

The Equity in OC (EiOC) Initiative was a limited-term project funded by the Centers for Disease Control and Prevention (CDC) under the National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved, Including Racial and Ethnic Minority Populations and Rural Communities (CDC-RFA-OT21-2103). The initiative concluded in May 2024. This document and any associated EiOC branding were developed as part of that grant-funded effort.

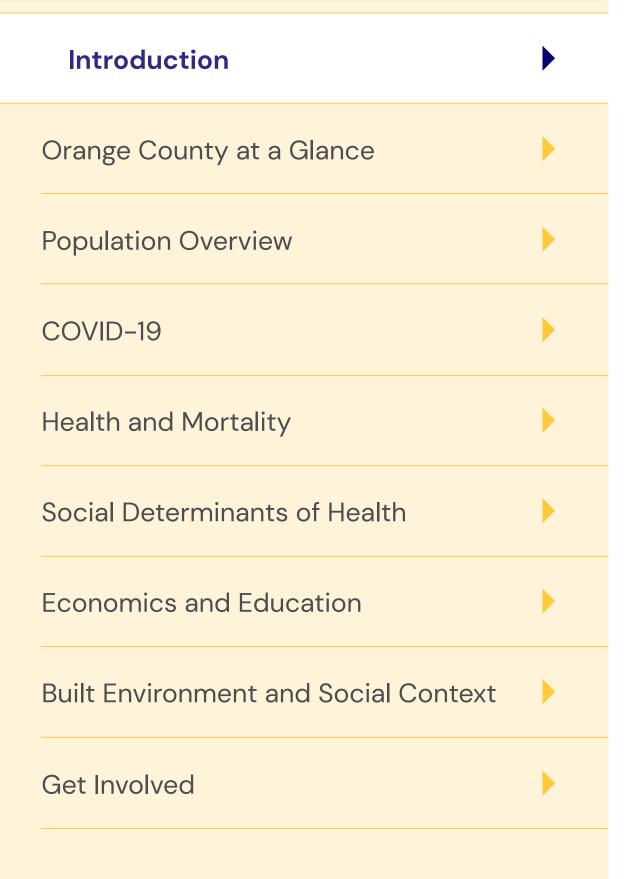
Population Overview

PERSONS WITH DISABILITIES





PEOPLE WITH DISABILITIES



Addressing health inequities across
Orange County
by enabling
system change.



Achieving Equity in Orange County

Health inequities are differences in health status or in the distribution of health resources among various populations. This is due to the social conditions in which people are born, grow, live, work, and age. Across Orange County (OC) we see differences in the length and quality of life; rates of disease, disability, and early death; severity of disease; and access to treatment because of these inequities.

Equity in OC is an OC Health Care Agency (HCA) initiative in collaboration and partnership with local Orange County community partners. Funded by a grant from the Centers for Disease Control and Prevention (CDC), the Equity in OC Initiative is a community-informed and data-driven initiative to address health inequities and disparities in Orange County by laying the foundation for creating a healthier, more resilient, and equitable Orange County.

Why Create Population Overviews?

These population overviews are snapshots of available data for various populations in Orange County. By laying out population—specific data in these overviews, we can identify systemic changes that can improve the quality of life within these communities. Since these population overviews are only the start of democratizing community–level data, we welcome feedback and input to further refine and improve this living document.

For more information go to www.equityinoc.com.



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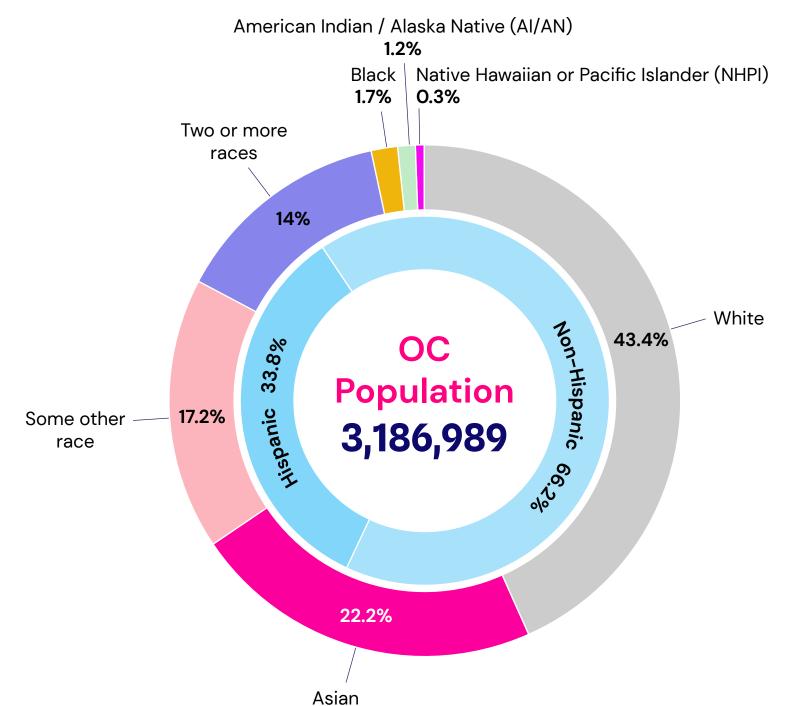
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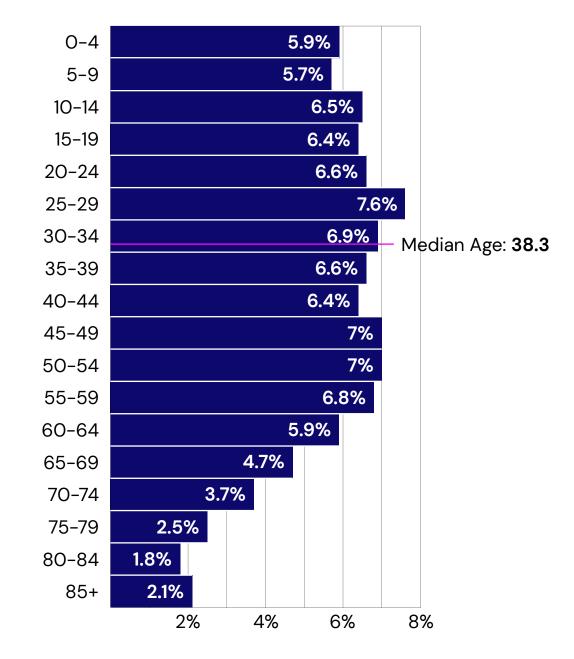
The United States (U.S.) Census
Bureau collects racial data according
to guidelines by the U.S. Office of
Management and Budget (OMB),
and these data are based on selfidentification.

Racial categories in the census survey reflect a social definition of race in the U.S. It is not an attempt to define race biologically, anthropologically, or genetically. Also, categories of race include national origin or sociocultural groups. People who identify their origin as Hispanic, Latino, or Spanish may be of any race.

About the Topic of Race (census.gov)

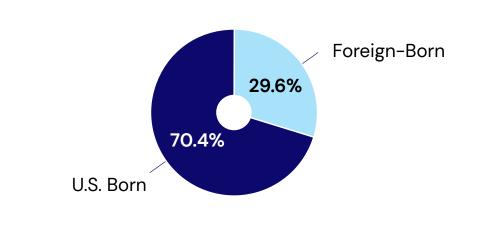
Source: 2020 Decennial Census

Population by Age Group



Source: 2020 ACS 5-Year Data, U.S. Census Bureau

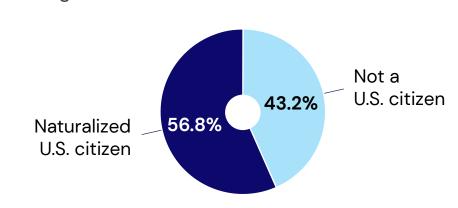
Population by Birth Origin



Source: 2020 ACS 5-Year Data, U.S. Census Bureau

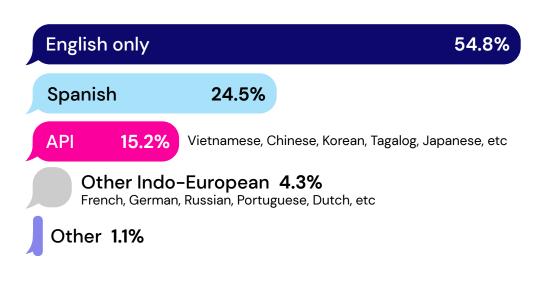
Population by Citizenship

of foreign-born residents



Source: 2020 ACS 5-Year Data, U.S. Census Bureau

Languages Spoken at Home



Source: <u>2020 ACS 5-Year Data, U.S. Census Bureau</u>



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\$94,441
Median Household Income

Source: 2020 ACS 5-Year Data, U.S. Census Bureau



56.9%
Home Ownership Rate
as of March 2022

Source: <u>U.S. Bureau of Labor Statistics</u>



1,129,785
Total Housing Units

Source: 2020 ACS 5-Year Data, U.S. Census Bureau



41.2%Bachelor's Degree or Higher

2020

Source: 2020 ACS 5-Year Data, U.S. Census Bureau



10.1%

Persons in Poverty

2020

Source: 2020 ACS 5-Year Data, U.S. Census Bureau



3.1%

Unemployment Rate

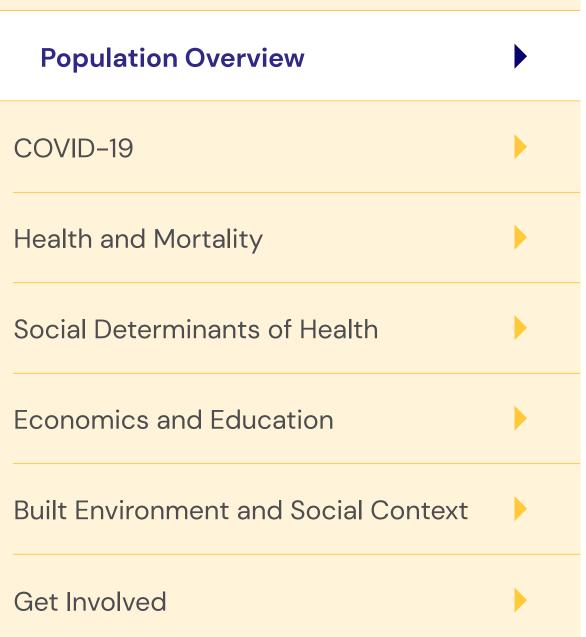
as of March 2022

Source: <u>U.S. Bureau of Labor Statistics</u>



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People with Disabilities Population Overview in OC

Understanding Terms

According to the CDC, "A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)." Studies have indicated that race, class, and sex can intersect to influence access to resources, healthcare, and opportunities, impacting the prevalence and experience of disabilities. A disability can be caused by a variety of factors and can take on many forms, from physical limitations to intellectual differences (neurodivergence). A disability can be related to conditions present at birth or can be because of an injury that occurred later in life. Disabilities can include Cerebral Palsy (which affects a person's ability to move and maintain balance and posture), Down Syndrome (a genetic condition in which a person has an extra chromosome), autism spectrum disorder (which is related to brain development and includes a wide range of symptoms related to social and communication perception and interaction), and traumatic brain and spinal cord injuries (which can vary in physical severity).

In 2001, the WHO created the "International Classification of Functioning, Disability, and Health," (ICF) to help categorize the "dimensions" of disability to better serve the community. The first dimension involves loss of a limb, vision, or memory ("impairment"). The second dimension includes difficulty seeing, hearing, walking, or problem solving ("activity limitation"). The final dimension includes barriers to normal daily activities like working, obtaining health care and preventative services, or taking part in community activities ("participation restrictions"). Disability can also be classified as progressive (e.g. muscular dystrophy), static (e.g. limb loss), or intermittent (e.g. multiple sclerosis).

Even with these classifications in hand, it is important to remember that people with disabilities deserve to be treated and spoken to with <u>respect</u> like all others. According to the World Health Organization (WHO), disability is a human rights issue – people with disability are among the world's most discriminated against people, often experiencing violence, prejudice, and denial of autonomy as well as facing barriers to care. Part of respecting this community includes acknowledging their differences as you would acknowledge anyone else's uniquenes. As the <u>CDC</u> affirms, while "people with disabilities" can "sometimes refer to a single population, this is actually a diverse group of people with a wide range of needs." A disability can vary in severity and impairment. While some individuals with disabilities may be easily identified, other disabilities are not as easily recognized.

Additionally, language surrounding persons with disabilities is constantly evolving, as euphemisms such as "differently abled" and "special needs" have resulted in some <u>pushback</u> due to their evading nature in acknowledging these people. This has thus led to discussion amongst this community surrounding <u>reclaiming</u> the word "disabled", and empowering their identities. People with disabilities have different preferences on which language they use. Some prefer person-first language, which puts the person before the disability (e.g., person who has cerebral palsy) while others may prefer identity-first language, which puts the disability before the person (e.g., autistic woman).

In dialogue, it is critical to ask the person how they would like to be referred to. In this document, we will generally be using person-first language, though we recognize this is not a perfect solution. Ultimately, most people will experience or have a disability at some point over the course of their life. Learning to recognize the diversity



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within this population can begin to increase our understanding and support of people with disabilities.

People with Disabilities: A Historical Context

The history of attitudes toward people with disabilities has been marked by societal fears, intolerance, ambivalence, prejudice, and ignorance. Throughout the ages, people with disabilities have been subject to myriad heinous acts, from isolation to infanticide, institutionalization to sterilization. Many of these practices continued until the end of World War II (1939–1945). Though they were drastically curtailed in the last half of the 20th century, many atrocities continue to this day; these include the use of prisons and asylum–type settings. To make matters worse, the United Nations did not adopt their "Principles for the Protection of Persons with Mental Illness" until 1991 and the "Convention on the Rights of Persons with Disabilities" until 2006.

There is no simple answer as to why people with disabilities have historically been treated so inhumanely. What is clear, however, is that the improvement in treatment and perceptions of people with disabilities was largely due to people with disabilities demanding and creating changes for themselves and their communities. A few activists of note include: Ed Roberts (pioneering leader of the disability rights movement), Lex Friedan (one of the "chief architects" of the Americans with Disabilities Act), Judith Heumann (known as the "Mother of the Disability Rights Movement"), Alice Wong (founder of the "Disability Visibility Project (DVP)"), and Haben Girma (a disability rights advocate and the first deafblind graduate of Harvard Law).

Like many other civil rights movements, the disability rights movement has a long history filled with valiant activism and unifying protests.

Section 504 of the Rehabilitation Act of 1973 was a major victory for people with disabilities as it forbade organizations and employers from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services. It also laid the groundwork for the 1990 Americans with Disability Act (ADA) and its amendments

(2008), which, to date, are among the movement's greatest legal achievements. The ADA is a major civil rights law that ensures that people with disabilities can participate fully in employment, state and local government services, public accommodations, transportation, and telecommunications. The overarching goal of the ADA is to promote equal opportunity, full participation, independent living, and economic self–sufficiency for Americans with disabilities.

