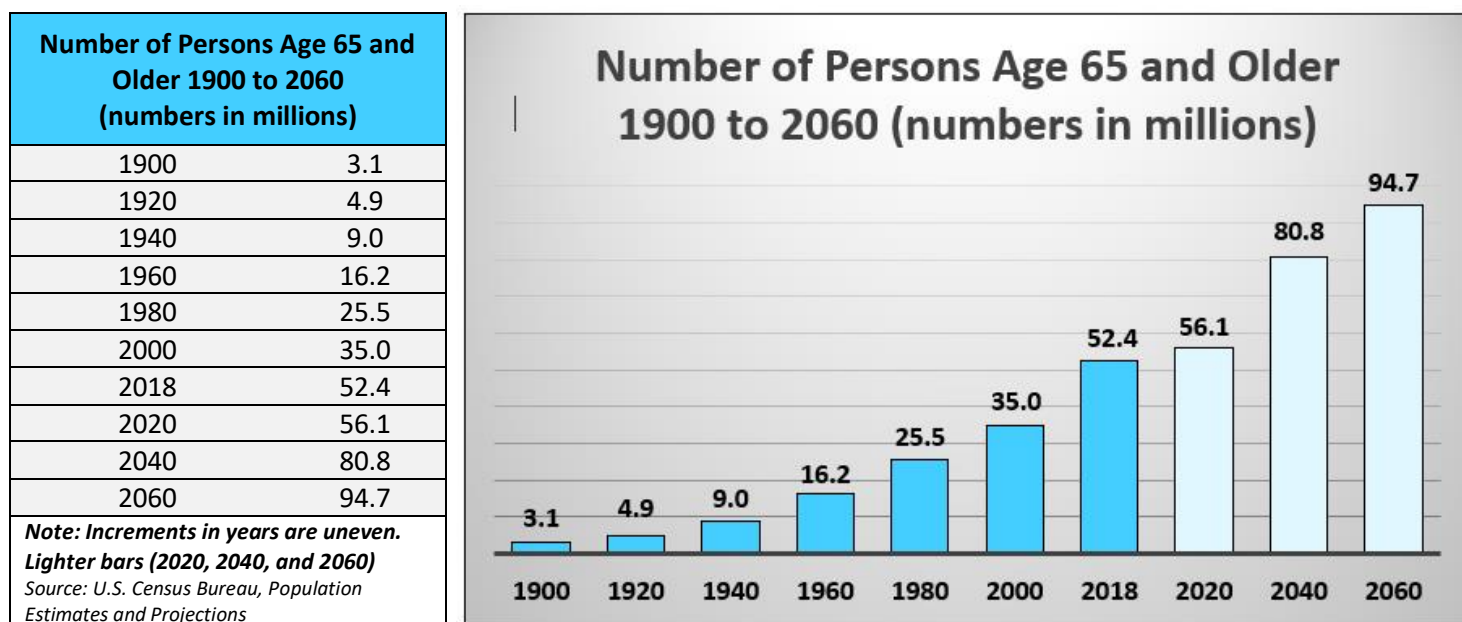
For this population of less-educated and mostly rural and white Americans, the context of their lives has failed them. Their current context is creating and amplifying functional limitation and early death. It makes a lot of people angry and resentful. There is a bad habit among the fortunate to imagine that they are solely responsible for the lucky context of their lives. The luxury of that conceit is not available to the least lucky among us. Context is mutable but only if it is understood as a social responsibility in which we all have a stake.

Elderhood

Unless we die young, we will all get old. Some level of functional limitation, often more than one or even two, is a universal experience if we live a typical lifespan. As Dr. Louise Aronson argues in *Elderhood*, late life is our third act and varies significantly over time and is shaped by the choices we make earlier in life. She makes the case that we should consider age a life

stage equal to childhood and adulthood and not just a general slide into death. Not surprisingly, the overall prevalence of impairment over 65 is at its highest. But whether or not impairments become disabling is just as much a contextual phenomenon in elderhood as at any other time of life.

Over the past ten years, the population age 65 and older increased from 38.8 million to 52.4 million in 2018 and is projected to reach 94.7 million in 2060. By 2040, the proportion of racial and ethnic minorities is projected to be 34 percent of older adults.



We will only consider two of the most significant reasons for functional limitation most common to elderhood. They are frequently given too little attention as conditions whose negative impact can be substantially impacted by the environment and attitudes: hearing and sight limitations and dementia.

Hearing and Sight Limitations

Acquired hearing loss is prevalent in nearly two-thirds of Americans over 70. Accurate data on hearing aid use is not available but it's estimated that 40 percent of people with moderate hearing loss use hearing aids but only 3.4 percent do who have mild hearing loss. Among the oldest adults, only about one-fifth use hearing aids.

There is a hypothesis that hearing loss, particularly without the use of hearing aids, contributes to cognitive and physical decline. That includes driving difficulty, susceptibility

to falls, and in some studies, increased risk of dementia. Hearing loss, especially undiagnosed or untreated, is a common precipitant to a shrinking and isolated world.

The Black population has lower odds of hearing loss than any other group - just two-thirds of white prevalence. Research affirms the accuracy of the pattern but there is no clear reason that has been identified.

Visual Impairments

Acquired visual impairment or blindness also correspond to age with many degenerative conditions taking years and sometimes decades for serious vision loss to occur. Those 80 years or older have the greatest burden. People with vision loss are 4.6 percent of the whole adult population in 2020. With the rise of the 65+ population to 2050, visual impairment and blindness are expected to double.

Blindness and visual impairment impact populations differently. In terms of absolute numbers, white women have the highest rates. Blacks have the second highest prevalence rates with high risk rates for developing glaucoma, the number one cause of blindness among Black Americans. The leading cause of blindness in American adults between 20 and 74 is diabetic retinopathy, most common to Black and Hispanic/Latino populations. Screening works to identify and stabilize the disease but only two-thirds of people for whom it is recommended get screened. It can be stopped by early detection but half the population with glaucoma are not tested before vision loss occurs.

Cataracts are the leading cause of blindness worldwide. Treatment is widely available and cost-effective in the U.S. Among Black Americans, unoperated cataracts in elders remains one of the leading cause of blindness. Glaucoma and cataracts account for 60 percent of blindness among Blacks. Pervasive screening would sharply diminish the projections for blindness and vision limitations in the US.

Dual Sensory Impairment (DSI)

The prevalence of dual sensory impairment, both hearing and vision loss, rises with an aging population. It's projected that up to 21 percent of Americans over 70 have it. Though it can occur for those with congenital sight or hearing conditions, most cases are acquired. Since most strategies to compensate for either sight or hearing loss depend on acuity of the other

sense, people with DSI present a particular challenge. Though awareness of its prevalence is rising, there is little research to advise on effective interventions.

Severe impact to Instrumental Activities of Daily Living (IADLs) may include shopping, meal preparation, money management, and home maintenance. DSI also likely impairs Activities of Daily Living (ADLs) such as bathing or dressing. The dual sensory limitations can be predicted to be accompanied by a reduction in age-related manual dexterity, complicating the use of ordinary tools that can make life easier as well as technology and critical assistive technology like hearing aids most commonly designed with small controls and operable parts, assuming visual acuity and dexterity.

Perhaps the most significant harm of DSI, especially when it is not known by the clinician or acknowledged by the person, is health communications. Failure to understand diagnostic information or instructions for care or medication puts the person with DSI at extreme risk. It's compounded by the likelihood of memory impairment even if it is only because of the extra effort required to communicate. With the near certainty of DSI rising in prevalence in the decades ahead, screening needs to be a priority as well as a call for innovative technologies responsive to this ordinary pairing of functional limitations.

