State of Disability Equity and Access

A 2023 special report by Easterseals and The Coelho Center with support from Voya Financial
Improved access to education, employment, healthcare, and transportation for the community at large is critical to respond to the urgent and evolving needs of 61+ million Americans with disabilities. During the last 50 years, the United States has made significant progress advancing disability rights and leading accessibility on a global scale. This progress is due to landmark legislation and thanks to the advocacy by disabled civil rights leaders who boldly break down barriers, challenge perceptions, demand access, and provide a crucial baseline for future generations to build upon.

The United States is the Disability Rights Global Leader

There is no doubt: the United States is the global leader on disability rights, made clear by the last 50 years of disability rights and access legislation which improved communities nationwide and the lives of 61+ million Americans with disabilities today.

- In 1968, the Architectural Barriers Act required new construction built with federal funds to be accessible.
- In 1973, Congress passed Section 504 of the Rehabilitation Act, making it illegal for the federal government or entities receiving federal funding to discriminate against people with disabilities.
- In 1975, the Individuals with Disabilities Education Act (formerly the Education for All Handicapped Children Act) secured “free appropriate” public education including special education and related services for children with disabilities who had previously been excluded.
- In 1984, the Voting Accessibility for the Elderly and Handicapped Act ("Voting Accessibility Act") promoted the fundamental right to vote when it called for accessible polling places.
- The Fair Housing Act of 1988 prohibited discrimination in housing against people with disabilities.

Each of these civil rights laws helped pave the way to 1990 when Congress passed the Americans with Disabilities Act (ADA), the most comprehensive piece of disability rights legislation that promoted inclusion in society for people with disabilities – a powerful victory that Americans with disabilities have continued to build upon for 33 years.

“Change never happens at the pace we think it should. It happens over years of people joining together, strategizing, sharing, and pulling all the levers they possibly can. Gradually, excruciatingly slow, things start to happen, and then suddenly, seemingly out of the blue, something will tip.”

Judith Heumann, lifelong civil rights leader and disability advocate, globally recognized as The Mother of Disability Rights.
It has been more than 30 years since the passage of the Americans with Disabilities Act (ADA) and, in many respects, it is time for a modern-day refresh: updated legislation and a civic movement to build upon this baseline to truly meet the current needs of the disability community. It is now time to ensure people with disabilities, older adults, and veterans have every opportunity to contribute to their communities and build lives of their choosing.

Disability impacts us all. In the United States, one in four individuals identify as having a disability. The disability community is unique—it is the largest, most intersectional, and most diverse minority group in America. It is also the only minority group that anyone can “join” at any point in their lives—through birth, injury, accident, disease or simply through aging.

For more than 61 million people with disabilities, myriad disparities exist and persist in every community throughout the country, especially in education, employment, healthcare, and transportation. And today, these disparities are only exacerbated by the ongoing impacts of the COVID-19 pandemic.

Closing these gaps is critical to individuals with disabilities themselves and is also important and valuable to society at large. Progress in improving equitable access and inclusion to education, employment, healthcare, and transportation is possible and within reach so that every community can benefit from the full participation of people with disabilities.

This Easterseals report examines the disparities and opportunities and highlights the most pressing issues and solutions to move forward to ensure disability equity across America. The report compiles a 2023 baseline of existing data around the social determinants of health for people with disabilities. Our intention is to annually track and highlight progress to enhance advocacy efforts on behalf of, and in partnership with, the disability community to improve disability outcomes and equity in education, employment, healthcare, and transportation.

While the needs of the community are varied and great, to ensure a more equitable and inclusive future for all Americans, these pressing issues must be urgently addressed:

- **Education**: Respond to systemic disparities, especially among Black, Indigenous, and people of color (BIPOC) students with disabilities who have been most impacted; continue focus on early identification and intervention services; and remedy ongoing impacts of the COVID pandemic on disabled students.

- **Employment**: Bolster public and private sector commitments to provide disability employment opportunities and to fully embrace Diversity, Equity, Inclusion and Access initiatives.

- **Healthcare**: Increase access to home- and community-based services and Medicaid funding necessary to support millions in critical need of these services.

- **Transportation**: Advance accessible air travel and continue to increase mobility and access in other community transportation modes.

"Advocacy is not just a task for charismatic individuals or high-profile community organizers. Advocacy is for all of us; advocacy is a way of life. It is a natural response to the injustices and inequity in the world."