It has been over 30 years since the landmark Americans with Disabilities Act (ADA) was passed and while there have been significant efforts to increase access and accommodations for individuals with disabilities, continued barriers in the workplace, public spaces, and within communities continue to negatively impact those living with a disability. As of 2020, disability-related complaints were the largest category filed with federal agencies that enforce fair housing and employment laws. Moreover, many people with disabilities continue to fight for inclusion in both the physical world and the digital world. People with disabilities continue to encounter inaccessible voting experiences both in-person and online and inaccessible COVID-19 websites and vaccine registration forms. At a more fundamental level, the ADA's guarantee of rights did little to address the historical inequalities that have pushed people with disabilities to the margins. In education, these inequalities include that children with disabilities are less likely to graduate from high school and far less likely to attend college and they are also disciplined far more often in school. They are also overrepresented in the criminal justice system, and prisons are rarely set up to accommodate their needs. As long as these inequities persist, more work must be done.

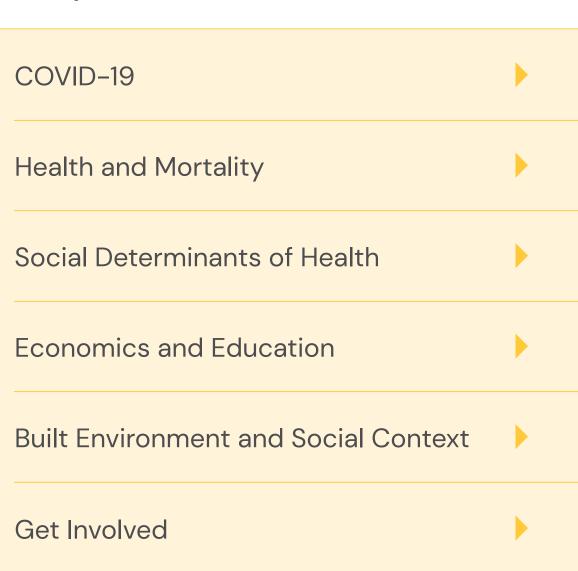
Ultimately, much more progress is needed to see equality, health equity, and inclusion for this population. People with disabilities have been labeled as "outsiders" for centuries, and it will take time, commitment, and resources to undo that stigma. Disability does not discriminate — anyone can become disabled at any point in their lives. We must be mindful of that and advocate for this community.



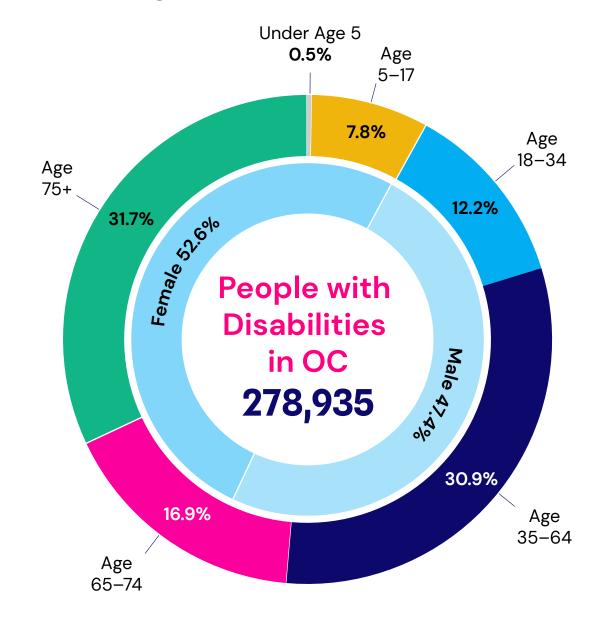
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Data gathering for persons with disabilities in Orange County is currently in progress and the latest round will be available in 2024.



Source: <u>U.S. Census Bureau</u>

People with Disabilities in the U.S.*

2021

13%

18%

24%

46%

Women

Non-Hispanic AI/AN

Adults 65–74

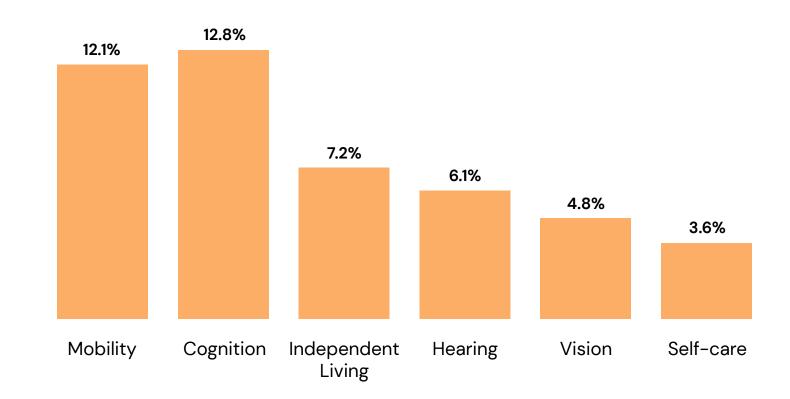
Adults 75+

Source: Pew Research Center

*It is important to note that this is likely an underestimate of the actual number of persons with disabilities, as this is excluding many mental disabilities and other forms of disabilities that are more difficult to identify. Mental or intellectual disabilities are defined by either difficulties in intellectual functioning (such as learning, problem solving, judgment), and/or adaptive functioning (activities of daily life such as communication and independent living). They are separate entities from mental illnesses, but may be a resulting condition of a mental or even physical illness.

Percentage of Adults with Select Functional Disability Types in U.S.

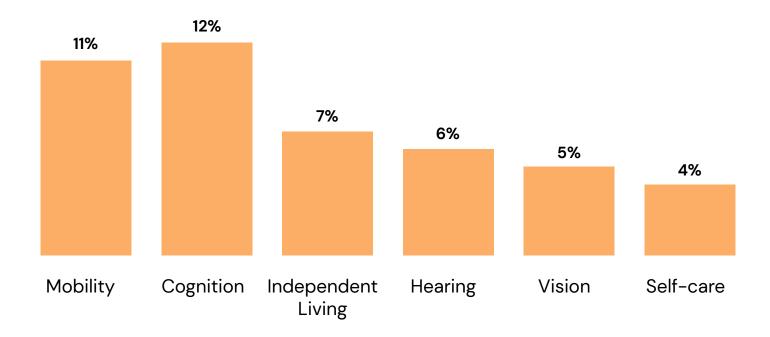
2023



Source: CDC

Percentage of Adults with Select Functional Disability Types in California

2023



Source: CDC

*The <u>CDC</u> defines these functional disabilities as the following: Hearing (serious difficulty hearing), Vision (serious difficulty seeing), Cognition (serious difficulty concentrating, remembering or making decisions), Mobility (serious difficulty walking or climbing stairs), Self-care (difficulty dressing or bathing), Independent living (difficulty doing errands alone)



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Top 10 Cities of People with Disabilities

According to the U.S. Census Bureau, approximately 5.3% of the Orange County population under the age of 65 has some type of physical or intellectual disability (2017–2021). The rate of disability from ages 65 to 74 is about 18%; that more than doubles after 75 years to 45.9% and affects millions of Americans each year. With that said, it is important to take this data with a grain of salt. Not only is participation in the census voluntary, but the stigma surrounding disability likely leads to underreporting in Orange County and across the country.

Top Cities of People with Disabilities

2015-2020, number and percent of population with disabilities

City			City	
Anaheim	31,514	9.0%	Fullerton	12,419 8.9%
Santa Ana	26,120	7.9%	Orange	11,517 8.5%
Huntington Beach	20,046	10.1%	Westminster	10,958 12.1%
Garden Grove	18,579	10.8%	Costa Mesa	9,412 8.4%
Irvine	14,804	5.4%	Mission Viejo	9,371 9.9%

Geographical Markers

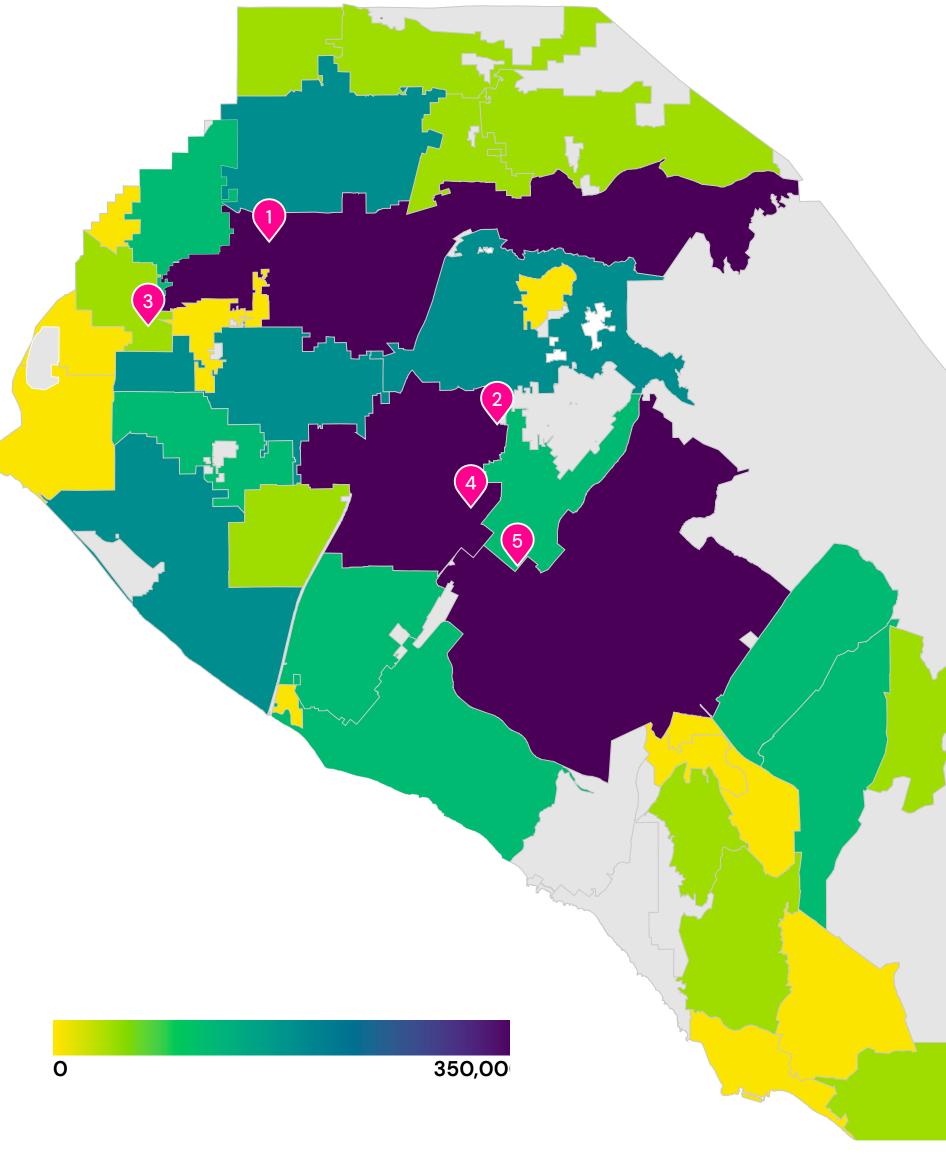


2 Regional Center (Main Office)

3 Regional Center (West Area Office)

4 Orange County Social Services

5 Sweet Shade Ability Center



Source: U.S. Census



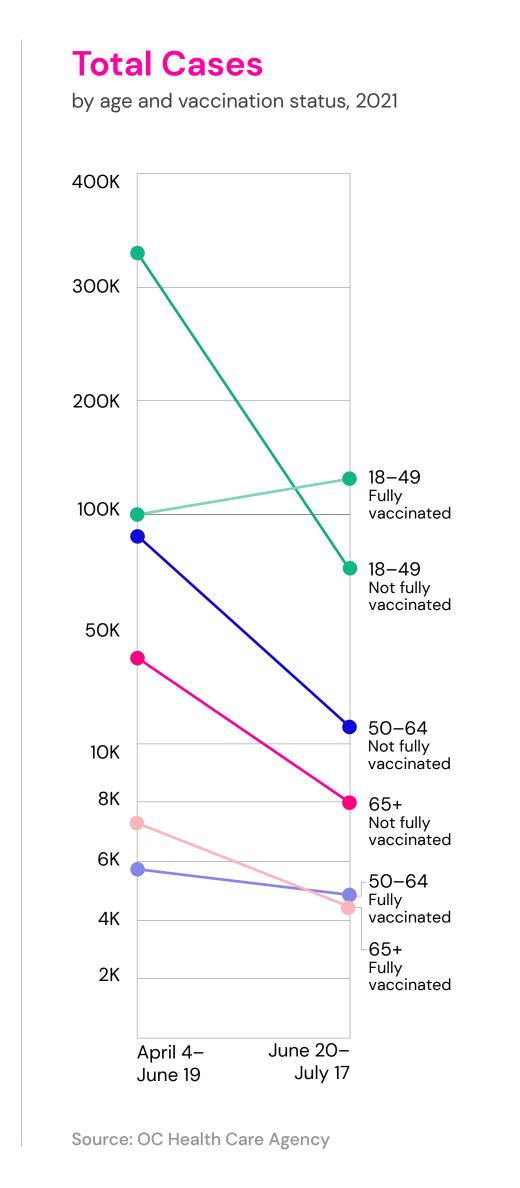
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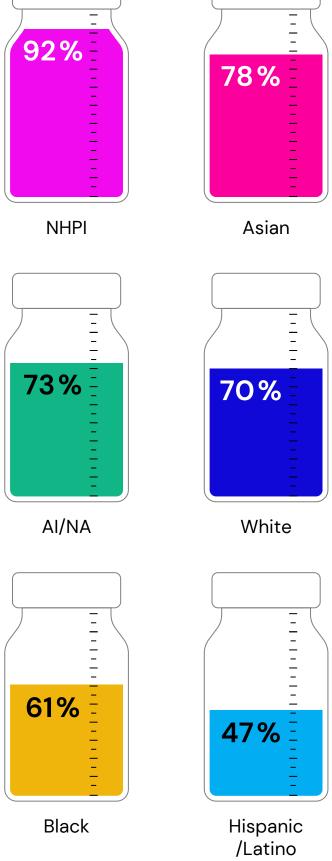
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People with Disabilities and COVID-19 in Orange County

While the COVID-19 pandemic was an unexpected shock to everyone and regulations proved to have many challenges for the public, people with disabilities (PWD) faced disproportionately more difficulties and higher rates of exposure. According to the CDC, the majority of individuals with disabilities are no more likely to become infected or become severely ill from COVID-19 than the general population. Various underlying health conditions, the need for congregate living settings, and health or social inequities result in higher rates of infection and severe illness, however. Individuals with limited mobility cannot socially distance with support providers or family members, for example. Furthermore, individuals with spinal cord injuries (SCI) and other physical disabilities reported difficulty acquiring personal protective equipment (PPE) and difficulty acquiring food and groceries during the pandemic, hindering their daily functioning. Lastly, some disabled individuals may not be able to communicate symptoms of illness, further delaying the access to medical care. For example, individuals with intellectual developmental disabilities are three times more likely to die of COVID-19 with infection, and some disabilities make social distancing, masks, and heightened hand hygiene difficult.