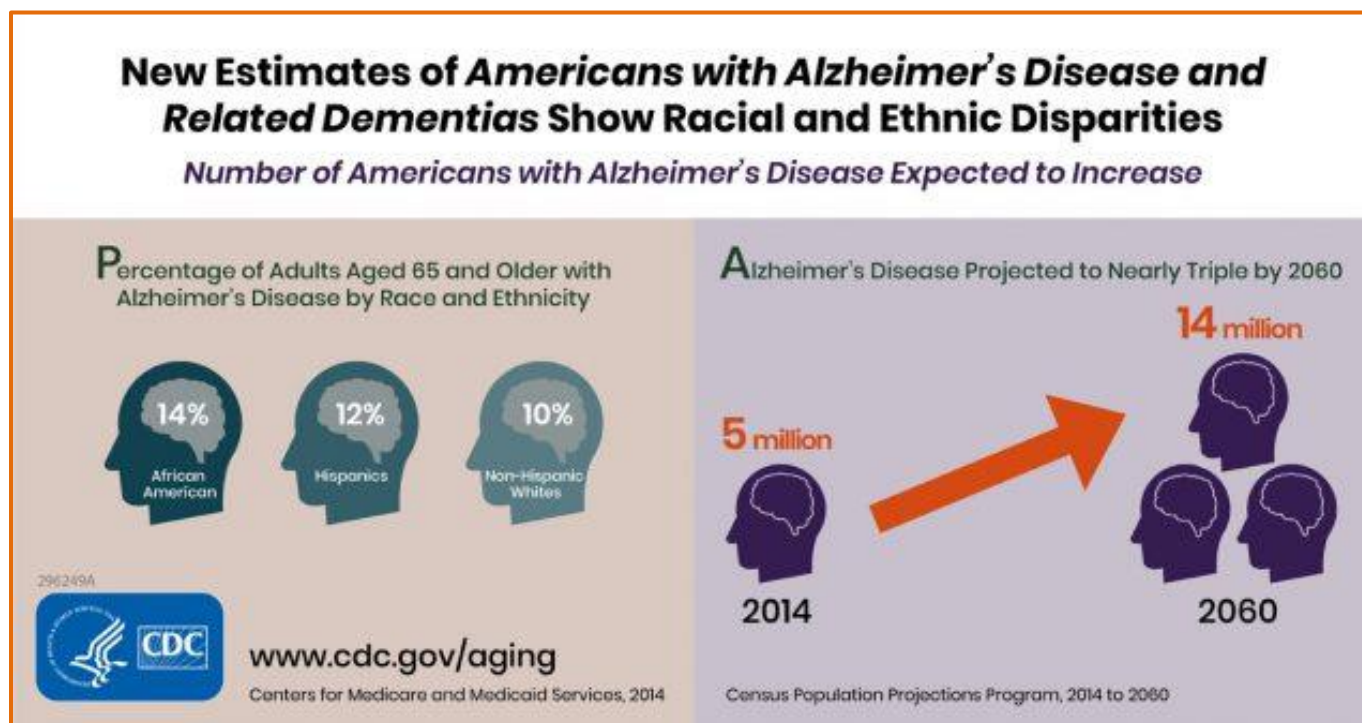
Dementia

Dementia, the loss of memory and other cognitive functions in older adults, has been evident throughout history. Higher rates of survival into late age raise its prevalence and significance today. In 2014, 1.6 percent of the population or 5 million people had Alzheimer's or related dementias and prevalence is expected to double by 2060 to 13.9 million people or 3.3 percent of the population. Though people with dementia make up nearly half of all Americans in long-term care settings, approximately 70 percent of them live in the community with about one quarter living alone.

Almost two-thirds of older Americans with Alzheimer's and other dementias are women. African Americans have the highest prevalence with double the likelihood of whites to have Alzheimer's or other dementias. Researchers assume the trend over the next several decades will be for Hispanic/Latino Americans to have the largest increase but, because of the size of the population, whites will still have the largest numbers.

Though dementia is not commonly framed as a disability in the US, there is little ambiguity that the functional limitations that define it would qualify for coverage under the ADA as well as the WHO ICF. In England, an initiative to promote the human rights of people with

dementia was published in 2019, by the All-Party Parliamentary Group (APPG) on Dementia who committed to adopt a rights-based approach to achieving positive change for people with dementia.



Chapter 4: Methodology — Qualitative and Quantitative

Chapter Sections:

- Qualitative—Archetypes and Documentary to Tell the Story
- Quantitative—A Brief Overview of the SIPP: The BIG Data Picture

Methodology — Qualitative and Quantitative

This is the first phase of an effort to generate attention to the changing story of disability in America thirty years after the passage of the ADA. We are especially motivated to tell the story of the portions of the spectrum of people with functional limitations that get little or no attention. The original ADA definition shrank and then expanded over time. In 1990, 43 million adults had a disability, today it's 61 million American adults. No one could say how many of the people CDC counts would affirm an identity as a person with a disability. We are not concerned with a counting exercise or in who self-identifies as a person with a disability. Nor are we concerned with eligibility for benefits or services, a common motivation for tightening the definition of disability.

We are anchored in the contextual definition of disability and its relevance to American society today. Our interest is to illuminate functional limitation as an ordinary part of life but focus on the opportunity to shape the social, economic, and social context to minimize the negative aspects of functional limitation(s) and sound the alarm that context can also generate disability.

Our interest is to illuminate functional limitation as an ordinary part of life. We also, however, want to shape the economic and social contexts in order to minimize the negative aspects of functional limitation(s) and, at the same time, sound the alarm that context can also generate disability. For all the attention given to creating a 'culture of health' in a society rife with inequity, we must ensure that disability is part of that urgent conversation.

Qualitative—Archetypes and Documentary to Tell the Story

We have chosen to use archetypes to tackle the qualitative research aspects of this project. Archetypes are stories that symbolize something universal in the human experience. For this project, the archetypes are stories of individuals sharing similar traits and experiences through seemingly unrelated situations. The accompanying film documentary of the same name, *Changing Reality of Disability in America 2020*, is our primary vehicle for individual story telling intended to shed light on compelling realities at the population level. The film also confirms reasons for hope that there are proven strategies for designing environments that work to support people to live fully.

The thematic categories are representative but surely not an all-inclusive sample of current patterns that get scant attention as issues of disability. They are uniquely American. We do not assume that the people in the stories self-identify as a people with disabilities. They are keenly aware of their functional limitations but also viscerally understand the reality of barriers in their environments. They share an intent to secure what they need so that they can keep or find the lives they choose to lead.

It is important to note, with the exception of the neglected issue of aging with chronic health conditions in rural America, the archetypes are stories about contexts that *create* or at least significantly exacerbate one or more functional limitations including military service, incarceration, homelessness, and environmental racism.

One of the other reasons for choosing this set of stories is to include sub-populations that are not included in the large national disability databases. People who are homeless and people in correctional facilities are not counted in national surveys and include high proportions of people with disabilities. Even veterans with functional limitations are difficult to count with the exception of those who receive their healthcare from the Veterans Administration - a minority of veterans.

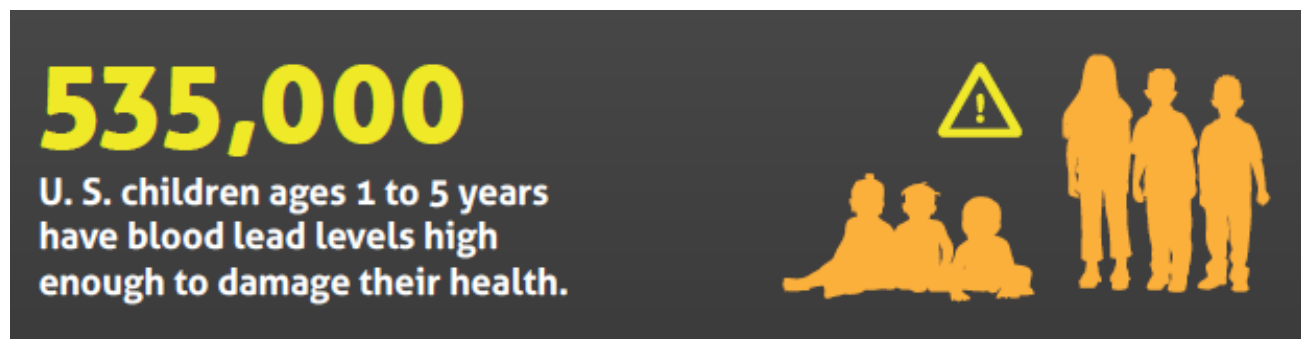
The CDC tells us that Native Americans and Black Americans have the highest rates of disability with the exception of people 65+. Those prevalence rates are based upon the quantitative data of the CDC Survey of Income and Program Participation (SIPP) administered as a household survey and includes only people with a personal address. Given the high proportion of disability and racial minorities among homeless and incarcerated people, the racial prevalence disparities evident in the SIPP would be more extreme if homeless and incarcerated people were included.

Environmental Exposure and Learning Disability

The CDC reported in 2013 that 2.6 percent of all children sampled aged 1-5 had a higher amount of lead blood levels than recommended (an estimated 535,000 nationally), with 5.6 percent of African American children being disproportionately affected (CDC, 2013). While adults only absorb 10-15 percent of lead that they come into contact with, pregnant women and children can absorb up to 50 percent. This has long-term consequences for child development including poor stress responses, learning disabilities, and social and behavioral problems. Evidence demonstrates that these effects can last through generations.

The impoverished city of Flint, Michigan, has an on-going poisoning crisis of lead in the drinking water that has threatened the health and well-being of more than 26,000 children. Lead has a significant and devastating effect on children's developing brains. In a 2017 article in the Harvard Environmental Law Review, the authors note that children and adults exposed to the neurotoxin regularly experience an elevated risk for permanent brain damage, disability, and, at higher levels, death. Further, a recent study showed that exposure to lead in the preschool years significantly increases the chance that children will be suspended or incarcerated during their school careers, suggesting that lead exposed-children are more likely to be involved in crime as adults.

Flint's special education system has been overwhelmed with students needing services, with almost twice the national average of students requiring special education services. While Flint has become a national story, there are over 2,600 areas in the US with recorded lead poisoning rates at least double those in Flint during the peak of that city's contamination. From South Bend, Indiana, to a rural mining town in Missouri's Lead Belt to the economically depressed North Side of Milwaukee, how we respond to disabilities acquired through environmental exposure is an increasing challenge in cities and towns across the US.





Source: www.cdc.gov/nceh/lead

On August 19, 2020, the New York Times announced that the State of Michigan agreed to pay \$600 million to victims of the Flint water crisis based on a suit filed by the American Civil Liberties Union (ACLU). The money is expected to be designated largely for the children in Flint who were poisoned by lead in the local water, a toxic condition that began in 2014.