Alice Wong, Disability Rights Activist, Founder, and Director of the Disability Visibility Project
BUT FIRST, STIGMA

Long-held, outdated stereotypes, and misguided attitudes about disability remain across every aspect of American life, regardless of legislative success or improved community outcomes for people with disabilities.

No conversation about education, employment, healthcare, or transportation is complete without understanding the deep-rooted role that stigma and ableism play in advancing disability equity and inclusion.

Historically, people with disabilities have been vastly underrepresented across film and TV, whether in front of or behind the camera, even though they represent the largest minority group. Disability representation lags far behind every other marginalized group, with only 3.1 percent of disabled characters in film. This statistic is reflective of scripts that are being developed. While inclusion seems to be improving for BIPOC and women writers, nevertheless, 93 percent of writers said their most recent writers’ room had no disabled writers.

Why is this so important? Entertainment and media, in all forms, have immense power to shape ideas, both negatively and positively, and can perpetuate more misunderstanding and stigma. The fact is, television, films, news, and social and digital media influence how we see others, and how we see ourselves.

Accurate, authentic representation can break down barriers, open us to new ideas, create powerful role models, and even be a source of empowerment.

Consider this: people with disabilities are 34 percent more likely than the general population to feel there isn’t enough inclusion of their identity group in media, and more than half say the portrayals they see inaccurately represent their individual identity groups.

Simply stated: societal stigmas, misperceptions and negative attitudes are the most challenging obstacles for our country to overcome. That said, progress is being made. Today’s disabled community is galvanized, empowered, and prideful—signature character traits of any community that fights tirelessly for inclusion.

Ableism is the discrimination of and social prejudice against people with disabilities.

- Lack of compliance with disability rights laws like the ADA
- Segregating students with disabilities into separate schools
- Segregating adults and children with disabilities in institutions
- Failing to incorporate accessibility into building design plans
- Buildings without braille on signs, elevator buttons, etc.
- The continued development of inaccessible websites
- The assumption that people with disabilities want or need to be ‘fixed’
- Using disability as a punchline, or mocking people with disabilities
- Refusing to provide reasonable accommodations

"Authentic representation and inclusion of people with disabilities is crucial to breaking down incorrect stereotypes of our community. Having authentic representation helps create a more equitable world for us all."

Nic Novicki, Actor, Advocate, and Founder of the Easterseals Disability Film Challenge
Every child deserves a quality education that will prepare them for life including readiness to work. In 1975, Congress passed the Education for All Handicapped Children Act, now the Individuals with Disabilities Education Act (IDEA), to address the historical exclusion of disabled students in schools. Since then, there have been positive strides forward to advance equitable public education for students with disabilities.

According to the National Center for Educational Statistics, in school year 2020-21, the number of students ages 3-21 who received special education services under the Individuals with Disabilities Education Act (IDEA) was approximately 7.2 million, or 15% of all public-school students.²

That said, there is no doubt that the COVID-19 pandemic negatively affected students with disabilities far more than their non-disabled peers.²

The pandemic brought to light the educational disparities that still exist today for students with disabilities – reminding us that a special education system, already stressed and at capacity in its ability to successfully support children with developmental disabilities, including autism, and other disabilities, needs to better address racial and gender disparities, and bring more resources to help students regain ground lost during these past years.

BIPOC students with disabilities have been disproportionately impacted, especially those students who do not have access to the critical technology needed to participate and remain connected in the classroom and in society at large.⁸

For children with autism and other neurodiverse conditions or developmental delays, timely evaluations, diagnoses, and referrals to providers of the services and supports they need were disrupted during the pandemic, resulting in the decline of early detection of autism in 2020, compared to previous years.⁹

More than ever, children’s mental health is a critical educational issue. According to the Centers for Disease Control and Prevention (CDC), 1 in 5 children are estimated to have a mental health disability¹⁰ and an estimated $280 billion is spent each year on treatment and management.¹¹ Children with disabilities often demonstrate high rates of depression, anxiety, and exhibit anger due to low self-esteem, loneliness, and rejection,¹² and yet about half (49.4 percent) of children with a mental health disability are not receiving treatment or counseling from a mental health professional¹³ and less than one percent of children have school-based
According to the U.S. Department of Education, for the school year 2019-2020:\(^{15}\)