Vaccination Rate per 100K population, 2021



Source: OC Health Care Agency



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People with Disabilities and COVID-19 in OC (continued)

With regards to health care access, individuals with disabilities were disproportionately affected by the COVID-19 lockdown as many health care services were either shut down completely or faced reduced capacity. Transportation to in-person health services were also reduced due to the lockdown restrictions; this had a profoundly negative affect access to care and community. Children with disabilities experienced a greater decrease in access to health care services due to closure of medical settings, caregiving agencies, and schools providing therapy. Many parents also expressed reluctance to seek medical care for fear it would lead to their child contracting COVID-19.

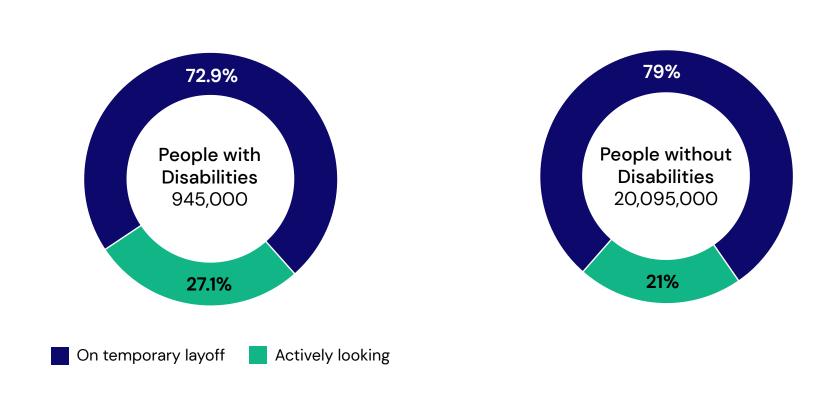
Data also suggests that individuals with physical disabilities from marginalized communities (i.e. disabled older adults, non–Hispanic Black and Hispanic disabled people, disabled individuals experiencing homelessness) were overrepresented in COVID-19 hospitalizations. All of this was compounded by disability-focused providers leaving the field due to low pay, burnout, or both and a 2022 report by the California State auditor that found the California Department of Developmental Services, "not ensuring regional centers have the necessary resources to serve Californians with intellectual and developmental disabilities."

In terms of employment, prior to the pandemic, people with disabilities already faced disparities in employment with only 36% of individuals with disabilities being employed compared to 77% of the total population. The COVID-19 pandemic only further accentuated the labor disparities many people with disabilities face through working conditions that often-placed people with disabilities at a greater risk for negative health outcomes. Additionally, California only passed a bill prohibiting the payment subminimum wage (via "sheltered workshops") to workers with disabilities in

2021; employers have until 2025 to fully implement the change. Some people with disabilities also fear losing disability benefits if they pursue more gainful employment. As a result, the number of employed working-age people with disabilities fell by 20% compared to only 14% of working-age people without disabilities from March 2020 to April 2020. In addition, as seen in the graph below, there is a higher percentage of people with disabilities who are actively looking for work compared to those without a disability. Even among people with disabilities who are employed, individuals who are deaf, hard of hearing, and people who are blind experienced significant barriers to communication when moving to remote work.

Unemployment

U.S., April 2020



Source: Kessler Foundation

*While the graph indicates that people with disabilities have less temporary layoffs and more individuals actively seeking work, it is important to note that PWD tends to be in programs that subsidize employment and thus, they face higher unemployment rates. Additionally, PWD often pursues employment that pays below minimum wage in order to receive benefits.



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Health and Mortality

Inequities in Health Care

People with disabilities face many barriers to achieving good quality healthcare. According to the CDC, individuals with disabilities are more likely than the general population to report having poorer overall health, having less access to adequate health care, and engaging in risky health behaviors (e.g. smoking, physical inactivity). Secondary conditions such as pain, fatigue, obesity, and depression can also occur because of having a disabling condition. These issues can all be made worse by inaccessible health care facilities and equipment, lack of disability–specific knowledge among medical professionals, transportation difficulties, and higher rates of poverty among people with disabilities.

Primary barriers to health and health care for the general population are becoming well documented and heightened national awareness of these obstacles has spurred numerous proposals for health care reform. Even as information remains limited, recent studies indicate that people with disabilities experience both health disparities and specific problems in gaining access to appropriate healthcare, including participation in health promotion initiatives and disease prevention programs and services. They also frequently lack either health insurance or coverage for necessary services such as specialty care, long-term care, prescription medications, durable medical equipment, and assistive technologies.

Although attempts have been made to address some of these barriers, significant problems remain. For example, federal health care funding agencies such as the Centers for Medicare & Medicaid Services (CMS) do not conduct oversight of ADA architectural and programmatic accessibility compliance by provider, health plan, or

state. They also do not assess health providers' disability cultural competence or etiquette / "bedside manner." This is compounded by the fact that few health care training programs address disability issues in their curriculums. Most federally funded health disparities research does not recognize or include people with disabilities as a disparity population. Given these changes, it is critical to understand the complex and interrelated factors that contribute to health and health care inequities for people with disabilities. This must then lead to the identification and implementation of practical solutions.

Health Care Access Barriers for Adults with Disabilities

2023

1 in 4

Have an unmet health care need because of cost in the past year

18-44 years old

1 in 5

Did not have a routine check-up in the past year

45-64 years old

1 in 3

Do not have a usual healthcare provider

18-44 years old

Source: CDC



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Health and Mortality (continued)

Access to Care

According to the Center for Medicare / Medicaid Services (CMS), adults with disabilities are almost twice as likely to report having unmet health care needs related to the accessibility of a doctor's office or clinic compared to the general population. Moreover, compared to people without disabilities, people with disabilities are:



Less likely to receive comprehensive preventative care



Less likely to have an annual dental visit



Less likely to receive diagnostic imaging



Less likely to receive recommended cancer screenings

Source: Center for Medicare/Medicaid Services (CMS)

Though progress has been made to improve access in medical buildings and offices, patients still face barriers in physician suites. To that end, a 2021 survey of U.S. physicians across seven specialties found that among those seeing patients with significant mobility limitations, only 40% "always," or "usually used," accessible exam tables or chairs. It should go without saying that inaccessible equipment can affect treatment, personal safety, and quality of care. Having accessible equipment is not enough; office rules and procedures must reasonably accommodate every patient that walks through the door and physicians must consider and address any biases they may hold.

Moreover, access to care for children with disabilities is extremely important as they often need <u>substantial health care</u> and intervention services. An issue often cited by the community is the lack of early identification and intervention for children with developmental disabilities. Data to support the low screening rates for children with disabilities is currently unavailable. As such, effort must be made on the part of the medical establishment to gather said data and better meet the needs of the patients they serve.

Medicare and Medicaid

Both Medicare and Medicaid / Medi-Cal were passed to serve as safety nets for the country's most vulnerable populations. Even a half-century after their passage, however, people with disabilities continue to face unmet healthcare needs. The community is frequently forced to face health disparities due to cultural incompetency, stigma and misunderstanding, and an inability to create meaningful policy change to cover the entirety of the disability community.



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Health and Mortality (continued)

The disparities faced by this community are many: in comparison to the general American population, people with disabilities are more likely to be unemployed, impoverished, and have less than a high school education. They also have higher levels of risk factors such as obesity, smoking, and being physically inactive. Moreover, disability prevalence is higher among racial minorities such as Black Americans, American Indians, and Alaska Natives. These disparities do not arise simply from having a disability, however; they arise from structural racism. Society and policymakers must do more to integrate the disabled community into the health care system.

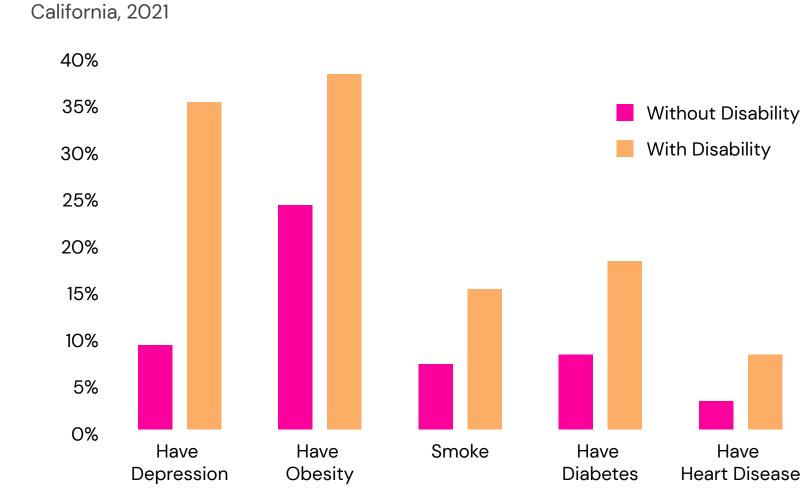
The Affordable Care Act (ACA) has taken some steps to assist, including the expansion of coverage. Unfortunately, disparities arise from health status and access to care. A recent study of Medicare recipients found that nearly 50% of respondents with disabilities reported putting off or not seeking care due to cost concerns. Furthermore, these beneficiaries were three times more likely to have difficulties finding a doctor who accepted Medicare (let alone the correct equipment to address their specific needs). Unfortunately, almost one–fifth (15%) of patients with disabilities who found a doctor still struggled to find clinicians who understood their disability and how to treat it.

The ACA does contain provisions aimed at tackling some of these barriers. They include standards for accessible medical diagnostic equipment and the development of cultural competency training for providers serving people with disabilities. Training of medical professionals is one step among many to address the disparities faced by people with disabilities, as the health care system was not designed with them in mind.

Life Expectancy

According to Syracuse University's Lerner Center for Public Health Promotion, in the U.S., on average, adults with any type of developmental disorder (DD) died 23.5 years earlier than adults without a DD. However, the average age at death varies significantly by the type of DD. Adults with cerebral palsy or other rare developmental disabilities tend to be the hardest hit, passing between 24–34 years earlier than those without such conditions. Adults with an intellectual disability, by comparison, pass 13 years earlier than the general population. The disabilities themselves were unlikely to be the sole explanation for this disparity, however. Poverty, socioeconomic disadvantages, psychological distress, and limited access to healthcare services are also likely contributors.

Likelihood of Adults with Disabilities to...



Source: CDC



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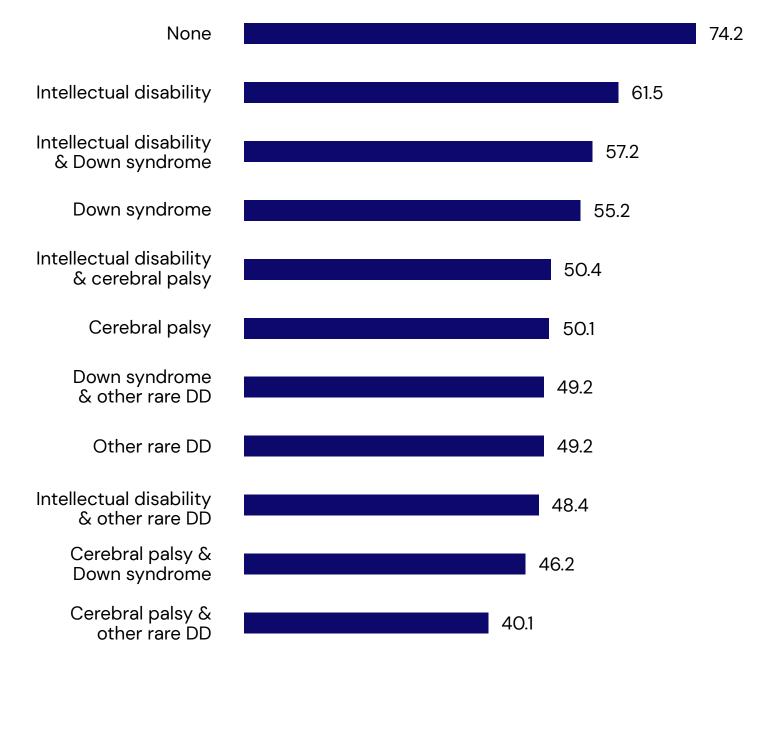
Health and Mortality



Health and Mortality (continued)

Life Expectancy of Adults with Developmental Disabilities

U.S. averages, based on 2012-2016 data



Source: Syracuse University Lerner Center for Public Health Promotion

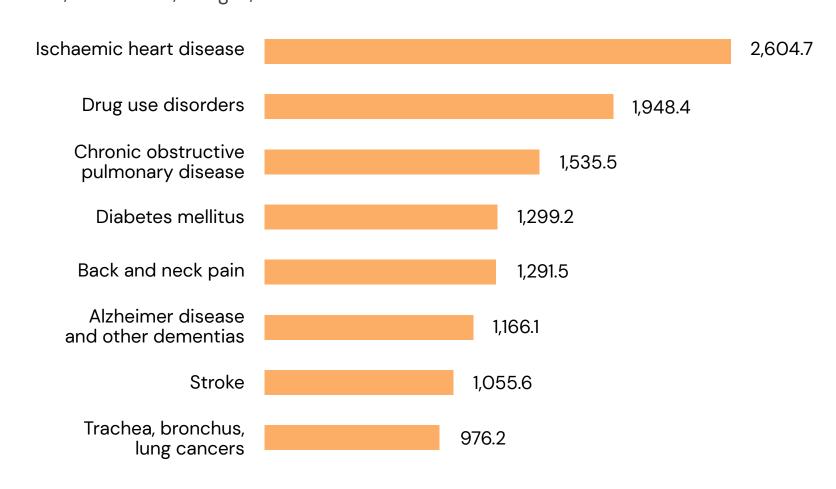
Disability-Adjusted Life Years

The World Health Organization found the top 20 causes of Disability-adjusted Life Years (DALYs) in the United States in 2019. DALYs are defined as losing an equivalent of one full year of health due to disability. As seen in the graph below, the leading cause in the United States was, by far, ischemic heart disease with 2604.7 in 100,000 individuals.

Individuals with different types of disabilities, however, experience different health needs and challenges. For example, individuals with intellectual disabilities experience higher probability of mortality from malignant neoplasms compared to those with other disabilities, but experience lower levels of influenza and pneumonia.

Top Causes of Disability-Adjusted Life Years

U.S., both sexes, all ages, 2019



Source: Pan American Health Organization



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Health and Mortality (continued)

Disabilities From Birth vs. Developed Disabilities

Disabilities at Birth

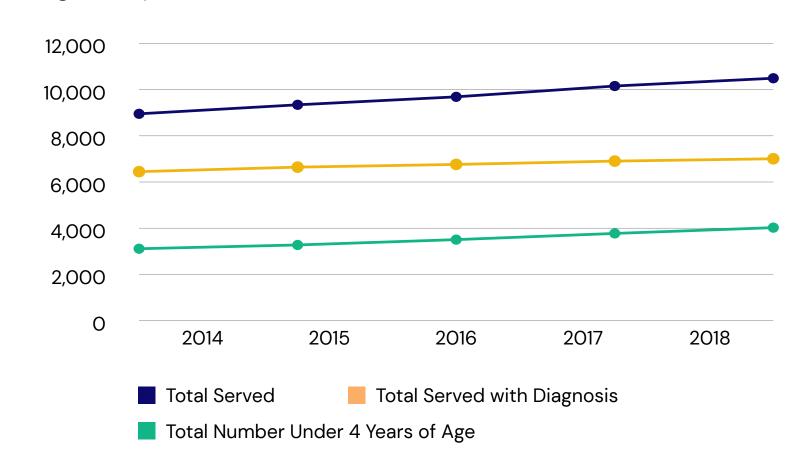
<u>Disabilities at birth</u>, often discussed as congenital challenges, are differences caused by genetics and environmental factors. Some have unknown causes and can result in physical, developmental, or mental disabilities. For most congenital challenges, the cause is unknown, but it can be influenced by <u>factors</u> such as smoking or drinking alcohol during pregnancy, certain medical conditions (i.e. obesity), family genetics, or having pregnancy at an older age. In the United States, congenital challenges are very common with <u>one in 33 babies</u> born with challenges each year.