Homelessness and Behavioral Health

People with disabilities are disproportionately represented in the chronically homeless adult population. National data is limited about people currently homeless relative to demographics or health conditions. Homelessness had been decreasing between 2007 when nationwide data collection began but has been on the increase each of the last three years from 2017.

Information is most reliable for those programs that provide Permanent Supportive Housing (PSH) for homeless adults. PSH is defined by its flexibility in that people can secure housing without sobriety or a commitment to use support services. It is possible that those fortunate enough to land PSH may exclude some homeless people with disabilities including those sleeping out of doors not in shelters or those with no known history of using services.

In 2016, nearly three in four adults living in Permanent Supported Housing (PSH) for individuals (73 percent) had a mental health disorder, substance use disorder, or co-occurring mental health and substance use disorder, and more than one in four (27 percent) had a physical disability. Homelessness presents significant barriers of access to treatment for those suffering from mental health and/or substance use disorders, and nearly

impossible odds of staying in recovery. High rates of relapse are understandable for someone living on the street or in emergency shelters.

Yet homeless individuals are typically omitted in the conventional disability rights narrative. The U.S. Interagency Council on Homelessness highlights the lack of an up-to-date nationwide picture of the characteristics, demographics, service and shelter utilization, and needs of people who are experiencing chronic homelessness now. We need to know who's at risk of homelessness and what policies have proven effective in supporting and stabilizing people with disabilities who are homeless.

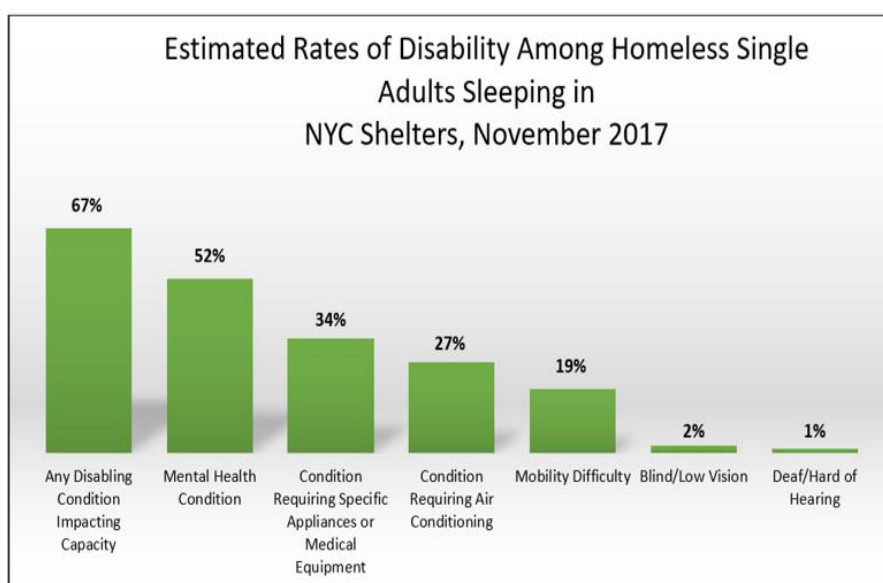
Studies have proven the effectiveness of approaches that work:

- Housing First, such as the Permanent Supported Housing programs, work. Having a stable home with voluntary access to services before having to earn housing through compliance with treatment has a long-term retention rate of 98 percent.
- Real engagement of homeless people with disabilities in designing programs, solving problems, and evaluation works. Collaborating meaningfully builds hope, a critical feature of recovery and stability.

Significant gaps in information remain:

- Deeper understanding of the risk and protective factors that might help better forecast which people with disabilities and which families with disabled heads of households are more likely to experience chronic homelessness.
- Greater understanding of the risk factors that contribute to some people with disabilities remaining homeless for long periods of time, and the interventions that might help more people with disabilities return to housing more quickly after they experience an episode of homelessness, instead of aging into chronic homelessness.
- Deeper understanding of the ways people with disabilities experience both chronic homelessness and contact with institutions in order to identify opportunities to offer interventions that engage individuals and heads of household with complex needs in the services and supports that will facilitate their recovery and long-term stability.

| Estimated Rates of Disability Among Homeless Single Adults Sleeping in NYC Shelters, November 2017 | |
|--|-----|
| Any Disabling Condition Impacting Capacity | 67% |
| Mental Health Condition | 52% |
| Condition Requiring Specific Appliances or Medical Equipment | 34% |
| Condition Requiring Air Conditioning | 27% |
| Mobility Difficulty | 19% |
| Blind/Low Vision | 2% |
| Deaf/Hard of Hearing | 1% |
| <i>State of the Homeless 2020 by Giselle Routhier, Policy Director Coalition for the Homeless - NYC Notes: Categories are not mutually exclusive. Categories were assembled by DHS according to their analysis of capacity needs. Source: NYC Department of Homeless Services.</i> | |



Veterans and Brain Injury

Starting in 2001, the growth rate of service-connected disabilities has grown substantially despite the decrease in the size of the veteran population. Military medicine in the field has improved substantially and service members survive their wounds and injuries, leaving some surviving more complex impairments than in previous wars. Nearly half (47.7 percent) of Gulf War II veterans with a disability reported a cognitive impairment, higher than for any other period of service.

Traumatic Brain Injury (TBI) has been called a “signature injury” of the military conflicts in Iraq and Afghanistan though quite similar in prevalence to Post-Traumatic Stress Disorder (PTSD). The Defense and Veterans Brain Injury Center reports nearly 350,000 incident diagnoses of TBI in the U.S. military since 2000. Among those deployed, estimated rates of probable TBI range anywhere from 11–23 percent.

Over one-third of veterans with a history of TBI suffer from depression, suicide, cognitive impairment, substance use disorder, pain disorders, and unemployment. Additionally, the Social, Economic, and Housing Statistics Division of the U.S. Census Bureau found that nearly half (47.7 percent) of all Gulf War II veterans with a disability reported a cognitive difficulty.

Veterans exposed to blasts from bombs, grenades, and other devices may still have brain damage even if they have no clear symptoms of TBI, according to a 2015 study by researchers at Veterans Affairs' (VA's) Mid-Atlantic Mental Illness Research Education and Clinical Center (MIRECC) in Durham, North Carolina, and Duke University. Symptoms of mild

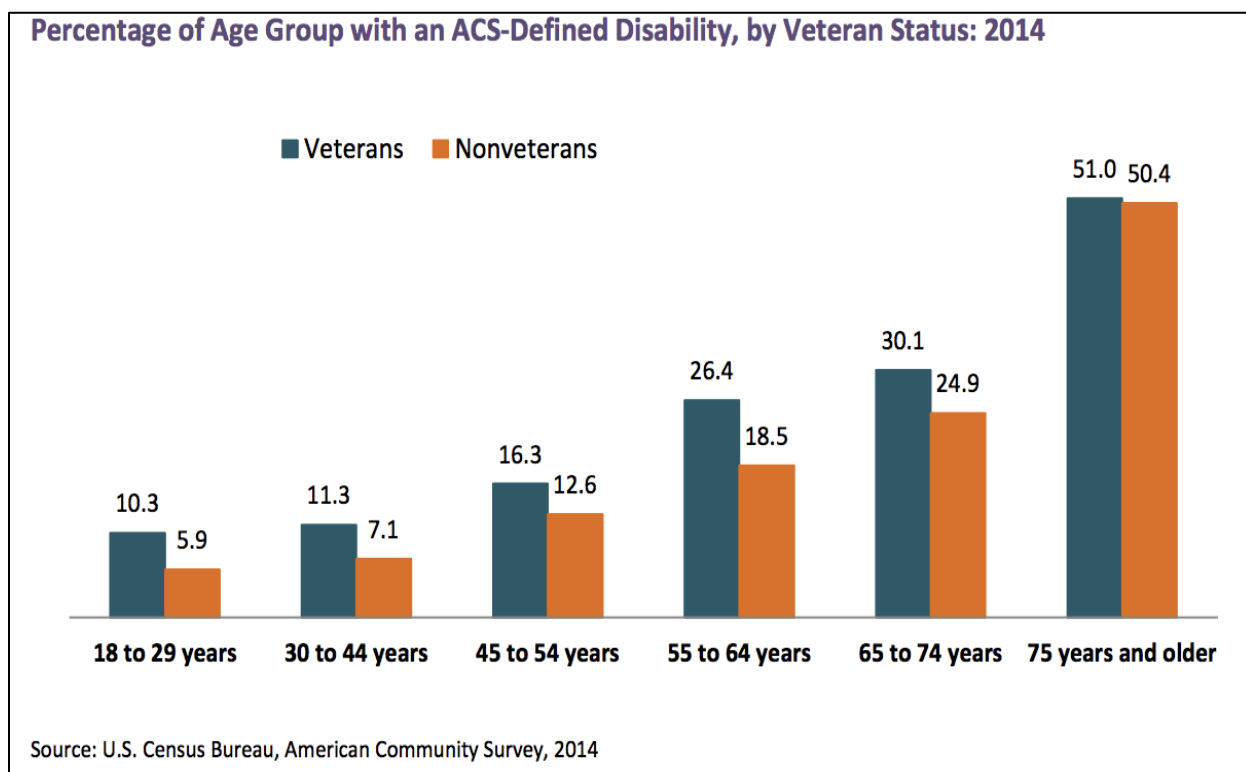
TBI are similar to symptoms of other co-occurring disorders such as PTSD - this leaves individuals undiagnosed and at risk for multiple TBIs throughout their military careers and the potential of chronic traumatic encephalopathy (CTE) leading to early dementia.