- Asian students with disabilities are more likely to be identified with autism or hearing impairment than all students with disabilities. They are less likely to drop out and more likely to graduate with a regular high school diploma than all students with disabilities.
- Black students with disabilities are more likely to be identified with intellectual disability or emotional disturbance than all students with disabilities and more likely to receive a disciplinary removal than all students with disabilities.
- Hispanic students with disabilities are more likely to be identified with hearing-related disability or specific learning disability than all students with disabilities.
- American Indian or Alaska Native students with disabilities are more likely to drop out than all students with disabilities and less likely to be inside regular class less than 40 percent of the day than all students with disabilities.
- White students with disabilities are more likely to be served inside a regular class 80 percent or more of the day than all students with disabilities and less likely to be identified with specific learning disability or intellectual disability than all students with disabilities.

Increasing emphasis on school-based mental health counseling services may help eliminate some of these barriers and create opportunities for children to receive services to support mental health concerns. Many organizations, like Easterseals and The Coelho Center, are committed to ensuring that students with disabilities who face a multitude of barriers are getting critical supports and services to access their education, from the first years of life to every stage that follows.

There are areas of promise as pandemic restrictions have been lifted, or virtual options have been created, so that evaluations, supports, and services resume.

Educators, providers, families, as well as public and private sector leaders today are now more attune to the benefits early identification and early intervention can have for millions of children. Quality early education and early support for children with developmental delays or disabilities can make all the difference; they are cornerstones to a child's overall growth and wellness.

The first five years of a child's life provide the foundation for kindergarten readiness and are a key indicator for life-long success. Early Head Start (ages 0-3) and Head Start (ages 3-5) Programs promote school readiness and provide tools for every child to succeed, in addition to parental resources and support at no cost for children of qualifying families. Many awareness campaigns and focused efforts to educate the public about the crucial role early intervention plays are beginning to change perceptions and ultimately, behaviors, for the better.

According to the CDC’s most recent autism prevalence rates among children, now 1 in 36, more girls and BIPOC students are included within their findings – which means that more girls and BIPOC children are being identified with autism.\(^{16}\) It is not that girls and BIPOC children didn’t have autism before, but these new prevalence numbers indicate we’re getting better at identifying young children with autism, which is the first step to accessing early intervention services and supports.

Moving forward, those responsible for making decisions about education have an obligation to ensure that all children with disabilities have the supports, services, and instruction they need to succeed, and as early in life as possible.

"My Jaxon is proof that with early intervention and access to appropriate services delivered by dedicated experts, young people with disabilities can thrive and live a life that exceeds all expectations."

Kim Sydello, Jaxon’s Mom, and Continuing Education Administrator, Easterseals DuPage and Fox Valley (IL)
People with disabilities constitute the segment of society that is historically the least employed. And yet, for people with disabilities, employment means greater economic self-sufficiency, an opportunity to use their skills, and more active participation in community life. For employers, there are a host of competitive advantages, including increased productivity, reduction in turnover and several other tangible benefits.

The changes in work patterns brought on by the pandemic, combined by the availability of new technologies that make it easier to work remotely, have ushered in a new era for disability employment. The increased popularity and broad acceptance of remote work has helped to level the playing field and opened new employment opportunities for people with disabilities.

In fact, the U.S. labor market saw an uptick in rates of disability employment in 2022. According to the U.S. Bureau of Labor Statistics, 21.3 percent of persons with a disability were employed, up from 19.1 percent in 2021.17

At the same time, there is a heightened focus and improved action from corporate America to advance Diversity, Equity, Inclusion and Access (DEIA) initiatives. A growing number of employers have expanded their DEIA initiatives to include disability representation.

Today, societal attention has been activated, and new awareness has developed to the issues that the disabled community faces. This has led to focused intention in driving real opportunities for people with disabilities in employment, resulting in people with disabilities finally getting a seat, albeit small, at the corporate table – with a clear path forward emerging.

However, the employment rate of people with disabilities still pales in comparison to the 65.4 percent employment rate among their non-disabled peers in 2022, up from 63.7 percent in the prior year.17 This glaring discrepancy reinforces the unfortunate truth that people with disabilities still constitute the segment of our society that is historically un- or under-employed.