Common challenges in California include cleft lip and cleft palate, Down syndrome, and spina bifida. The extent to which congenital challenges become a disability as the child grows up can vary greatly. Medical or surgical interventions with good follow-up care can be used in some cases such as congenital heart defects or cleft lip/palate to reduce morbidity and mortality. Similarly, treatment of endocrine conditions such as hypothyroidism with medication in early stages can greatly mitigate what otherwise would develop into serious intellectual disability.

Some congenital challenges can result in serious disabilities or even death. In Orange County specifically, 22% of infant deaths were caused by congenital challenges. For others who grow up with this disability, there are some resources available to aid in development needs. "Early Start", for instance, is a program funded by the federal government that caters to children under three years old who are at high risk for developmental disabilities. In Orange County, a total of 10,493 children were served in 2018 through the Early Start program.

Children Receiving Services for Developmental Disabilities*

Orange County, 2014–2018



Source: Orange County Children's Partnership

Later Onset Disabilities

The age of a disability's onset as well as its duration can affect a person's health. People who acquire a disability later in life may be more likely to rate their health more poorly and have greater difficulty adjusting to the disability. Earlier onset, longer term disabilities may allow for more time to adjust mentally, emotionally, and psychologically, by comparison. This, in turn, may lead to higher reported general health. Also, though people who are aging often don't think of themselves as having a disability, they may still meet the ADA's definition (having a "physical or mental impairment

^{*} This graph shows the number of children under age 18 who use services at the Regional Center of Orange County (RCOC).



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that substantially limits a major life activity"). More than 30% of Americans over the age of 65 have a disability, and over 50% of those over the age of 75. These disabilities range from difficulties seeing, hearing, walking, and thinking. Per the ADA, it is not the cause of the disability that matters, but how it affects a person's life.

Brain Injuries

According to the Brain Injury Association of America (BIAUSA), acquired brain injuries are: "an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma." These can further be divided into traumatic and non-traumatic brain injuries. The latter sometimes also called an, "acquired brain injury," is caused through internal factors such as lack of oxygen or pressure from a tumor. The former, by contrast, is caused by an external force (e.g. via a fall, a vehicle accident, sports, military injury, etc). Ultimately, any form of brain injury has the potential to lead to disability; according to a recent study, an estimated 48% of people who experience a traumatic brain injury incur lifelong disability.

Non-Traumatic

A non-traumatic brain injury causes damage to the brain by **internal factors Examples:** Stroke, near-drowning, aneurysm, tumor, infectious disease, lack of oxygen supply to the brain.

Traumatic

An alteration in brain function, or other evidence of brain pathology, caused by an **external force**. Traumatic impact injuries can be defined as closed (or non penetrating or open (penetrating)

Examples: Falls, motor vehicle accidents, struck by object, sports, assaults, IED

Chronic Conditions

According to the <u>World Health Organization</u>, individuals with disabilities are at higher risk for developing chronic conditions. For instance, they are two times more at risk to develop asthma, depression, diabetes, obesity, oral diseases, and stroke, often due to unfair circumstances rather than underlying health conditions. These <u>inequitable circumstances</u> include negative attitudes of health care providers, inaccessible health centers (due to physical barriers, financial barriers, or lack of transportation), and presentation of health-related information in formats that cannot be understood. These circumstances can be exacerbated further if an individual is a member of other minority groups (e.g. racial minorities, gender minorities, etc).

On the other hand, chronic conditions are one of the leading causes of disability in the United States. Some chronic conditions include heart disease, cancer, and diabetes. Oftentimes, chronic illness may be classified as a disability as they can substantially limit one's major life activities. For instance, chronic illnesses tend to result in severe pain and fatigue, which hinders individuals from everyday activities such as walking, concentrating, and learning. Additionally, people with physical chronic illnesses such as arthritis or endometriosis experience overwhelming weakness. However, individuals with severe chronic illnesses often are not recognized as having a disability and, thus, have been discriminated against under the ADA.



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Sexual Health and Sexuality

Historically, people with disabilities have been excluded from the normative definition of sexuality as a result of cultural scripts. This exclusion is compounded when disability is viewed as purely clinical and social health is ignored. The stigma around sexuality and disability has also negatively affected individuals, especially young people with disabilities, as it can cause confusion regarding sexual identity, reduced self-esteem, and self-doubt about their status as sexual beings. As stated in the Sexuality and Developmental Disability Resource Guide by Melissa Crisp-Cooper, she states in response to the common misconception that all people with disabilities are asexual or heterosexual: "First, people with disabilities fall along the same sexuality spectrum as nondisabled folks. We desire intimate connections and have sexual relationships. We represent every sexual orientation. Our preferences and partners are as complex and varied as those in the larger population.

People with disabilities also have <u>lower levels of sexual education knowledge</u> compared to their non-disabled peers and are more vulnerable to unsafe sex because of historical segregation and lack of resources. Quality sexuality education must be made accessible, including creating books on puberty and safe sex in Braille, presenting sexual education in simple language and ideas, or providing accommodations for physical <u>limitations</u>. Sex education is critical because unsafe sexual practices can lead to sexually transmitted infections (STIs). STIs, including HIV/AIDS, can, in turn, be a cause of long-term disability. With the appropriate support, equal access to resources and education, individuals with disabilities can not only establish healthy sexual relationships but also gain the tools to become parents.

Mental Health

According to a recent report by the <u>CDC</u>, adults with disabilities reported experiencing frequent mental distress almost five times as often as adults without disabilities. In 2018, an estimated 18 million (33%) adults with disabilities experienced frequent mental distress (which was defined as 14 or more "mentally unhealthy" days in the past 30 days). This was further exacerbated by the COVID-19 pandemic, where isolation, disconnection, disrupted routines, and diminished health services all had a large impact. Additionally, peer support specialists who worked with individuals with mental illnesses expressed concern for increasing isolation, substance use, housing instability, and food insecurity caused by COVID-19 restrictions.

According to the Disability Rights Education and Defense Fund (DREDF), adults with disabilities are three times more likely to die by suicide than peers without a disability. Sixty percent of people with a serious mental illness die 25 years earlier than their peers with preventable, co-occurring chronic diseases. Moreover, Black Americans with severe mental health disabilities are less likely than their white peers to access mental health services, more likely to drop out of treatment, more likely to receive poor quality care, and more likely to be dissatisfied with the care they received. Asian Americans and Hispanics are also less than half as likely as their white counterparts to receive mental health treatment. Clearly, this points to larger issues of racism and discrimination.

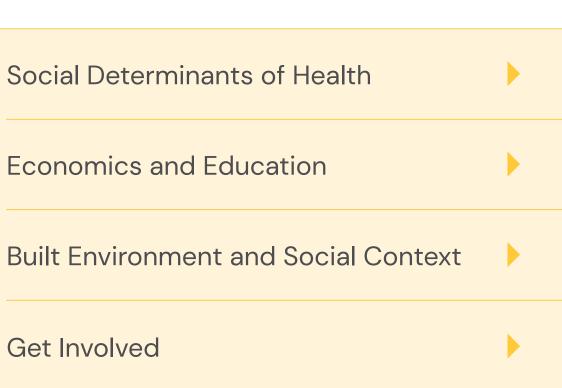
Unfortunately, it is also common for people with disabilities to encounter mental health practitioners who state they need to be "fixed," or that they cannot function as a full member of society. Clearly, this behavior is unacceptable. It is not without a name,



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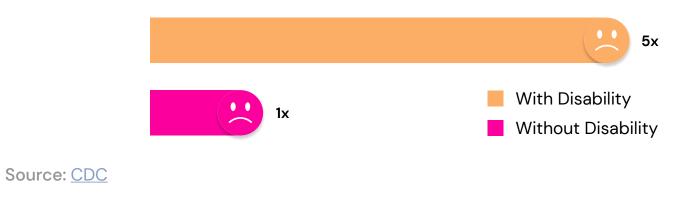
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Adults that report frequent mental distress U.S.



however; it is called ableism. Ableism has many facets, but is generally characterized by the practices and dominant attitudes in society that devalue and limit the potential of those with disabilities. This may include practices and beliefs that assign inferior value to people who have developmental, emotional, physical or psychiatric disabilities. Ableism does not positively contribute to the mental health of people with disabilities.

Lack of Integrated Care

A disability can affect all aspects of an individual's well-being and day-to-day life. As such, physical care may not be their top priority. They may also experience traumatic stress if the treatments they receive are painful, or depression and anxiety if they feel isolated by the experience. Physicians treat physical issues, but often miss the corresponding mental health component. Too often, they consider a by-product of the physical experience. As such, mental health issues can be overlooked or dismissed by physicians who focus on physical comfort or pain relief.

Poverty, Unemployment, and Cost

Lack of access to care in the US springs in large part from unequal access to employment and health insurance. According to the U.S. Bureau of Labor Statistics, approximately 20% of people with disabilities were employed in 2021. Moreover, those who were working were often only able to obtain part-time and/or temporary work; this meant these jobs often lacked access to health care benefits. The lack of health coverage and cost of treatments and medication can leave people with disabilities struggling to pay for both physical and mental health care. This is to say nothing of all the other expenses of daily life. Ultimately, solutions require collaboration between the public and private sector. This will need to include more collaboration, data sharing, and an honest admission that many current programs simply are not working (due to underfunding, lack of input from people with disabilities, or myriad other reasons).

Communication Barriers

Finally, if a person has a disability that affects how they communicate (i.e. how they hear, speak, or understand), it can be significantly more difficult to find a mental health professional who can provide the accessibility, inclusive resources, and tools necessary to have the best possible therapeutic outcome.



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What are Social Determinants of Health?

The World Health Organization (WHO) defines social determinants of health (SDoH) as the conditions in which people are born, live, learn, work, play, worship, and age that impact health outcomes of a person or community. These circumstances are shaped by the distribution of money, power, and resources at the global, national, and local levels. These forces are outside the control of an individual or community and can greatly affect their overall health and wellbeing. Addressing these SDoH requires collective community action on a systemic level. The following pages highlight the status of the Older Adult population in Orange County across three social factors:

Health and Mortality

Comparing how long a group lives and determining their quality of life to the population at large can be a baseline for whether systemic disparities exist and how these disparities impact the community.

Economics and Education

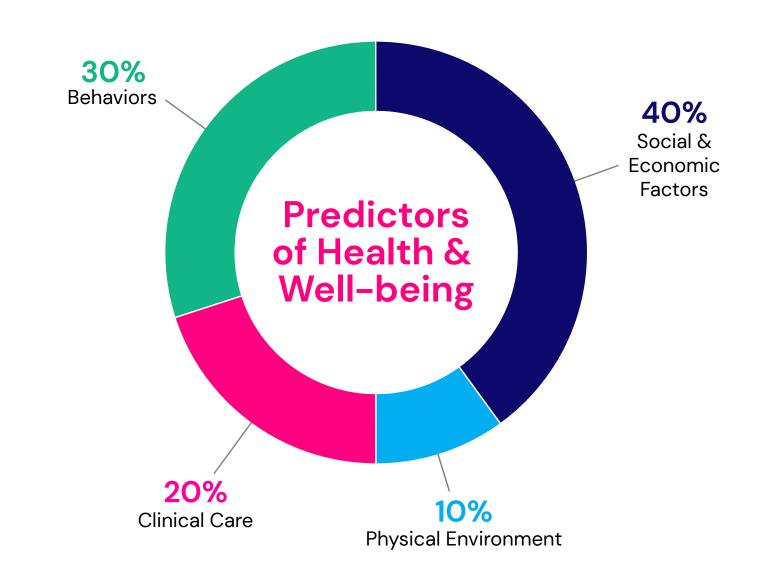
Education does more than determine one's income. Individuals with higher education are more likely to be healthier and live longer. Improving education in various communities can bring significant health benefits to everyone.

Built Environment and Social Context

Where someone lives, how an individual gets around, and what is going on in a person's community can greatly impact both individual and community health and well-being. Things like neighborhood walkability, cleanliness of air and water, and even the age of buildings in the community can affect quality of life.

It is unreasonable to expect that people will change their behavior easily when so many forces in the social, cultural, and political environment conspire against such change.

National Academy of Medicine



Source: County Health Rankings



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Mapping the Disparity

The COVID-19 pandemic impacted Orange County communities unequally and disproportionately. In partnership with AdvanceOC, a local non-profit, we identified vulnerable communities using comorbidity risk factors and social vulnerability. This rigorous analysis resulted in the Orange County Equity Map and guided the county's response and management of the pandemic.

What We Learned

The OC Equity Map measures social progress in various census tracts of the county. Analyzing and layering COVID-19 cases in Orange County showed that higher concentrations of COVID-19 cases occurred in low social progress areas. The pandemic exposed and magnified existing racial, gender, and socioeconomic inequities, including flaws in the county's social safety net.

We cannot treat and heal individuals then send them back to the systems and conditions that made them sick in the first place.

Orange County sees COVID-19 as an opportunity to improve the health and well-being of all community members. As Orange County charts a path forward to rebuild and strengthen our communities, the Health Care Agency will center these efforts around community-informed, data-driven, and equity-oriented approaches in partnership and collaboration with community members.

Social Progress Index Social progress is defined as the capacity of a society to meet the basic human needs of its citizens, establish the building blocks for citizens and communities to enhance and sustain the quality of their lives, and create conditions for all individuals to reach their full potential.