Studies have proven the effectiveness of approaches that work:

- Services to veterans by veterans have the highest success rate.
- Integrated networks of wrap-around services including health and wellness, housing, and financial stability, including work, deliver the best outcomes.

Significant gaps in information remain:

- Little is known about the co-occurrence of TBI, mental health disorders, and pain.
- The majority of Afghanistan and Iraq veterans don't use Veterans Affairs (VA) or Veterans Health Administration (VHA) healthcare and there is no system for gathering data across other healthcare systems.



| Most Prevalent Service-Connected Disabilities for Veterans Receiving Compensation: FY 2013 | |
|--|---------------|
| Disability | Number |
| Tinnitus | 1,121,709 |
| Hearing loss | 854,855 |
| Post traumatic stress disorder | 648,992 |
| Scars, general | 574,191 |
| Limitation of flexion, knee | 453,704 |
| Lumbosacral or cervical strain | 440,795 |
| Diabetes mellitus | 398,480 |
| Paralysis of the sciatic nerve | 346,572 |
| Limitation of motion of the ankle | 343,834 |
| Degenerative arthritis of the spine | 335,692 |
| NOTE: Veterans can receive compensation for multiple disabilities. | |
| Source: Department of Veterans Affairs, Veterans Benefits Administration, Annual Benefits Report, Fiscal Year 2013 | |

Aging, Chronic Health Disorders, and Rural America

The 49.2 million Americans ages 65 and older will grow faster than any other age cohort over the next 40 years, reaching over 80 million in 2040. The number of adults ages 85 and older, the group with the highest rates of disability, will nearly quadruple between 2000 and 2040. By 2040, about one in five Americans will be age 65 or older, up from about one in eight in 2000.

We chose to tell a story of a particular subset - an older woman living alone in rural America. More than one in five older Americans (age 65+) live in a rural area especially in the South and Mid-West. A recent US Census report, “The Older Population in Rural America: 2012-2016” shows that 17.5% of the rural population is 65 years and older, compared to 13.8% in urban or metropolitan areas.

The actual population of older people is much larger in urban areas but the proportion of the rural population who are 65+ is larger. Aging brings inevitable change, including retirement, loss of a life partner and friends, and a mix of acquired functional limitations including the high likelihood of chronic health conditions. These changes influence living arrangements, lifestyle, and quality of life for countless individuals, often creating greater risk in isolated rural settings.

This story explores aging in rural America with increased social isolation. Limited access to healthcare and greater distances to services presents an increasing challenge for rural residents dealing with chronic health conditions including arthritis, diabetes, low vision, hearing loss, and mobility issues as well as acute conditions like cancer and accidents.

Disparity of access to healthcare is hitting rural America hardest. Two-thirds of shortages of health professionals are in rural communities. Rural residents are the most likely to be dually eligible for Medicaid and Medicare. The National Rural Health Organization reports that there are only 30 specialists per 100,000 people in rural communities compared to 263 specialists per 100,000 in urban areas.

A 2020 study by the Chartis Center for Rural Health reports hospitals closing at an alarming rate in rural America. Since 2010, as of January 2020, 120 rural hospitals of a total 1,821 have closed with 453 of the remaining rural hospitals considered vulnerable. The lack of specialists means that many of the remaining hospitals don't have Intensive Care Units (ICUs) or other specialty services that so many older people need.

Studies have proven the effectiveness of approaches that work:

- Rural communities are often creative models of maximizing the natural resources they have in place when there are few formal resources. The community can provide a collaborative support system that makes it possible to live well independently even with significant functional limitations. The local bank may do wellness checks on its customers. The fire station may be the site for social services on the weekend.
- CAPABLE (Community Aging in Place - Advancing Better Living for Elders) is a client-centered national model designed by Johns Hopkins University for rural elders. The client sets the goals and a team with an Occupational Therapist, a Registered Nurse, and a handyperson help them to meet their goals. Their documented return on investment is 6 to 1.

Significant gaps in information remain:

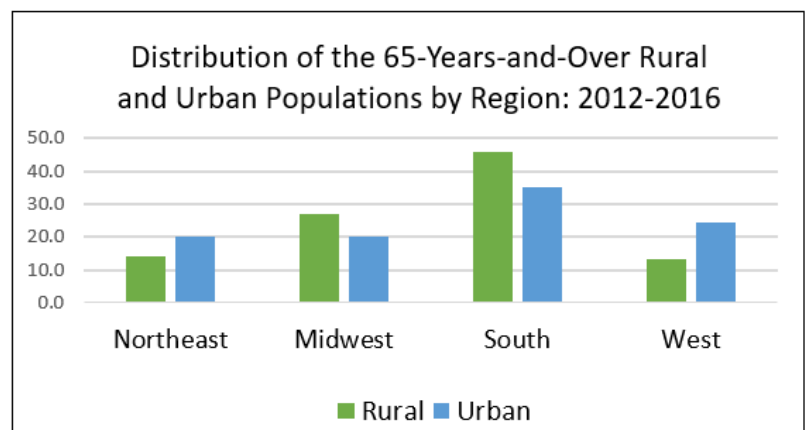
- Telemedicine has exploded in the COVID crisis as a viable option for connecting to physical and mental health clinicians for those with difficult live access to medical care in rural communities. But it requires broadband access. The Broadband Data Act (Public Law 116-130, signed into law March 23, 2020) seeks to improve the accuracy of the Federal Communications Commission's (FCC) broadband availability maps. These maps are used to allocate federal funding to expand broadband to rural areas. It would be

valuable to link disability status to broadband access in order to ensure that people with disabilities across the lifespan are prioritized.

- Rural transportation challenges fall heaviest on people with disabilities. It’s time to stir together “special” transportation, energy efficient initiatives, and innovations like autonomous vehicles into a coherent plan for environmentally and socially sustainable transportation systems that anticipate and include everyone. See position paper from the Association of Programs for Rural Independent Living (APRIL). <https://www.april-rural.org/index.php/advocacy/accessible-rural-transportation>

| Distribution of the 65-Years-and-Over Rural and Urban Populations by Region: 2012-2016 | | |
|--|-------|-------|
| | Rural | Urban |
| Northeast | 14.0 | 20.1 |
| Midwest | 26.9 | 20.2 |
| South | 45.9 | 35.1 |
| West | 13.2 | 24.6 |

Note: Data based on sample. For information on confidentiality protection, sampling, error, nonsampling error and definitions, see www.census.gov/acs. Source: U.S. Census Bureau, 2012-2016 American Community Survey, 5-Year Estimates.



Incarceration and Disability

By the early 2000s, the US led the world in incarceration, and rates were five times the historic average and five times as many as the comparable Organization for Economic Co-operation and Development (EOCD) developed nations.

The Prison Policy Initiative estimates that nearly 2.3 million Americans are currently incarcerated. According to the Bureau of Justice Statistics (BJS) National Inmate Survey conducted in 2011–12, an estimated 32 percent of prisoners and 40 percent of jail inmates reported having at least one disability, and more than half of prisoners and jail inmates with a disability reported a co-occurring chronic condition. Additionally, approximately 2-in-10 prisoners and 3-in-10 jail inmates reported having some form of disability impacting brain function, the most commonly reported disability in each population.

Overall, according to the Center for American Progress, incarcerated persons are at least three times as likely to report having a disability as the nonincarcerated population. In a

study with the Hammill Institute on Disabilities, researchers found that disability prevalence remained substantially higher among prisoners than among the non-institutionalized population. Prisoners were also more likely to report specific learning, sensory, and speech-related disabilities than non-institutionalized adults.

In addition to facing disproportionate rates of incarceration, people with disabilities are also especially likely to be the victims of police violence. Freddie Gray, Eric Garner, Kristiana Coignard, Ethan Saylor, and Daniel T. Prude were all people with disabilities whose tragic stories of being killed at the hands of police officers garnered significant recent national media attention. They are but five high-profile examples of a widespread occurrence. While data on police-involved killings are extremely limited, one study by the Ruderman Family Foundation estimates that people with disabilities comprise a staggering one-third to one-half of all individuals killed by law enforcement.

Ultimately, across the US, for some states the prison system has become a de-facto mental health facility, warehousing people in settings with inadequate staff, services, or support. Many inmates with disabilities are held in solitary confinement—reportedly, in many cases, for their own protection, due to a lack of appropriate alternative accommodations. A growing volume of research reveals that even short stays in solitary confinement can have severe and long-lasting consequences for people with disabilities, and particularly those with mental health conditions. Many prisoners who had not previously lived with mental health conditions experience significant psychological distress following solitary confinement.

People with disabilities already face barriers to employment, stable housing, and other necessary elements of economic security. Adding a criminal record into the mix can pose additional obstacles that make living with a disability an even greater challenge. Meanwhile, reentry programs for formerly incarcerated individuals often lack necessary accommodations and connections to community services, making them incapable of meeting the needs of participants with disabilities.

Pete Earley, a member of the Interdepartmental Serious Mental Illness Coordinating Committee of the Substance Abuse and Mental Health Services Administration (SAMHSA) wrote a Washington Post Op-Ed piece, *Mental illness is a health issue, not a police issue* (June 15, 2020). He stated that people with serious mental illness “. . . remain in jail four to eight times longer than people without mental illnesses charged with the exact same crime, cost seven times more than other inmates in jail, are less likely to make bail and more likely to gain new charges while incarcerated.”