Stigma and obsolete stereotypes of people with disabilities at work are perpetuated by outdated and antiquated systems that keep employment of people with disabilities low. Examples include:

- Income limits set on beneficiaries of Social Security programs including Medicaid and Medicare, making it difficult for people with disabilities to find gainful, meaningful employment without disrupting medical and home- and community-based care.18

- Paying disabled workers subminimum wages (less than the Federal minimum wage).19
People with disabilities seeking employment fear losing critical healthcare coverage and benefits through programs like Supplemental Security Income (SSI), a needs-based program, and Medicaid. To get SSI, an individual's countable resources must not be worth more than $2,000 for an individual or $3,000 for a couple. This is known as the "resource limit."

These outdated systems keep employment numbers down and often relegate people with disabilities to live in poverty, further perpetuating the stigma that people with disabilities are not valued, equal, or contributing members of society.

Momentum is shifting as diversity, equity, and inclusion initiatives in employment are increasingly including "access." The change from DEI to DEIA reflects movement toward the full diversity of the nation, including people with disabilities. The most prominent example of this: in an executive order in the first year of his administration, President Joe Biden stated that the "Federal Government must be a model for diversity, equity, inclusion, and accessibility (DEIA)".20

Accenture Study
Getting to Equal: The Disability Inclusion Advantage

Companies deemed "Disability Inclusion Champions" in the Study have reported:21

- Higher shareholder returns and were, on average, two times more likely to outperform their peers in terms of total shareholder returns compared with the rest of the sample.
- Achieve 28 percent higher revenue and 30 percent higher profit margins compared to companies that do not include people with disabilities in their diversity and inclusion strategies.
- Higher employee retention rates, increased productivity, and enhanced employee morale – among other qualitative benefits.

As employers grapple with a new reality in the wake of an evolving workplace landscape, "Employment Extenders" – people working beyond traditional retirement age – are a growing segment of the population. Thirty-two percent of individuals ages 65 to 74 are projected to be working in 2030, according to the Bureau of Labor Statistics.22 Amidst a realignment in American working habits, it is imperative for employers to support their aging workforce and position them for a successful transition into retirement.

Now is the time to break down barriers to meaningful work, including subminimum wage and income limits at a minimum, but also by supporting policies that expand workplace flexibility and inclusion. And most importantly, to continue to reinforce and celebrate the positive momentum and corporate leadership that are advancing disability equity at work.
Medicaid is a joint federal and state program that provides health coverage to more than 90 million Americans, including children, pregnant women, parents, seniors, and individuals with disabilities.

After declines in enrollment from 2017 through 2019, preliminary data from November of 2022 show that total Medicaid/Children's Health Insurance Program (CHIP) enrollment grew to 91.8 million, an increase of 20.6 million from enrollment in February of 2020 (29.0 percent), right before the pandemic and when enrollment began to steadily increase.²³

Medicaid is the single largest source of health coverage in the United States and critical to the disability community because it provides home- and community-based services (HCBS). HCBS allow Medicaid recipients to receive services in their own home or community rather than institutions or other isolated settings. The Affordable Care Act (ACA) established a new methodology for determining income eligibility for Medicaid, which is based on Modified Adjusted Gross Income (MAGI). The ACA gave states the option to extend eligibility to adults with income at or below 133 percent of the federal poverty level.

The right to home- and community-based services (HCBS) was provided under both the ADA and the Olmstead Decision of 1999. And yet, decades later, adequate funding has not been made available to provide such critical supports and services to millions of people with disabilities, seniors, and their family caregivers, as well as direct service professionals who support them every day.

Too many people continue to go without the critical services and supports they need, deserve, and have every right to access. Home- and community-based services are essential to our country’s infrastructure, now more than ever, but continue to be underfunded. Without addressing funding in the near term, the impact could be devastating and would exacerbate the challenges of an already burdened system trying to address the growing demand for these services, let alone the uncharted impact of a global pandemic.

Consider the lives impacted through Home- and Community-Based Services (HCBS), pre-pandemic:²⁴

- Nearly one million people with disabilities are currently on waiting lists for HCBS, meaning people go without having their basic daily needs met (bathing, making meals, mobility, transportation, and other essential activities).
• Direct support professionals are in crisis, as they face dramatically increasing demand for HCBS services, yet receive inadequate pay, benefits, and professional development. There are simply too few direct support professionals to deliver this care, and not nearly enough resources available to meet the demand.

• Without appropriate funding, states are facing increasing pressure to reduce access to these services, even while demand grows exponentially due to direct care workforce shortages and an insufficient supply of affordable and accessible housing, both lingering key issues which have been further exacerbated by the COVID-19 pandemic.