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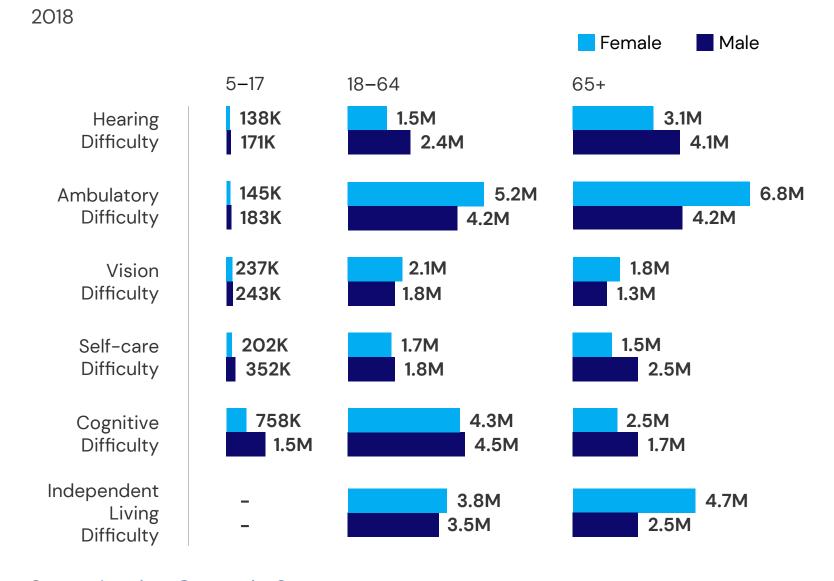
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SDoH Impacting People with Disabilities

Orange County, California, has approximately 308,000 individuals with a disability, based on results from the 2018 American Community Survey. This is approximately 10% of the total population of the county (3,186,989). Moreover, this group of individuals with a disability is split relatively evenly between individuals under 65 (160,000) and individuals who are 65 and older (150,000). In the United States more broadly, 18% of individuals ages 65–74 are diagnosed with a disability, which increases to 45.9% once they reach age 75. Disabilities can be categorized into the following categories: lifelong/congenital, trauma (e.g., car accidents, sports injuries, veterans), age-related (e.g., arthritis, instability), chronic diseases (e.g., cancer, diabetes, Parkinsons, Alzheimers).

The four main types of disabilities for individuals ages 65+ in the County include the following: hearing disability, vision disability, self-care disability, and independent living disability. Based on these categories, there are 17,787 individuals with hearing difficulty, 7,411 with vision difficulty, 12,599 with self-care difficulty, and 21,345 with independent living disability. According to OC Healthier Together, there has been a 1.2% gradual decline for the 65+ disability population since 2008; the Affordable Care Act contributed to the disability population decline from 31.6% to 30.4% when it was introduced in 2010.

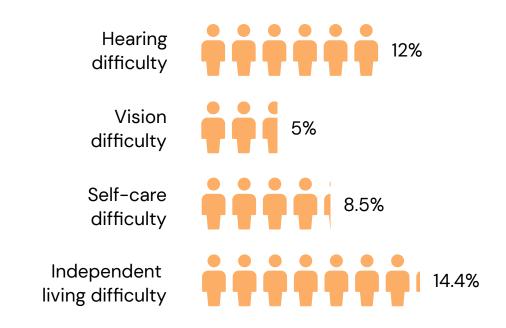
Americans Living with Disabilities



Source: American Community Survey

Types of Disability

Percentage of adults aged 65+ with disability in Orange County, 2022



Source: American Community Survey



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SDoH Impacting People with Disabilities (continued)

Health Care Expenditures and Settings

California's state-wide disability-associated health care (DAHE) expenditures were \$102.8 billion compared to the national DAHE expenditures of \$868 billion. The DAHE cost per person with a disability in California was \$19,949 in 2021. If this figure is similar for Orange County, the cost of care would cover approximately 307,583 disabled individuals, totaling \$6.1 billion annually. Moreover, many patients with a disability experience barriers to care due to a lack of patient-centeredness, poor communication during clinical interactions, and insufficient assistance with health care system navigation. For example, people with disabilities who require canes, wheelchairs, or walkers may face physical challenges when entering health care settings.

Health Insurance

According to the <u>Social Security Administration</u>, Social Security Disability Insurance (SSDI) is a social insurance program in which employees with a disability earn coverage benefits and pay taxes on their work earnings for their insurance eligibility. Individuals who are disabled are eligible if they cannot work as a result of a severe medical condition that has lasted over one year. Based on this fact, Social Security disability beneficiaries are triple as likely to pass away compared to individuals of the same age. Additionally, among individuals who receive disability benefits when they reach age 55, 1 in 6 men and 1 in 8 women are more likely to pass away within five years from the onset of their disability. More disabled workers and their families now qualify for Social Security disability benefits to address the current population trends, with baby boomers reaching their disability-prone years and more employees starting in the workforce.

Supplemental Security Income (SSI) is a monthly payment administered to adults and caregivers of children with a disability who meet certain financial limits. Caregivers of children under age 18 with mental or physical conditions that prevent them from pursuing their everyday activities for over a year and live in a household with limited income and resources may also qualify. Based on these facts, households with somebody who faced employment or income challenges during the COVID–19 pandemic were three times more likely to apply for SSI or plan to do so in the next 12 months than households not experiencing employment or income hardships. On the other hand, individuals who do not receive SSI can qualify for Medicaid with the Affordable Care Act's Medicaid expansion based on their income, which helps people with disabilities gain access to services that bring forth self–care and independent living needs as key sources of support for individuals with disabilities.

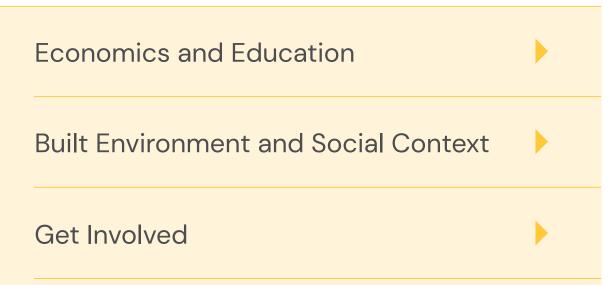
The <u>Children's Health Insurance Program (CHIP)</u>, run by Medicaid, is tailored to children who live in households with income above the Medicaid threshold but who cannot afford private health insurance. Coverage can be provided to children with special health care needs; services include hearing, vision, prescription drugs, and mental health resources. Fifty percent of children with special health care needs in the United States were more likely to come from lower-income communities and various ethnic minority groups. Ultimately, it may be <u>more affordable</u> to enroll in CHIP than private insurance alone, due to Medicaid's benefit package.



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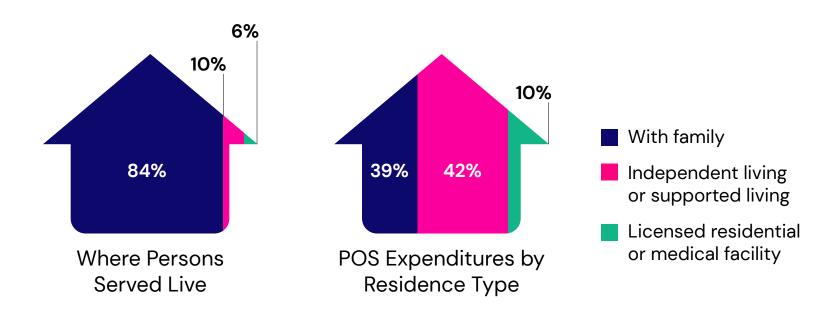
SDoH Impacting People with Disabilities (continued)

Housing

In 2021, the Orange County Regional Center distributed its services to over 24,000 individuals with a disability and spent \$482.8 million dollars serving this community. Although about half-billion dollars were utilized for services tailored to people with disabilities, wide gaps exist, with independent white adults residing at home spending \$6,567 more than Hispanic adults at home, alongside \$21,562 more spent on independent white adults at home with some form of support compared to other ethnic/racial groups living independently with support. However, among residential group home settings, Orange County displayed the smallest disparities in California, with \$11,134 more allocated to individuals with a disability who are not in a major ethnic/racial category than spent on white residents.

POS Expenditures Based on Where Persons Served Live

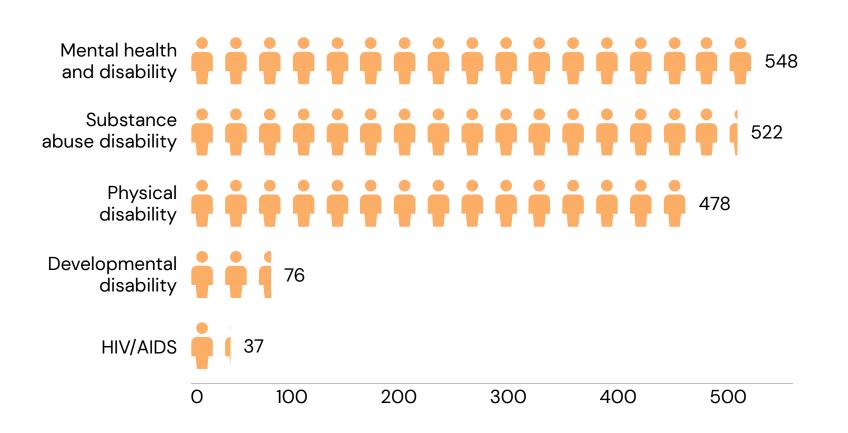
Orange County



Source: Regional Center Orange County

Disabilities Reported by Persons Sheltered

Orange County, 2020



Source: Orange County Business Council

Abuse and Violence

People with disabilities experience higher likelihoods of abuse and violence. They are 2.5 times more likely to experience violent victimization than individuals without a disability, alongside serious crimes (e.g., aggravated assault, sexual assault, robbery) that are three times more likely to affect people with disabilities. People with disabilities experience certain barriers contributing to their vulnerability to abuse, as abuse depends on control and power over an individual or group. For instance, people with developmental disabilities commonly face abuse and dehumanization in institutions that account for 82% of their experiences with violence. Sexual assault at the institution will is seven times more likely against people with an intellectual disability. Moreover, just under 50% of institutionalized individuals with a developmental disability have experienced some form of sexual abuse at least 10 times in their lifetime.



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SDoH Impacting People with Disabilities (continued)

Household abuse among people with disabilities is evident, with individuals with a disability experiencing higher percentage risks of violence conducted by family members and close acquaintances, representing 50% of the total violence people with disabilities face.

Additionally, cases of violence from romantic relationships have a 40% more likelihood of impacting <u>women</u> with disabilities than women without a disability. Furthermore, <u>children</u> and families with disabilities are also at risk of domestic violence, with over <u>550 cases</u> reported over the last 5 years, including cases that may have been unreported.

Race

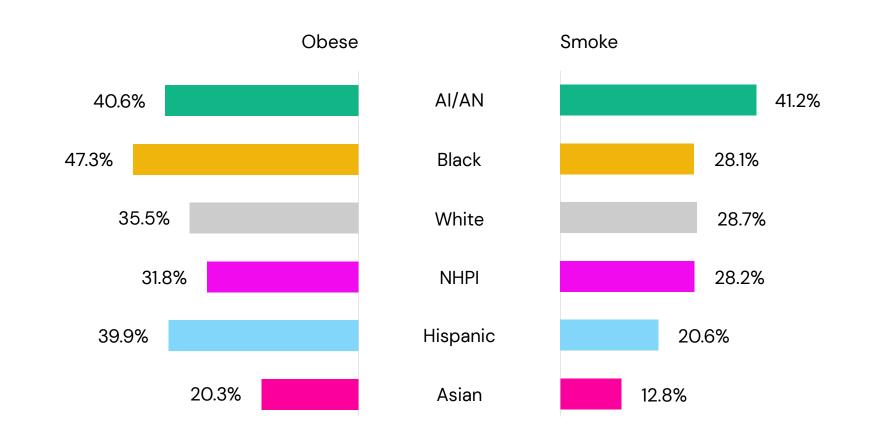
As explained by Isabella Kres-Nash: "Racism and ableism are often thought of as parallel systems of oppression that work separately to perpetuate social hierarchy. Not only does this way of looking at the world ignore the experiences of people of color with disabilities, but it also fails to examine how race is pathologized in order to create racism. Meaning that society treats people of color in specific ways to create barriers, and these poor conditions create disability. The concept of disability has been used to justify discrimination against other groups by attributing disability to them."

There are many <u>examples</u> of the role that race plays in the health outcomes of people with disabilities. Among adults with a disability, 55% of Hispanic people and 47% of African Americans report fair or poor health, as compared to 40% of their white counterparts. The deaf community has a 4.6% HIV/AIDS infection rate, which is four times higher than the African American population (the most at-risk racial group in the US). Both Hispanics and African Americans have higher rates of visual impairment than their white peers. Finally, among

people who are deaf, women of color appear to experience the greatest health disparities and difficulty accessing appropriate care.

Ultimately, we cannot assume that because people with disabilities of color may need more health care services that they receive it, let alone that they receive it easily. This is doubly true with the additional barriers of coverage limitations and stereotypes are at play. People of color with disabilities, thus, may face "double discrimination," that no single movement is effectively identifying or addressing.

Adults with a Disability Who are Obese or Smoke U.S.



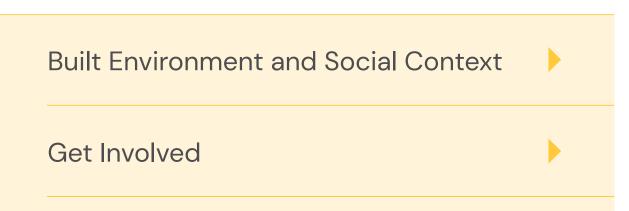
Source: CDC



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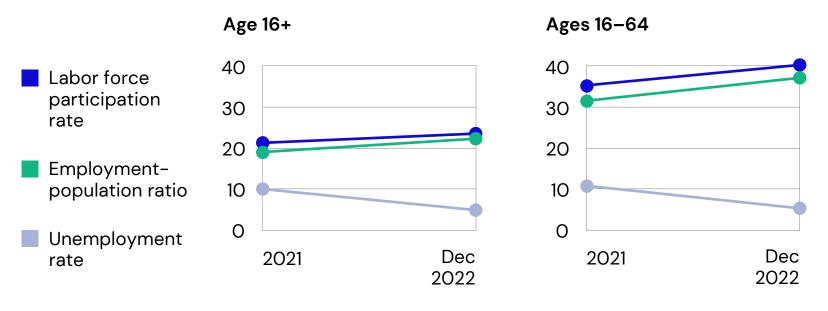


Economics and Education

Working adults with a disability have additional living costs compared their peers without a disability. They are also 2 times more likely to be considered unemployed with incomes below the poverty threshold than those employed without a disability. Data from the National Disability Institute highlights major health disparities that cannot be accounted for when using only a racial lens. Although ethnic/ racial communities are more likely to be in poverty regardless of disability status, black and indigenous people with disabilities have a higher likelihood of experiencing poverty than individuals in these communities without a disability.

Persons with Disabilities in Labor Force

by age, 2021-2022



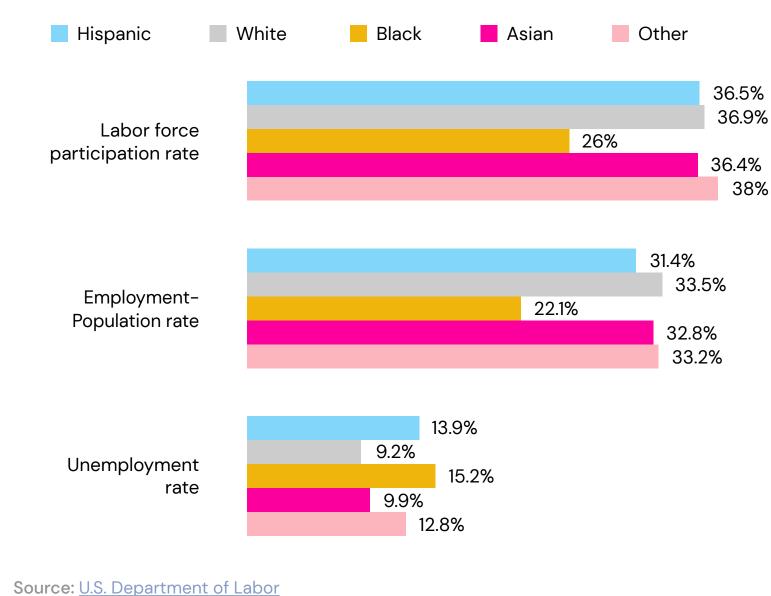
Source: U.S. Department of Labor

Work Discrimination

Legal protection exists at both the federal and state levels to protect workers with disabilities from discrimination in their workplaces. The goal is to help ensure that America's workplaces are environments within which disabled workers can do their work without being treated inequitably.