Studies have proven the effectiveness of approaches that work:

- Break the cycle upstream. Reduce the risk of incarceration of people with serious mental illness and substance use during a crisis. Use mental health interventions as an alternative to a police response. A mix of national models exist that use mental health professional to intercept a crisis and stabilize a person with a disability. They range from 24/7 Assertive Community Treatment Teams (ACT) that provide services to individuals by a mobile, multi-disciplinary team in community settings to specialized behavioral health teams as an alternative to police response to 911 calls for mental health crises.
- Since 2014, Disability Rights Washington, the state Protection and Advocacy Organization, created Amplifying Voices of Inmates with Disabilities (AVID), a project with the sole purpose of protecting and advancing the rights of inmates with disabilities and assisting those who are reentering society. Their sustained focus and publications have shone a light on the prevalence of disability in the incarcerated population and the lack of compliance among jails and prisons with their responsibilities under the Americans with Disabilities Act (ADA).

Significant gaps in information remain:

- Need better data on brain-based conditions in jails and prisons at the local, state and national levels. The literal public costs and the human costs make a powerful argument for alternatives to incarceration but today are fragmented and not standardized.
- Need longitudinal data on costs and types and patterns of functional ability for people with serious mental illness diverted from incarceration.

Prevalence of disabilities among state and federal prisoners and the general population, standardized, 2011–12

| Disability | State and federal prisoners | | General population** | |
|--------------------|-----------------------------|----------------|----------------------|----------------|
| | Percent | Standard error | Percent | Standard error |
| Any disability | 31.6%** | 1.40% | 10.9% | 0.06% |
| Vision | 7.1** | 0.69 | 2.1 | 0.02 |
| Hearing | 6.2** | 0.61 | 2.6 | 0.02 |
| Ambulatory | 10.1** | 0.76 | 5.1 | 0.03 |
| Cognitive | 19.5** | 1.13 | 4.8 | 0.04 |
| Self-care | 2.1 | 0.29 | 2.1 | 0.02 |
| Independent living | 7.5** | 0.71 | 4.0 | 0.03 |

Note: See *Methodology* for definitions of disabilities.

*Comparison group.

**Difference with the comparison group is significant at the 95% confidence level.

^aData were standardized to prisoners in the National Inmate Survey, 2011–12 based on sex, age, race, and Hispanic origin.

Source: Bureau of Justice Statistics, National Inmate Survey, 2011–12; and U.S. Census Bureau, American Community Survey, 2012.

Prevalence of disabilities among jail inmates and the general population, standardized, 2011–12

| Disability | Jail inmates | | General population** | |
|--------------------|--------------|----------------|----------------------|----------------|
| | Percent | Standard error | Percent | Standard error |
| Any disability | 39.9%** | 1.10% | 9.3% | 0.05% |
| Vision | 7.3** | 0.59 | 1.7 | 0.02 |
| Hearing | 6.5** | 0.46 | 1.9 | 0.02 |
| Ambulatory | 9.5** | 0.63 | 3.7 | 0.02 |
| Cognitive | 30.9** | 0.91 | 4.7 | 0.04 |
| Self-care | 2.8** | 0.33 | 1.7 | 0.02 |
| Independent living | 8.7** | 0.61 | 3.4 | 0.03 |

Note: See *Methodology* for definitions of disabilities.

*Comparison group.

**Difference with the comparison group is significant at the 95% confidence level.

^aData were standardized to jail inmates in the National Inmate Survey, 2011–12 based on sex, age, race, and Hispanic origin.

Source: Bureau of Justice Statistics, National Inmate Survey, 2011–12; and U.S. Census Bureau, American Community Survey, 2012.

Co-Occurring Trauma, Mental Health, and Substance Use Disorder

The Substance Abuse and Mental Health Services Administration (SAMHSA) defines trauma. *Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being.* SAMHSA reports that trauma is an almost universal experience of people with mental and substance use disorders. Reports of trauma exposure show that approximately 62 percent of Black males have directly experienced traumatic event and that approximately 72 percent have witnessed a traumatic event and 59 percent have learned of a traumatic event involving a family member or friend. A prevalent cycle of trauma, commonly co-occurring with mental health and substance use for Black men 18 and over, is costly for individuals, families, communities, and society.

In addition, SAMHSA found in their 2018 National Survey on Drug Use and Health that there have been rising rates of major depression in adolescents and adults 18-49 years old, that illicit substance use increases risk for other hazardous substance use and mental illness, that mental illness is a risk factor for illicit substance use, and that there is a need for ongoing efforts in prevention of substance use disorders. Ultimately, research findings suggest a need for a broadening of the menu of self-change and community-based options that can facilitate and support long-term alcohol and other drug problem resolution.

Substance Use and the ADA

Since 1990, the ADA has provided protections for people with addiction to alcohol and in recovery from opioids and other drugs. However, this element of the ADA is the most underutilized part of the law. Today, it is estimated that 22 million people are in recovery. And thousands remain unaware of their civil rights under the law. The ADA is clear – people with addiction are people with disabilities and have civil rights under the law if they meet the ADA’s definition of disability (Americans with Disabilities Act as Amended, 2008).

A major distinction in protections is the ADA applies to alcohol use disorder (AUD) and substance use disorders (SUD) very differently. For alcohol use disorder, it applies to anyone who has a past and/or current addiction. On the other hand, for substance use disorder, a person must be in recovery for protections under the ADA. More detail is written about this in *Advances in Addiction and Recovery Magazine*.

In an attempt to make this element of the law more utilized, the ADA National Network’s ADA, Addiction and Recovery Fact Sheets (2019) explain these rights for addiction professionals and people with addiction recovery. Knowing one’s rights can have a transformative effect on how we think about trauma and its impact.

Studies have proven the effectiveness of approaches that work:

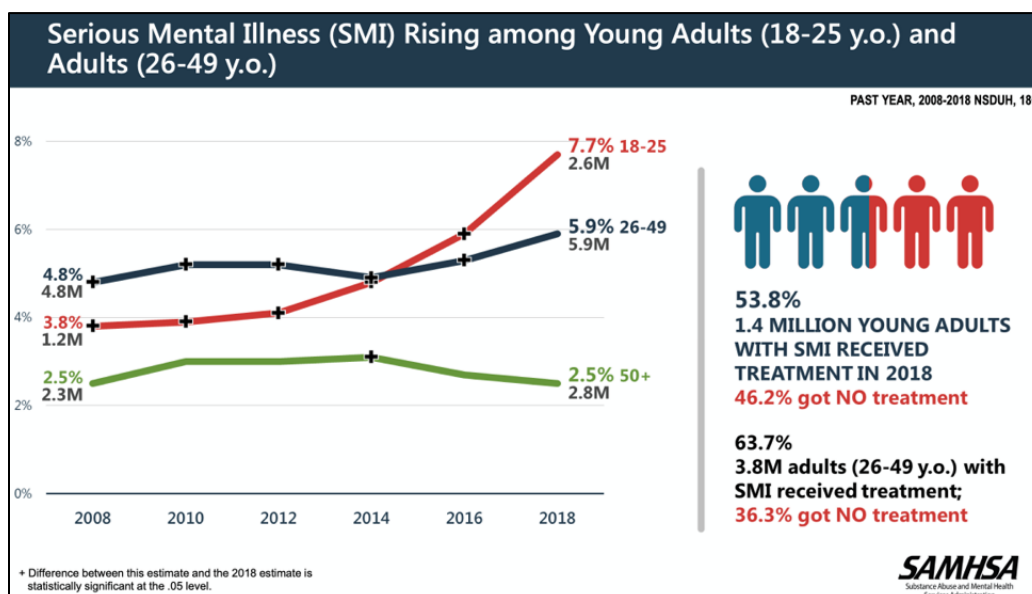
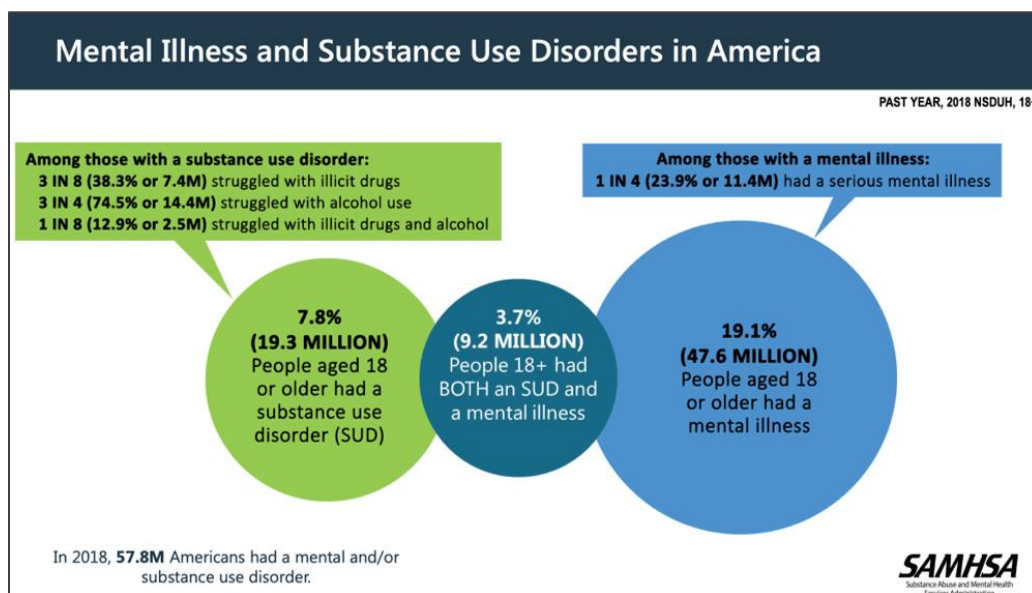
- SAMHSA recommends Trauma-Informed Care in Behavioral Health Services [Treatment Improvement Protocol (TIP).
- There is some evidence that Black men are more willing to accept mental health treatment that is part of holistic health promotion rather than a distinct treatment.