Persons with Disabilities in Labor Force





There are five important federal <u>laws</u> that protect individuals with disabilities from discrimination in employment and the job application process:

- 1) Americans with Disabilities Act
- 2) Rehabilitation Act
- 3) Workforce Innovation and Opportunity Act
- 4) Vietnam Era Veterans' Readjustment Assistance Act
- 5) Civil Service Reform Act



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To date, only 17.9% of American adults with disabilities are employed. Workers with disabilities have historically faced varying levels of disability discrimination in their places of work. As recently as 2019, the U.S. Equal Employment Opportunity Commission received and resolved 24,238 disability discrimination claims (this does not include data from the states or local levels). Disability discrimination can be hard to eradicate because of its tendency to shapeshift. It can manifest as several different conscious and unconscious behaviors. Disability discrimination is often the result of outdated organizational policies or a long history of homogeneous hiring. It's important for employers to be proactive, designing and implementing processes, policies, and procedures that accommodate employees' disabilities.

It is also important to consider systemic barriers. Systemic barriers are defined as "procedures, protocols, or policies that place undue burdens on individuals with disabilities." People with disabilities often face higher living costs due to specific needs like assistive devices and increased healthcare needs. Programs like CalWorks and Supplemental Security Income (SSI) can create disincentives to work.

For example, CalWorks adjusts assistance based on income, which can discourage disabled individuals from seeking employment if it leads to a net loss of income. Moreover, SSI benefits can decrease or stop if income exceeds certain limits, discouraging disabled individuals from working more or advancing their careers.

These systemic barriers can trap people with disabilities in a cycle of dependency on government support, making it difficult for them to achieve economic self-sufficiency. Addressing these barriers involves policy reforms and promoting workplace inclusivity and accessibility.

There are four types of disability discrimination in the workplace: direct discrimination, indirect discrimination, harassment and retaliation, and failure to accommodate reasonable requests. Direct discrimination is when decisions are made against an employee based on their disability status. This could include passing over an employee with a disability for a less credentialed employee with no disability. Indirect discrimination is when an employer has a policy, eligibility requirement, or general practice that applies to all but places employees with disabilities at a disadvantage. Examples include requiring a person with a mobility issue to take their break in a breakroom despite how long it may take them to get there and back. Harassment is when an employee is subjected to unwelcome conduct regarding their disability. This includes asking a job applicant questions about past medical conditions. Retaliation is a related issue, and is when an employee faces further harm because they reported harassment.

Failure to accommodate reasonable requests makes up the bulk of disability discrimination cases. It can be defined as failing to make an adjustment or modification that allows an employee with a disability equal opportunities as those without a disability. Examples include failing to provide an ergonomic keyboard or a modified work schedule. It is also important to note that the employer's responsibility to accommodate starts before at the interview process. For example, if a person using a screen reader cannot access an application due to an accessibility issue with the company's website, the responsibility would fall on the employer to allow that person to apply.



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Education

According to the California Department of Education, in the 2020–2021 school year, students with disabilities had a graduation rate from a 4-year high school of 68.6% (an increase of 0.6% when compared to the 2019–2020 graduation rate). While it is encouraging to see these graduation rates increasing, it is still lower than students without disabilities: 25.5% lower than the graduation rate for Asian students, 19.6% lower than the graduation rate for White students, 11.9% lower than the graduation rate for Hispanic students, and 3.9% lower than the graduation rate for Black students. Students with known disabilities account for 13.3% of all high school students in California, with an enrollment total of 819,700 in the school year 2020–2021.

Challenges

Although much progress has been made in assisting students with disabilities in the classroom, there are still some current barriers that prevent students from reaching their full potential. At all levels of education, from kindergarten to college, students with disabilities continue to face:

1. Insufficient Funding

Most schools do not have enough funds to provide students with disabilities with the appropriate accommodations, which can hinder their learning process and overall success. Insufficient funding is not a new phenomenon and most schools within the U.S. face this challenge, but students with disabilities feel the weight of this burden at a disproportionate rate.

2. Inaccessible Conditions

Any schools were built prior to legal requirement for access and do not have enough money to rebuild inaccessible classrooms, which causes yet another difficulty for students with disabilities. Ramps or elevators may be lacking, doors may be too heavy to open, inaccessible bathrooms or transportation may be present and they also may not have standing desks, captioned equipment, and other needed resources.

3. Lack of Individualization

Most schools create curriculums for typically-developing students and are inadequate for students with disabilities. By law students with disabilities have access to Individual Education Plans and also to 504's, but many parents are not aware of these due to lack of information from the school.

4. Troubled Communication with Peers

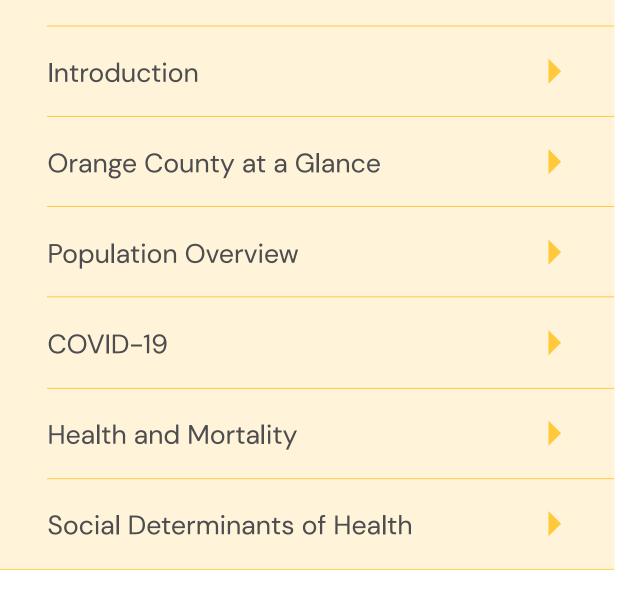
Culture, social norms, discrimination, and stereotypes have the potential to create barriers between those with physical and/or developmental disabilities. This includes deaf students may also struggle to communicate as freely as their hearing counterparts.

5. Lack of Specialists

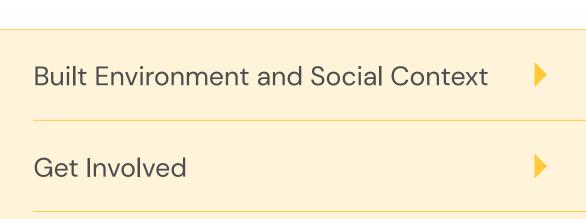
The shortage of specialists in educational institutions not only affects the quality of education but also restricts access to education for children with disabilities. Some administrations of schools and colleges do not train their teachers and professors to interact well with any students, let alone students with disabilities. This is compounded by the fact that schools are struggling due to shortages, resulting in limited access to essential services, a lack of early intervention programs, and too much focus on special education rules. Fixing these shortages is crucial for providing students with the support they need to succeed.



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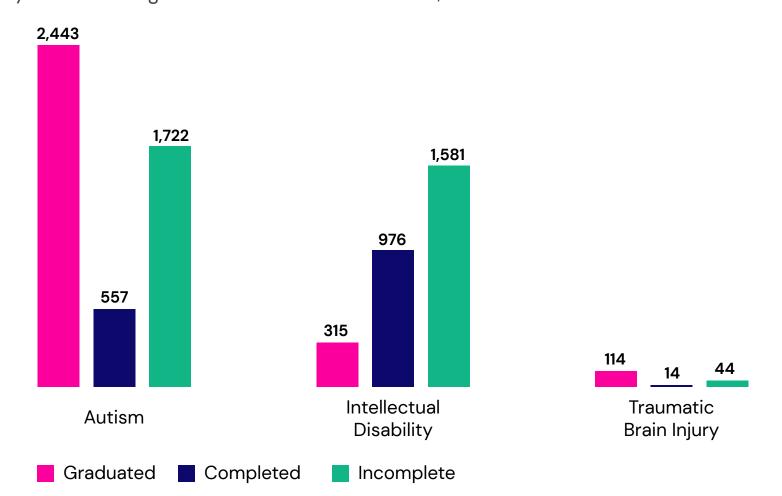
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Students with Disabilities

by number of high school students in California, 2017–2018



Source: CA State Council on Developmental Disabilities

Disability Inclusion

What is disability inclusion?

According to the CDC, disability inclusion is defined as: "including people with disabilities in everyday activities and encouraging them to have roles similar to their peers who do not have a disability." Though the goal of disability inclusion is to help everyone live an equitable life, it does not stop at the individual. It also requires that adequate policies and practices are in effect at the community and organization level to serve people with disabilities. This, in turn, allows people with disabilities to take advantage of the same health promotion and prevention activities as individuals who do not have

a disability. This includes education and counseling programs and screening for illnesses.

Disability inclusion is important because disability affects more than one billion people worldwide. In the United States, disability affects approximately one in four (26%) people living in communities. This is essential work, as approximately 10% of Orange County's population is disabled (according to the Orange County Strategic Plan for Aging).

Federal and state laws under the ADA

<u>Title I of the ADA</u> prohibits discrimination against people with disabilities in employment. It protects the rights of both employees and job seekers. <u>One of the key</u> non-discrimination aspects of Title I is the requirement to provide reasonable accommodations for employees and job seekers with disabilities.

<u>Title II of the ADA</u> requires state/local governments to give individuals with disabilities an equal opportunity to benefit from all of their programs, services, and activities. Under this law, state/local governments can't deny people with disabilities the chance to participate in different programs. Examples of state/local programs, services, or activities include: Public education, Public transportation, Recreation, Health care, Social services, Courts, and Voting. Agencies that have a role in enforcing, or investigating claims involving this law include: the <u>U.S. Department of Justice</u>, the <u>U.S. Department of Health and Human Services (HHS)</u>, and the <u>Civil Rights Center (CRC)</u>.

<u>Title III of the ADA</u> applies to business. Almost all types of businesses that serve the public regardless of their size or age must follow the ADA. This law includes businesses that serve the



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public or public accommodations such as restaurants, hotels/ motels, shops, movie theaters etc. The U.S. Department of Justice enforces these regulations.

Community Integration

The ADA bans the unnecessary segregation of people with disabilities via the "integration mandate." As such, state and local governments that provide services to people with disabilities must offer said services in homes and communities. It is not sufficient to offer them in institutions alone. This applies to anyone with a disability who receives services from a state or local government that supports their disability-related needs (unless it would result in a "fundamental alteration"). It also applies to individuals with a disability who are institutionalized or at risk of institutionalization due to lack of services.

Disparities in federally-sponsored health disparities research

Although people with disabilities are described as the world's largest minority group, U.S. agencies and foundations direct few resources to studying and addressing health disparities within this population. The National Institute of Health (NIH) <u>designates</u> the following minority groups as U.S. health disparities populations: racial and ethnic minorities, socioeconomically disadvantaged populations, sexual and gender minorities, and rural populations. People with disabilities are absent from this list.

Based on eligibility criteria in NIH-funded clinical trials, most studies (75%) had eligibility criteria that directly and/or indirectly excluded adults with an intellectual disability. This included approximately

one third of studies with a direct exclusion criteria based on cognitive impairment. Nearly 65% of studies indirectly excluded adults with an intellectual disability based on functional capacity, inability to read/write, or "research staff discretion." These are exclusion criteria that adults with intellectual disability may be more impacted by due to systemic oppression and other social factors.

Another study found that the underrepresentation of people with disabilities from clinical research persists and is understudied, and the public health and clinical implications remain underappreciated. One critical example included that few trials for Alzheimer's disease have been conducted for people with Down syndrome, even though approximately 90% of people with Down syndrome will develop Alzheimer's disease or dementia by age 55. This is also despite evidence indicating that people with intellectual disabilities generally wish to participate in clinical trials.

Why is it important to include this population?

Clinical trails improve the health and well-being of individuals and populations via the development of ways to detect, diagnose, treat, and prevent diseases. When we have representation from all segments of society, we can best ensure all people benefit from ensuing discoveries. Persistent and widespread exclusion and underrepresentation from clinical trials means clinicians may not know whether a particular medication or treatment is safe and effective for their patients. Full representation in clinical trials is, thus, a step towards health equity and is rightly encouraged, and sometimes mandated, by federal agencies funding health research. The National Institutes of Health (NIH), for example, has a dedicated program— the INCLUDE Project—to advance the inclusion of individuals with Down syndrome in clinical trials.



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Types of Barriers

The <u>WHO</u> describes the barriers faced by people with disabilities as being more than just physical obstacles; they include: "factors in a person's environment that, through their absence or presence, limit functioning and create disability. These factors manifest in many ways, including and not limited to, an inaccessible physical environment, stigma towards disabilities and individuals with them, and a lack of technology, services, and policies that assist individuals with disabilities in all aspects of life." Not all individuals with disabilities face the same barriers, and some may not experience certain barriers over others. However, there are seven <u>classes of barriers</u> that this population frequently experience: attitudinal, communication, physical, policy, programmatic, social, and transportation barriers.

Attitudinal Barriers

Attitudinal barriers result when people think and act based on false assumptions about individuals with disabilities. This is the most basic barrier as some people may be unaware that their attitudes can be harmful and uninformed about more inclusive behaviors. Some <u>examples</u> of common attitudinal barriers that this population faces include:

- Stereotyping: People often assume that the quality of life of people with disabilities is poor or that their impairments cause them to lead an unhealthy lifestyle. In turn, people impose "help" rather than offering it to this population. This takes away the autonomy and voice of People with Disabilities (PWD) and prevents them from making their own decisions.
- **Dehumanizing:** In social settings, for example, PWD are often dehumanized as they tend to not receive eye contact while being spoken to, are not acknowledged in conversation, and are only

seen in terms of their disability. Overall, this population is met with lower expectations as people believe that a disability defines what individuals are capable of.

Generalizing: Individuals of this population are compared to each other as people tend to believe that all disabilities are alike or that one person is just like everyone else with disabilities.

Rather than considering disabilities as a limitation, people can start to break down attitudinal barriers by taking a social responsibility to support this population. This can mean having discussions about disability to increase awareness or using gender-, disability-, and culturally-sensitive language. Not only will this make it easier to address the obstacles that PWD face, but it will also allow this population to live more independent lives.

Communication Barriers

Communication barriers between people with disabilities and those currently without disabilities lead to both increased stigma and inaccessibility. Examples of this include:

- Written informational materials that are not accessible to people
 with visual impairments. For instance, these materials may be
 written with small print. Materials may be also inaccessible if there
 is a lack of Braille versions.
- Auditory informational materials that are not accessible to those with hearing impairments such as a lack of closed-captioning or accompanying sign language interpretation.
- Informational materials with complex words and lengthy sentences that make it difficult for people with cognitive impairments to understand.



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Without inclusive forms of communication, people with communication impairments may not receive information as easily as others. This only increases a gap in knowledge among PWD and introduces feelings of exclusion, loneliness, and isolation as this prevents them from participating in important conversations. These barriers also prevent individuals from finding job opportunities, accessing telehealth services, and participating in overall community life. In the context of health and healthcare, informed consent cannot be obtained unless the person receiving care can understand all the information being shared with them.

However, government programs like the Affordable Connectivity Program (ACP) run by the Federal Communications Commission (FCC) aim to combat these barriers by providing more equitable access to the internet, which has a plethora of accessibility resources. The ACP aids low-income households with the cost of internet service and connected devices like a tablet or laptop. People with disabilities are eligible to participate if they receive SSI benefits. If eligible, participants are provided a one-time discount of up to \$100 to purchase a connected device from participating providers while contributing a portion toward the purchase price. As of February 2022, around 10 million households have enrolled in the ACP program.

Physical Barriers

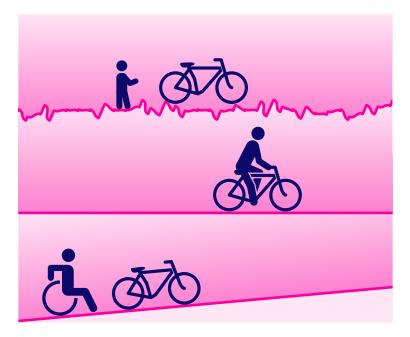
Physical barriers are perhaps the most noticeable hurdles to accessibility. These structural / architectural obstacles limit mobility for people who require mobility aids. <u>Examples include</u>:

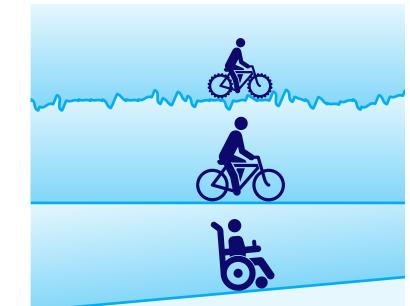
- Steps without ramps or rails
- Entrances without automatic or push-button doors
- Mammography equipment that requires people with breasts to stand
- Narrow doorways, walkways, or aisles
- Lack of accessible parking spots or restrooms
- High shelves

Equality versus Equity

EQUALITY: Everyone gets the same—regardless if it's needed or right for them

EQUITY: Everyone gets what they need—considering their barriers and circumstances







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Social Barriers

Social barriers are defined as the conditions in which people are born, grow, live, learn, work, and age that can contribute to decreased functioning among people with disabilities. These barriers impact the lives of PWD in all aspects that prevent them from participating in daily and community life. One prominent example includes access to work opportunities. PWD are far less likely to be employed as only about 35.5% of PWD ages 18 to 64 were employed (in 2019, per the Institute on Disability), almost less than half that of people without disabilities. Access to work opportunities is especially important for this population as their income may be their only source of support in the care they are able to receive. Other examples of social barriers include:

- Vulnerability to violence <u>children</u> with disabilities are about four times more likely to experience violence compared to those without disabilities.
- Lack of education <u>Adults</u> with disabilities are about 10% less likely to complete high school compared to those without disabilities.

A common result of barriers to social interaction include feelings of loneliness and isolation. In a study on social support and wellbeing among working aged adults with disabilities, PWD experienced social isolation, low social support, and feelings of loneliness at an increased rate compared to adults of the same age but without disabilities. Combating social barriers is important because the health outcomes from feelings of loneliness and isolation are consequential to the health of this population.

Transportation Barriers

Transportation barriers result when people with disabilities do not have access to inclusive modes of transportation. This ultimately prevents them from being independent and functioning in society. In particular, transportation barriers often reduce people's ability to find and hold jobs, as well as participate in community life. Like physical barriers, these obstacles especially impact people with mobility disabilities. Examples include:

- Lack of convenient transportation
- Public transportation in inconvenient locations and times
- Transportation methods without audible stop announcements for people with visual impairments or visual stop announcements for people who are deaf or hard of hearing
- Lack of (operational) elevators for train stations

In line with the Americans with Disabilities Act, the Orange County Transportation Authority (OCTA) established <u>OC ACCESS</u>. This initiative accommodates individuals who cannot utilize the regular OC Bus fixed-route service because of their disability. Eligibility is valid for up to five years and individuals must be recertified at the expiration of their eligibility. The first service offered is a curb-to-curb service that is available within a ¾ mile of, and during the same hours as, the OC Bus service. Customers pay a base fare for each one-way trip and individuals may be accompanied by one personal care attendant for free. Individuals also have access to a second service that provides a subscription for individuals who travel consistently on specific days



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of the week and to/from the same destination. In addition to the bus, OCTA also offers a same-day taxi service to all OC ACCESS customers, though the implementation of this program is often imperfect.

Policy Barriers

Policy barriers involve laws and regulations that prevent establishments, programs, and activities from being accessible to people with disabilities. Often overlooked, this type of barrier results from a lack of awareness about accessibility requirements or failure to enforce existing laws. This, in turn, prevents this population from accessing resources and other services required for daily life. Examples include policies that:

- Prevent eligible individuals from benefiting from federally funded programs, services, or other benefits
- Denying individuals with disabilities access to programs, services, benefits, or opportunities to participate because of physical barriers
- Denying <u>reasonable accommodations</u> to qualified individuals so they can fulfill responsibilities for a job for which they have applied or have been hired to perform

A prevalent issue surrounding this type of barrier involves excluding this population in conversations when writing current policies. Without a voice from someone with a disability, lawmakers and policy writers will never fully understand the experiences and obstacles that this population faces. Not only does this impact the quality of the laws that are written into our communities, but also, more importantly, it impacts the daily function and quality of life for people with disabilities as a result.

Caregivers of People with Disabilities

People with disabilities often require the assistance of a caregiver in their everyday life. A <u>caregiver</u> is someone who supports a person with disabilities in performing daily activities like cleaning, feeding, cooking, and giving medicine. Caregivers can include family members and friends of people with disabilities, often taking on this role in an informal and/or unpaid setting. In fact, around <u>25% of U.S. adults 18 years of age and older</u> reported providing informal and unpaid care to a person with a long-term illness or disability. Family caregivers can also get paid to provide non-medical assistance for people with disabilities through several <u>California government programs</u>:

In-Home Supportive Services (IHSS) is a Medi-Cal program that provides support to caregivers according to Medi-Cal's financial eligibility criteria. California allows IHSS program participants to choose who provides them with assistance. Siblings, adult children, nieces, nephews, friends, and even spouses can all participate in the program. Some counties also have contracted IHSS care providers whom the recipient can choose as their caregiver.

Veteran Directed Care (VDC) provides veterans a budget for caregivers similar to care given in a nursing home. With control of the budget, the veteran is able to hire family members, friends and even their spouses to provide them with the hands-on assistance with the activities of daily living they would otherwise receive in a nursing home.

The Paid Family Leave (PFL) Act allows relatives to take time off from their job to care for a family member while receiving compensation for their caregiving responsibilities for up to eight



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weeks. To be eligible, a family member must be related by blood or marriage to the individual who requires care and must also be employed and taking time off from their job to provide care.

Considering the spectrum of caregiving for PWD, family caregivers for children with disabilities typically involve the parents of the child by default. Other family members like siblings or trusted friends may also take on this role. Some children may require additional support in daily activities while others may not need any intervention at all. Responsibilities in caregiving for children often include educating oneself about the child's needs and disability, staying positive as children are highly intuitive with their parent or caregiver's emotions, and/or enrolling their children in special education if needed. To support the role of family caregivers in the care of children, financial assistance is available. Children with disabilities and under the age of 18 may qualify for Supplemental Security Income (SSI) depending on the family's income level and the type of disability involved. While the amount of financial support depends by state, the child's condition(s) are reevaluated on a regular basis. Children who turn 18 are still eligible for SSI benefits; however, their condition is re-evaluated based on an adult status. This means that the benefits may also change from the parent/guardian to the person with the disability.

Through their assistance, caregivers are the backbone of the care provided for PWD. This role involves many rewarding experiences in aiding a friend or loved one; however, caregivers are also at risk for negative health outcomes. These include increased risk of anxiety and/ or depression, increased use of psychoactive medications, worsened physical health, and compromised immune health. Health outcomes

are even worsened by the long hours that caregivers work. On average, caregivers spend around 57 hours a week caring for someone with disabilities. That is why caring for caregivers is important, not only for the caregiver themselves, but also for the people they care for as well. One can support family caregivers by staying informed about their condition, reaching out to local support groups for caregivers, advocating for caregivers and their circumstances, finding appropriate milestones for both caregivers and PWD to celebrate, and considering other caregiving options (e.g., respite care) in the event that family members are unable to fulfill the role.

Intersectionality

People are complex and multi-faceted; no single identity defines them. Coined by American civil rights advocate Kimberlé Crenshaw, intersectionality is best defined as "how a person's various marginalized identities work together to impact a person." For example, if someone is working class and has a disability, the combination of both factors together shapes a person's life experiences. Crenshaw states that "intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects. It's not simply that there's a race problem here, a gender problem here, and a class or LGBTQ problem there. Many times, that framework erases what happens to people who are subject to all of these things."

Disability occurs across all racial, ethnic, language and social groups, and people with disabilities who are also minorities often face multiple challenges within health systems. Therefore, understanding intersections of race and disability, and their



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3-5,000,000

LGBTQ+ people in the U.S. with disabilities

2 in 5

1 in 4

Transgender people have a disability

LGB people have a disability

Source: CDC

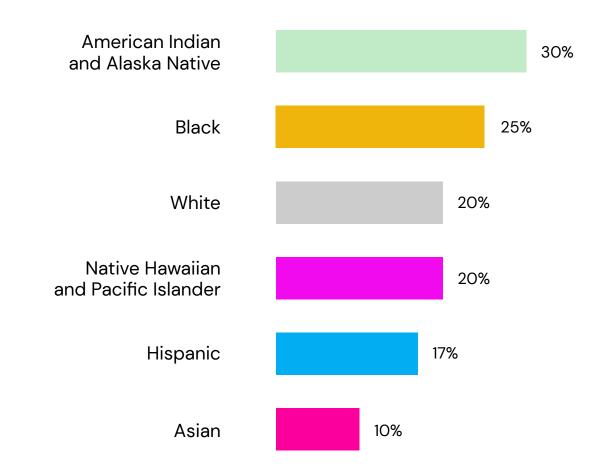
impact on health and access to health care, is an important public health goal. The lack of reported data that informs public health issues on the intersections of disability and racial, ethnic, and linguistic minorities likely contributes to the disparities in health outcomes within these communities. If an individual is low-income and lives with a disability, their life experience is changed by the scarcity of resources. In turn, the person's experience with poverty is affected by their disability. While a formal disability diagnosis would legally entitle them to workplace disability accommodations they cannot work without, obtaining said diagnosis may be time-consuming and expensive to receive.

Both class and disability status are inseparably connected in how they affect one another. By centering those most marginalized and taking an <u>intersectional approach</u>, we have the opportunity

to reimagine existing structures and systems—and create a world that works for and elevates everyone. Recognizing and understanding the intersection of identities and the realities that come with it can be a huge first step in addressing disparities and challenging biases.

Percentage of Population with Disability by Race

U.S., 2017



Source: CDC

*In 2017, disability prevalence rates in the U.S. varied by race and ethnicity. American Indian and Alaska Native populations had the highest rate at 30%, followed by Black individuals at 25%, and White individuals at 20%. Native Hawaiian and Pacific Islander and Hispanic populations had rates of 20% and 17%, respectively, while Asian individuals had the lowest rate at 10%. These statistics highlight disparities in disability prevalence among different racial and ethnic groups.



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Law Enforcement and Disability

With regards to law enforcement, racial profiling remains an ongoing issue in policing. Black Americans with disabilities may not be able to cooperate with or understand an officer's orders. In short, when a police officer lacks appropriate training or cultural understanding to work with people with disabilities and/or the Black community, it can lead to poorer outcomes for all involved.

There is no reliable <u>national database</u> to track cases of police misconduct affecting people with disabilities. Moreover, there is minimal media representation showcasing the experiences of police violence among people with disabilities. Though police agencies in the United States have provided crisis intervention training to their officers to help guide their interactions with people with disabilities, the quality of this training is not sufficient to address the underlying challenges that persist among individuals with a disability. To help protect this population, advocacy measures have been recommended that consist of minimizing interactions between people with disabilities and police officers, maximizing funds for support services tailored to individuals with a disability, and restructuring law enforcement policies to improve protection among the community.



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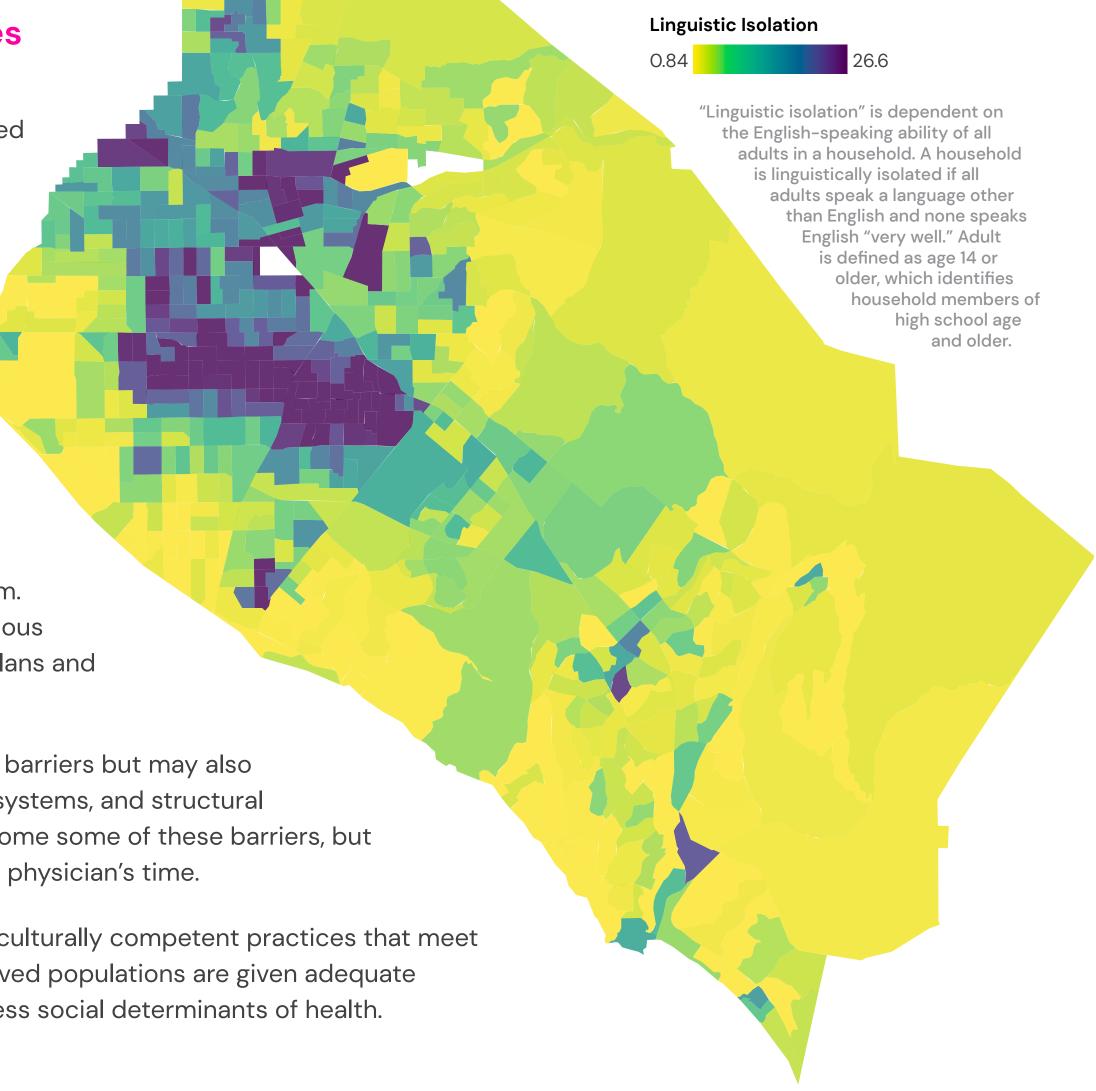
Orange County Language Opportunities and Services

Orange County residents who live in linguistically isolated communities are often from immigrant families. These immigrant families tend to gather in ethnic enclaves as a means of survival because of discriminatory practices or due to being shunned from other parts of the county.