“Trauma-informed care embraces a perspective that highlights adaptation over symptoms and resilience over pathology.”

Elliot, Bjelajac, Fallot, Markoff, & Reed, 2005, p. 467, SAMHSA TIP 57

Significant gaps in information remain:

- Black men with trauma histories are less likely to use mental health services. High levels of daily crisis and lack of information, and service eligibility to obtaining services appear to be significant barriers. Research is needed about effective methods for these men to access mental health services.
- More studies are needed to assess the kinds of social supports (e.g., family and friends, religious communities) that can serve as protective factors for people with stress and trauma histories.



Quantitative — A Brief Overview of the SIPP: The BIG Data Picture

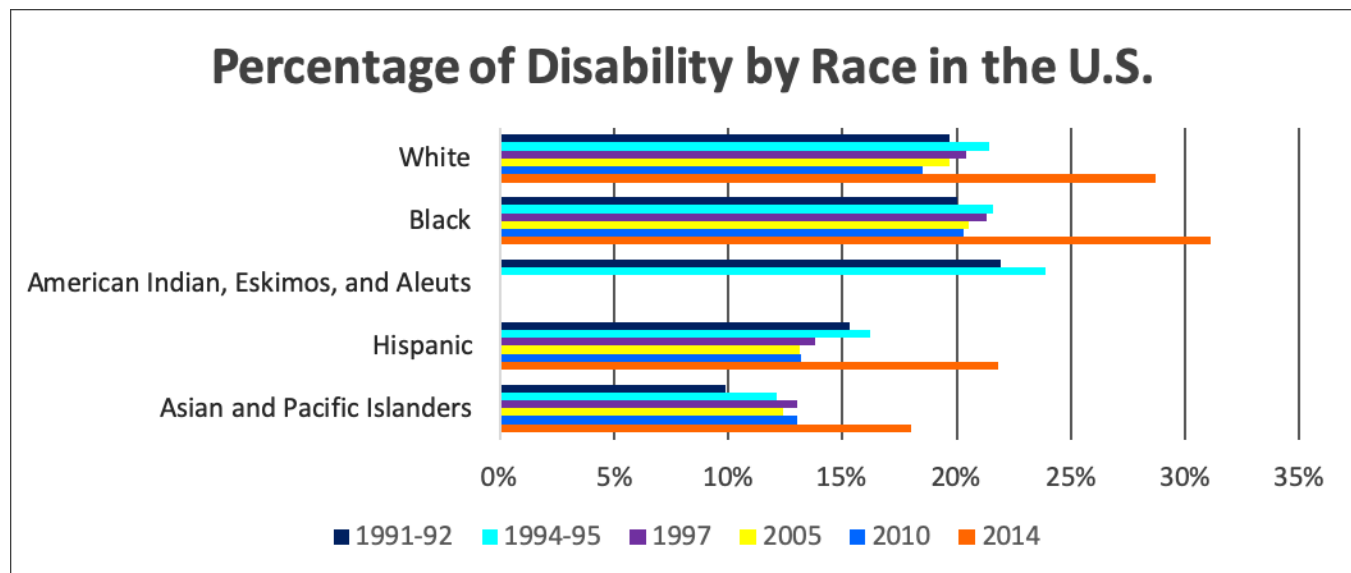
Beginning in 1983, the US Census Bureau has conducted the Survey of Income and Program Participation (SIPP) as a household-based statistical survey. The SIPP is organized as a continuous series of nationwide panels, each with a sample size ranging from approximately 14,000 to 52,000 interviewed households in the civilian non-institutionalized population. The primary objective of the SIPP is to provide accurate and comprehensive information about the income and program participation of individuals and households in the United States. However, the SIPP also collects extensive data on many additional topics including economic well-being, family dynamics, education, assets, health insurance, childcare, food security, and disability.

Among the national demographic tools, the SIPP captures the most content of the ICF *activities* and *participation* components though not the *environmental* factors.

We focus on results from the disability questions asked in SIPP panels from 1990 - 2014. Disability questions in the SIPP have formed the basis for the periodic report series *Americans with Disabilities*, which has reported on the prevalence of people with disabilities in the United States. Generally, the disability questions ask about difficulty performing certain activities due to a physical, mental or emotional condition, collected in a supplemental questionnaire to the core survey instrument.

What Does the SIPP Tell Us About Disability Trends Overtime?

| Percentage of Disability by Race in the United States | | | | | | |
|---|----------------|---------------|---------------|---------------|----------------|----------------|
| Metric | 2014 | 2010 | 2005 | 1997 | 1994-95 | 1991-92 |
| Total number with a disability (in millions) | 85, 289 | 56,672 | 54,430 | 52,596 | 53, 907 | 48, 936 |
| Total percent with a disability | 27.20% | 18.70% | 18.70% | 19.70% | 20.60% | 19.40% |
| Asian and Pacific Islanders | 18.00% | 13.00% | 12.40% | 13.00% | 12.10% | 9.90% |
| Hispanic | 21.80% | 13.20% | 13.10% | 13.80% | 16.20% | 15.30% |
| American Indian, Eskimos, and Aleuts | - | - | - | - | 23.90% | 21.90% |
| Black | 31.10% | 20.30% | 20.50% | 21.30% | 21.60% | 20.00% |
| White | 28.70% | 18.50% | 19.70% | 20.40% | 21.40% | 19.70% |
| Source: Survey of Income and Program Participation (SIPP) | | | | | | |



To determine the general prevalence of disability from 1990 – 2014, we used the metric “Total number and percent of those who reported either a severe or non-severe disability.” We also viewed these statistics within the lens of race. Ultimately, there was a 40% change in the total percentage of individuals with a severe or non-severe disability between 1990 and 2014. This SIPP 2014 change resulted in a count of 85 million (see chart above) Americans with disabilities. We will use the more conservative estimate of the CDC of 61 million but trust that the SIPP proportional breakdown by race has value. By race the 2014 SIPP reported: white individuals saw 46% increase; black individuals, a 56% increase; Hispanic/Latino, a 42% increase; and Asians/Pacific Islanders, an 82% increase. There is limited data on Native American, due largely to the small sample size of less than one percent of the US population. It is important to put these dramatic percentage changes over the course of 30 years in context, taking into consideration two factors that may have contributed to these increases: (1) Changes to the SIPP survey over time--with extensive changes in 2014, and (2) changes in the cultural understanding of disability that might impact how people view their own experience.

Changes in the SIPP Over Time

While the majority of SIPP survey questions on disability have been consistent across panels, there have been *gradual* changes over time in both the survey methodology and questions asked. Changes to survey methodology or questions can affect the prevalence of measures in ways that may make identifying real change difficult and thus often are

presented as “breaks” in the series of estimates. For estimates of disability from the SIPP, the most significant breaks occurred in 1996 and 2014.

In 1996, the SIPP underwent a design change as the administration of the survey moved from pencil and paper to a computer-based instrument. Concurrent with this change, the disability supplement was split into separate adult and child disability sections and asked several additional topics. For adults, the SIPP included blindness and deafness as a response option to the difficulty seeing and hearing questions, added questions about the ability to stand, stoop, crouch, kneel or reach for an extended period of time to the questions on limitations to physical functioning. The disability supplement expanded the mental and emotional disability sections with questions on depression, anxiety, concentration, and stress. For children, many of the disability questions that were previously only asked of adults were extended to children age 6 and older, including questions on functional limitations and difficulty with Activities of Daily Living.

The most drastic changes occurred in the 2014 survey, when the SIPP underwent a major overhaul, changing the frequency of interviews, topics covered, and sample size. For the 2014 panel, a disability section was added to the core instrument that covered a set of six functional limitations (hearing, seeing, cognitive activities, ambulatory activities, self-care activities, and independent living activities), along with six additional questions about children and the working-age population. The core six-question set is consistent with the standard disability questions implemented across multiple government surveys, including the American Community Survey (ACS) and the Current Population Survey (CPS). In addition to this set of disability questions asked in the core instrument, the Social Security Administration funded a supplemental questionnaire (referred to as the SSA Supplement) that included most of the disability questions from prior panels.

What Can’t the SIPP Tell Us?