People with limited English proficiency (LEP) are defined by the U.S. Census as those who speak English less than "very well." In 2020, 8.7% of Orange County residents are LEP. They experience high rates of medical errors with worse clinical outcomes than English-proficient patients. This higher incidence of medical errors could result in physical harm. LEP individuals also receive lower quality of care on various measures and are less likely to understand treatment plans and disease processes.

These disparities are rooted in obvious communication barriers but may also reflect cultural differences, clinician biases, ineffective systems, and structural barriers. Medical interpretation services can help overcome some of these barriers, but they have associated costs financially and in terms of a physician's time.

We must strive to remove language barriers and adopt culturally competent practices that meet residents where they are. This will ensure that underserved populations are given adequate resources to access healthcare and services that address social determinants of health.





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Air Pollution Exposure in Orange County

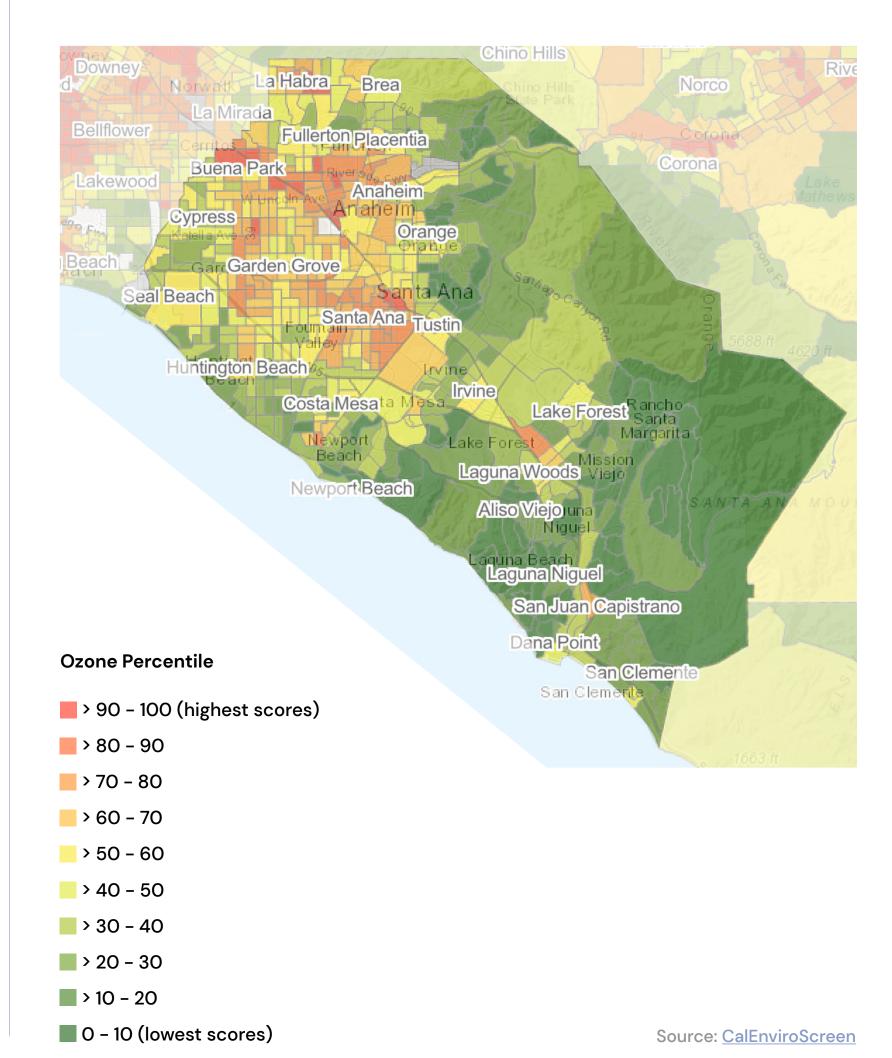
In California, environmental quality has improved over the last few decades. This is seen in improved water quality, reduced air pollution, decrease in pesticide use, continued cleanup of hazardous waste sites, increased recycling, and reduction of solid waste going into landfills. However, pollution reduction and the resulting health and environmental benefits are not uniformly distributed across the state, within a region, or among all population segments. Many communities continue to bear a disproportionate burden of pollution not only from multiple nearby sources but also from pollution in various forms, such as air and water.

Ozone pollution causes adverse health effects including respiratory irritation and worsening of lung disease. Adverse effects of ozone have been studied extensively since the late 1960s, and ongoing exposure to ozone shows inflammation and cell and tissue injury. People with asthma and chronic obstructive pulmonary disease (COPD) are considered sensitive to the effects of ozone. Studies also show that long-term ozone exposure affects respiratory and cardiovascular mortality. A 2019 study estimates 13,700 deaths in California in the year 2012 were due to long-term ozone exposure.

Of these deaths, 7,300 were from respiratory causes, and 6,400 were from cardiovascular causes. The CalEnviroScreen 4.0 draft ozone map of Orange County shows high levels of ozone pollution scores in north and central Orange County. In the OC Equity Map, these communities have low Social Progress Index scores.

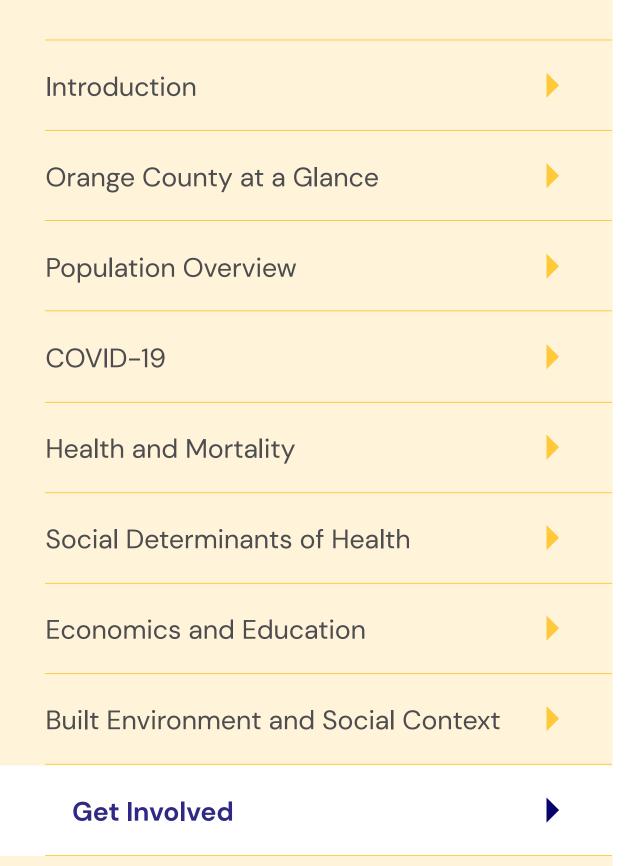
Ozone Levels by Pollution Score

2021



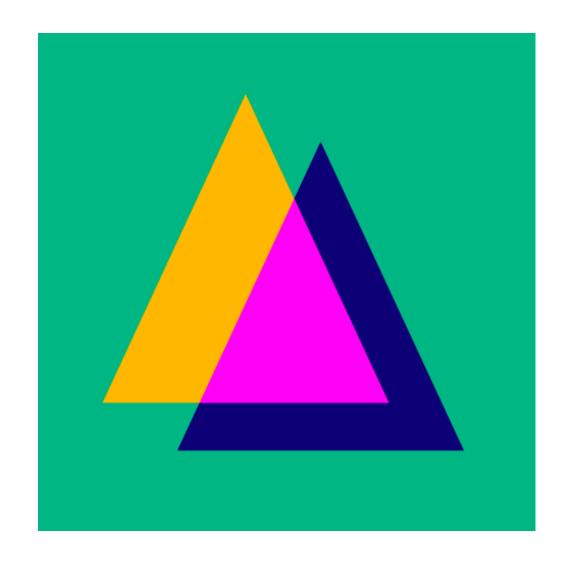


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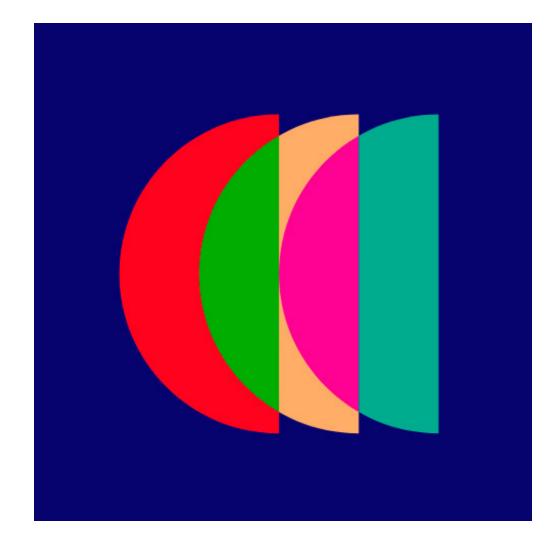
Health is a shared value. Your involvement will help create a healthier, more resilient, and equitable Orange County.

Here's how you can get involved:



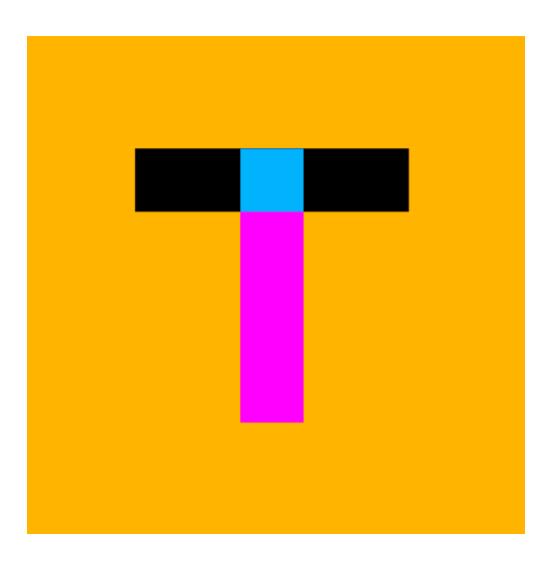
Participate in the EiOC Action and Learning Community

Learn More



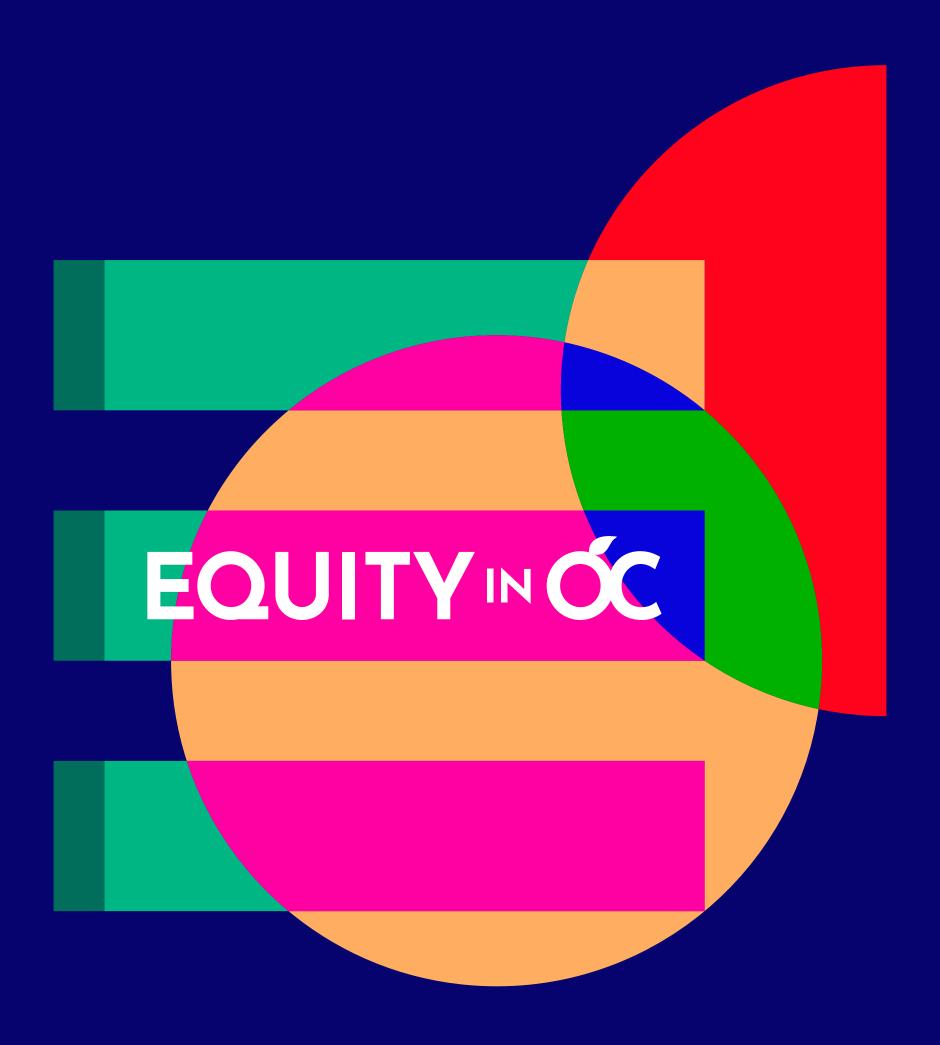
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