For each survey year, using the data gathered, a report is generated to more deeply characterize the nature of disability by severity and type and by socioeconomic characteristics such as age, race, job status, and income level. Unfortunately, these analyses, while significant and necessary, are not sufficient and give rise to significant questions about the extent to which big data can effectively capture the context-based and evolving realities of disability:

- How responsive is the SIPP (and the data/analyses generated) to our ever-changing world where leaders, legislators, and lay people alike have made (and continue to make) significant strides to ensure that those with disabilities are more able to function in their environment? Has the SIPP responded to increasing diversity, persistent socioeconomic disparities, and changes in stigma towards people with disabilities?
- Have these data effectively captured the concept of disability as not limited to impairment but as a contextual phenomenon? *Can* data capture this reality?
- Who has SIPP left out? Which populations are and are not included in big population-based surveys and analysis?
 - SIPP is a household-based survey so no homeless nor institutionalized people are included. Could a supplement gather national data on disability among homeless and incarcerated people?
 - Is there the will to gather data across health systems on veterans with disabilities?
 - The American Community Survey (ACS) provides consistent and accessible data that depict disability among Native Americans but the tradeoff for measuring small domains is the definition of disability is less comprehensive.

While we do not have direct and concrete answers to these questions, the goal of our report is to start a conversation about the limits of big data and to center the narratives of populations too often left out when national survey data is the sole source.

Chapter 5:

Conclusions and Recommendations

Chapter Sections:

- The Traditional Domains of Public Health Provide a Natural Structure for Recommendations

Conclusions and Recommendations

There is an expanded proportion of the US population with disabilities and a shift in reasons for disability. But that's not all that's changed. Disability is a social construct but also a choice to use as a political term. We are witnessing a rising tide of awareness that the evidence of harm to too many Americans impacts all of us and demands action. The catalysts are clear but action is still on the horizon. We suggest that it is appropriate to claim this long-building national health calamity as the public health crisis it is that creates and amplifies disability. Addressing it demands that we understand the power of the social contexts of safe water and air, home, learning and work environments, at minimum, to invent solutions that stop creating disability and minimize the negative impact of functional limitations for those who already have them.

The story of disability in America can be and often is the story of what's possible if people get not only their civil rights but also get what they need to build their own lives. It will always have a person-by-person element. But there needs to be a national policy commitment that owns the fact that we as a society have stolen the right to self-determination for millions of Americans. We have a chance to build up from the current crisis during a rare crisis time less burdened by the blinders and distractions of more typical times.

The Traditional Domains of Public Health Provide a Natural Structure for Recommendations

Educate and Empower

- Infuse awareness of disability as a contextual phenomenon in the national strategy to address inequity and racism. If we are going to tackle inequity systemically, we must make it clear that we need a priority creating environments that minimize functional limitations and prevent creating impairments.
- Learn from the people with lived experience of functional limitations and especially to understand cultural preferences and needs. Be humble about needing to learn what works. The effort will fail if intuition or expediency drive action. We need real

opportunities for engagement and participation. Every successful model of services and support shares a starting point of listening and responding.

Develop Policies and Mobilize Partnerships

- We must not waste the global crisis of the pandemic nor of Black Lives Matter. We need to make prevention of disability an overt commitment and restore and expand the regulatory protections for safe water and air.
- Elevate the national and philanthropic research agenda to tackle the gaps in population demographics related to functional limitation among Blacks, Native Americans, Hispanics/Latinos, and Asians.
- Commit to building consistent longitudinal data on people with disabilities who are incarcerated, homeless, and/or veterans.
- Sound the alarm that Deaths of Despair are a national public health and disability crisis impacting a mostly white, working class population. More than 600,000 deaths from 1999 to 2017 has been enough to reduce the US global rankings in lifespan to #43. This number nearly equals deaths from HIV/AIDS since the beginning of that crisis decades earlier. There is a shared responsibility for a population shunted aside by globalization and dismissed because they cannot reinvent themselves as competitors through more education.
- Establish a mandatory course on disability for the professions that can transform current habits of thought about disability to more accurately appreciate the relationship to inequity. Include healthcare, medicine, human services, design, planning, engineering, statistics, economics, and policy.
- Establish a mandatory course on Inclusive Design for designers, architects, planners, engineers, and public health practitioners. Inclusive Design is the most promising framework of the WHO ICF contextual model and can be used as a means to energize a sense of opportunity to transform, at the population level, the experience of a quarter of the population to live fully.

- Educate our public safety workforce (police, fire, EMTs, adjunct specialists) on the prevalence and symptoms of the spectrum of brain-based disabilities and sensory impairments and how to effectively manage and de-escalate intense situations.

Monitor and Evaluate

- Screen Black children and adults for trauma and PTSD in primary care settings as well as in jails and prisons. Undiagnosed and misdiagnosed conditions and neglect make treatable conditions permanent.
- Screen all women of childbearing age for risk of Fetal Alcohol Syndrome Disorders, more common than Down Syndrome or Autism Spectrum Disorders, and the leading preventable cause of intellectual limitations. Make evaluation for FASD standard in all early intervention programs.
- Add Medicare screening for hearing loss limitations for all people 55 and older and cataract screening for African Americans 60 and over.
- Mount a campaign to educate front-line elder healthcare providers to the prevalence of Dual Sensory Impairments (DSI) for people 70+.
- Follow the money. Responding to the Changing Reality of Disability in America requires tracking spending in more responsive and effective interventions over just the provision of healthcare. In 2020, the CDC provided detailed state-level snapshots of disability prevalence and disability costs in healthcare spending. They range from \$870 million in North Dakota to \$40.1 billion in New York. Track money that is spent to respond to inequity, including investments in the environment, and tie it to outcomes in improved health and participation.
<https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/index.html>

Chapter 6:

Key Project Staff Bio-Sketches

Chapter Sections:

- Team Leader
- Team Members

Key Project Staff Bio-Sketches

Team Leader

Valerie Fletcher, Team Leader, Writer and Researcher

Valerie Fletcher has been Executive Director since 1998 of the Institute for Human Centered Design (IHCD). Fletcher writes, lectures and works internationally. She currently oversees projects ranging from the development of design guides for accessibility compliance and inclusive design to a wide range of consultation and design services to public, and private entities in the US and globally. She created the IHCD User/Expert Contextual Inquiry Lab which has over 500 people with lived experience of a physical, sensory or brain-based functional issue engaged in the evaluation of places, products and services. Her research focus is integrated social and environmentally sustainable solutions for multifamily housing, healthcare, culture, workplaces, and the public realm. She has been a Special Advisor on Inclusive Design to the Open Society Institute and the UN Department of Economic and Social Affairs. She is on the North American representative on the Board of the International Association for Universal Design (IAUD) in Japan. Fletcher has a master's degree in ethics and public policy from Harvard University. The Boston Society of Architects awarded her the Women in Design award in 2005. She is a member of the Board of Trustees of the Boston Architectural College.

Team Members

Matthew Brault, Demographic and Statistical Research Consultant

Matthew Brault has been a demographic and statistical researcher consulting with IHCD's New England ADA Center since 2016. He has a decade of experience working as the primary disability subject matter expert with the U.S. Census Bureau's Health and Disability Statistics Branch where he authored reports on the prevalence and characteristics of the population of people with disabilities. His research has examined how people with disabilities and chronic conditions respond to surveys and how definitions of disability from various policies align with operational definitions of disability in household surveys.

Mr. Brault holds a Master of Public Policy from Georgetown and is currently a PhD candidate in Health Policy at Harvard University.

PJ Moynihan, Producer, Director, and Cinematographer

PJ Moynihan is an Emmy-Nominated Producer and Award-Winning Writer/Director. He is Founder & CEO of Digital Eyes Film, a full services production company specializing in social impact media, feature films, and independent distribution. Over nearly 20 years in the media & entertainment industry, Moynihan has logged experience creating, producing, and distributing countless productions, from short films for community-based clients to major motion pictures with Hollywood talent. His production credits include documentary films “Healing Voices” (2017), “Salmonboy” (2012), “Fight Town” (2011), “Eye on the Dream” (2007), and the feature film “Spaceman” (2016). Digital Eyes Film is currently in production with a documentary feature entitled “Recovering Addiction: A Public Health Rescue Mission” which is targeting a 2021 global release.

Dr. Erica Walker, Public Health Specialist, Writer, and Researcher

Erica Walker is an environmental epidemiologist and exposure assessments scientist interested in understanding how the built environment impacts human health. She is a postdoctoral researcher at Boston University School of Public Health in the Department of Environmental Health and is the Principal Investigator of Community Noise Lab. Community Noise Lab supports community identified sound and noise issues using real-time monitoring, smartphone technology, laboratory-based experiments, and community engagement activities. Her work has been featured in prominent media including The Atlantic, Boston Globe, New York Times, Wall Street Journal, and Washington Post. Dr. Walker earned a B.S. and B.A in both mathematics and economics from Simmons College; A MS in environmental economics and urban planning from Tufts University; and a ScD in environmental health from the Harvard T.H. Chan School of Public Health.

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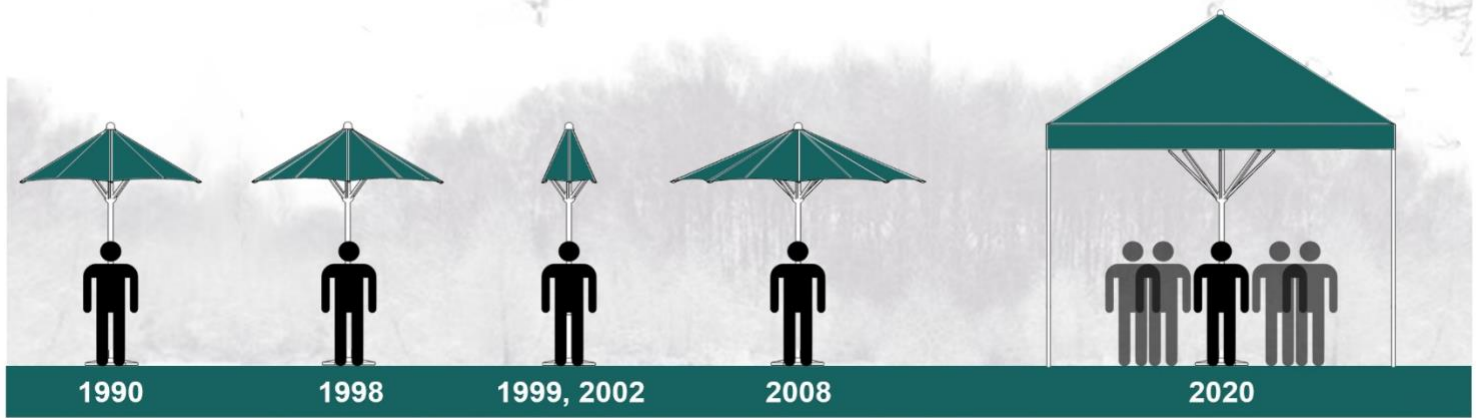
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2001 International Classification of Functioning, Disability and Health: Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).
https://www.who.int/disabilities/world_report/2011/chapter1.pdf?ua=1pdf?ua=1

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| 1990 | <p>Americans with Disabilities Act of 1990</p> <p>The ADA originally stated that the Congress finds that --1) some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older[.]*</p> <p>* https://www.eeoc.gov/ameri-cans-disabilities-act-1990-origi-nal-text</p> |
| 1998 | <p>Bragdon v. Abbott 1998</p> <p>This U.S. Supreme Court decision slightly expanded the definition of disability by including asymptomatic HIV as a disability possibly covered by the ADA. https://www.law.cornell.edu/supct/html/97-156.ZO.html</p> |
| 1999 2002 | <p>Sutton Trilogy 1999 and Toyota Motor Mfg., Ky. v. Williams 2002</p> <p>These four U.S. Supreme Court decisions substantially narrowed the definition of disability, possibly reducing the original 43 million covered to 13.5 million people. *</p> <ul style="list-style-type: none"> • Sutton v. United Airlines, Murphy v. United Parcel Service and Albertsons v. Kirkinburg (all 1999) • Toyota Motor Mfg. v. Williams (2002) <p>*Ruth Colker, "The Mythic 43 Million Americans with Disabilities," 49 Wm.& Mary L. Rev.1, (2007)</p> |
| 2008 | <p>American with Disabilities Act Amendments Act 2008</p> <p>This Act was passed "[t]o restore the intent and protections of the Americans with Disabilities Act of 1990." The text further states that "[t]he definition of disability in this Act shall be construed in favor of broad coverage of individuals under this Act, to the maximum extent permitted by the terms of this Act."* The ADA defines major life activities as follows: "Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working." "[A] major life activity also includes the operation of a major bodily function."</p> <p>https://www.congress.gov/110/plaws/publ325/PLAW-110publ325.pdf</p> |
| 2020 | <p>Changing Reality of Disability 2020</p> <ul style="list-style-type: none"> • 26% of US adults have a disability: 13.7% serious difficulty walking or climbing stairs, 10.8% serious difficulty* concentrating, remembering or making decisions. * • 40% of people 65+ and 40% Native American adults have a disability. * • 25% of Black adults have a disability. * • 19.1% people aged 18 or older had a mental illness (2018 National Survey on Drug Use and Health, 18+) • 7.8% people aged 18 or older had a substance use disorder (2018 National Survey on Drug Use and Health, 18+) • 12 M people 40 years and over in the United States have vision impairment* 48 M people have trouble hearing with one or both ears. * • 20% of children have a serious functional limitation related to developmental, emotional, and/or behavioral conditions (National Institute of Mental Health, 2015) <p>*https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html</p> |



Timeline from the Passage of the ADA to the Present Noting Pertinent Additional Milestones

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| 1990 | <p>Americans with Disabilities Act Signed by President George H. W. Bush</p>  <p>The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. With its provisions for technical assistance, research and enforcement, it remains the global model of best practice. Image courtesy of George Bush Presidential Library & Museum.</p> |
| 1990 | <p>Education for All Handicapped Children Act Is Amended and Renamed Individuals with Disabilities Education Act (IDEA)</p>  <p>Makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. IDEA included the Child Find mandate to all children residing within a state.</p> |
| 1991 | <p>Civil Rights Act of 1991</p>  <p>Included people with disabilities along with other groups covered by original civil rights laws to be able to be awarded damages in cases of deliberate employment discrimination. Image courtesy of Institute for Human Centered Design.</p> |
| 1992 | <p>Office of Environmental Justice (OEJ) created at the Environmental Protection Agency</p>  <p>The Office coordinates EPA efforts to address the needs of vulnerable populations by decreasing environmental burdens, increasing environmental benefits, and working collaboratively to build healthy, sustainable communities.</p> |
| 1997 | <p>Principles of Universal Design</p>  <p>Equitable Use, Flexibility in Use, Simple, Intuitive Use, Perceptible Information, Tolerance for Error, Low Physical Effort, Size and Space for Approach & Use. [Developed by a group of US designers and design educators from five organizations in 1997. Principles are copyrighted to one of them: Center for Universal Design, School of Design, State University of North Carolina at Raleigh. The Principles are in use internationally.] Image courtesy of NC State University.</p> |

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| <p>1998</p> | <p>Section 508 of the Rehabilitation Act of 1973 Amended</p>  <p>Amendment requires Federal agencies to make their electronic and information technology (EIT) accessible to people with disabilities. The law applies to all Federal agencies when they develop, procure, maintain, or use electronic and information technology. Under Section 508, agencies must give disabled employees and members of the public access to information comparable to the access available to others.</p> |
| <p>1998</p> | <p>First International Conference on Universal Design—Designing for the 21st Century</p>  <p>Event in New York attracted participants from 32 nations. The primary host was Adaptive Environments, now the Institute for Human Centered Design.</p> |
| <p>1999</p> | <p>Olmstead vs. L. C. Supreme Court Decision</p>  <p>The Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. Public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. Image courtesy of Peter Souza, The White House.</p> |
| <p>2001</p> | <p>World Health Organization (WHO) Introduces the “Contextual” Definition of Disability in the International Classification of Function, Disability and Health (ICF)</p>  <p>In ICF, the term functioning refers to all body functions, activities and participation, while disability is similarly an umbrella term for impairments, activity limitations and participation restrictions. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. Ratified by 191 member nations.</p> |
| <p>2002</p> | <p>Help America Vote Act</p>  <p>Law requires at least one accessible voting machine in each polling place, provides funding to States for making polling places and voting equipment accessible for people with disabilities, and provides for the nationwide Protection and Advocacy System to conduct training programs on accessible voting for people with disabilities. Image courtesy of hoyameg is licensed under CC BY 2.0</p> |

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| 2006 | <p>UN Convention on the Human Rights of People with Disabilities (CRPD)</p>  <p>The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. As of August 2020, 181 UN Member Nations have ratified the CRPD. Image: "Disability Pride Parade NYC" by US Department of State is licensed under CC by NC. 2.0.</p> |
| 2008 | <p>ADA Amendments Act</p>  <p>The ADA Amendments Act of 2008 (ADA Amendments Act) made a number of significant changes to the meaning and interpretation of the ADA definition of "disability" to ensure that definition would be broadly construed and applied without extensive analysis. Image: 2008 ADA amendment act from PYD history-timeline-2008</p> |
| 2010 | <p>Affordable Care Act Enacted</p>  <p>Under the ACA, everyone has the right to buy health insurance under what is known as the "guaranteed issue" provisions of the law. Insurance companies are prohibited from setting premiums based on your health conditions, so people with disabilities cannot be charged more, simply because of their disability.</p> |
| 2010 | <p>The Department of Justice Revised Titles II and III of the ADA and Adopted the 2010 ADA Standards for Accessible Design</p>  <p>Revised ADA design standards included the relevant chapters of the Access Board's 2004 ADA/ABA Accessibility Guidelines. These design standards were harmonized with the private sector model codes that are adopted by most States. These rules addressed recreation facilities, play areas, State and local government facilities (detention facilities and courthouses), and, finally, the revision of the Access Board's 1991 guidelines.</p> |
| 2017 | <p>Final Rule Goes into Effect for "Refresh" of Section 508 of the Rehabilitation Act</p>  <p>The rule updated and reorganized the Section 508 Standards and Section 255 Guidelines in response to market trends and innovations in technology and to restore provisions for TTY access that had been omitted. The refresh harmonized with international standards, most notably the Web Content Accessibility Guidelines 2.0 (WCAG 2.0),</p> |
| 2020 | <p>30th Anniversary of the ADA</p> <p>CDC reports 61 million American adults with disabilities, 26% of the population. As in 1990, the highest rates of disability are among Blacks, Native Americans, and people 65 and over.</p> |