• 76 percent of Americans recently polled voiced support for HCBS funding to improve care for people with disabilities and older adults.

Home- and community-based services are the solid building blocks needed for a better future for millions of people with disabilities and older adults – individuals going to school, work, traveling and participating in society like never before. Without this critical funding and support, our country is set back further and with too few resources to sustain a rapidly aging population and increasing needs of the disability community.

"Home- and Community-Based Services allow me to stay out of an institutional setting, which would drastically limit my autonomy and mental health. With HCBS services, I'm able to work from home and live life to my fullest potential. In an institution, I would not have this – I need to stay in the community. Disabled people shouldn't have to choose between personal freedom and receiving care we need to live."

Erin Hawley, Communications and Digital Content Producer, Easterseals

85% of Americans with disabilities receive some type of government assistance. (Medicare, Medicaid, Social Security, SSI or SSDI)

56% of beneficiaries claim that this assistance barely meets or does not meet their basic needs.²⁵

Of those:

35% claim their basic needs are just being met.

21% claim their basic needs are not being met.

(According to 2022 survey conducted by Pathfinder Opinion Research.)
People with disabilities are more mobile and more actively engaged in all aspects of life than ever before. From curb cuts to audible crosswalks, communities are becoming more welcoming and accessible for the tens of millions of people with disabilities nationwide.

To match and continue this progress, all forms of accessible transportation must be in lockstep, and keep pace. Mobility and transportation are vital for people with disabilities to fully participate in their communities, in school, work and life – whether via ride-shares, taxis, trains, buses, curb-cuts, intersection indicators and audible crosswalks, complete streets, and yes, airlines.

Thanks to the ADA, the work of many public/private partnerships across the country, and organizations like Easterseals, the nation’s disability community can travel on other forms of improved public transit – utilizing trains, buses, ride shares, and taxis. Air travel remains the most significant barrier to overcome.

The good news: there is increasing momentum to provide accommodations for people with disabilities. The advancements in accessible transportation that play a vital role in paving the way for accessible air travel are to be applauded including:

- Air Carrier Access Advisory Committee in 2019
- Airline Passengers with Disabilities Bill of Rights created by the U.S. Department of Transportation in 2022
- The unanimous pledge in November of 2022 from every member of Airlines for America to improve safe, accessible air travel to all passengers

Low estimates are that people with disabilities in the United States – not including their caregivers, families, and friends – have some $21 billion in discretionary income available to spend on such things as travel, entertainment, and more.26
Accessible transportation is a key social determinant of health. The time has come, 33 years after the ADA’s passing, for the airline industry to join other transportation providers in becoming accessible. The ADA legislation was a defining moment in our nation’s history. The airlines represent the last bastion of this integral change.

In November 2022, Easterseals submitted testimony for the record to the House Subcommittee on Aviation Hearing: “Accessible Air Travel: Addressing Challenges for Passengers with Disabilities.”

“Advocacy will not and cannot stop until every person with any disability, one in four Americans – whether invisible or visible, blind, hearing impaired, autistic, or with mobility issues – has equal access. And that includes a designated wheelchair spot for all types of wheelchair users,” said Kendra Davenport, President and CEO, Easterseals.

Airline Passengers with Disabilities

Bill of Rights

created by the U.S. Department of Transportation in 2022

- The Right to Be Treated with Dignity and Respect
- The Right to Receive Information About Services and Aircraft Capabilities and Limitations
- The Right to Receive Information in an Accessible Format.
- The Right to Accessible Airport Facilities
- The Right to Assistance at Airports
- The Right to Assistance on the Aircraft
- The Right to Travel with an Assistive Device or Service Animal
- The Right to Receive Seating Accommodations
- The Right to Accessible Aircraft Features
- The Right to Resolution of a Disability-Related Issue

“I have a high-level spinal cord injury and utilize a power wheelchair, but my injury and my chair do not stop my career aspirations. Unfortunately, in large part, the airlines do. Because there is no designated spot for a wheelchair, I do not fly. I cannot risk having my chair damaged or broken. Unfortunately, the lack of accessible travel to conferences and business meetings leaves me with less of an opportunity to achieve my goals. As a local elected official, I understand how impactful good legislation can be.”

Ben Trockman, Councilmember, Evansville (IN)
About this Report & Research

In preparation for the 2023 Easterseals Inaugural Policy and Partnership Forum, this report was prepared to provide a high-level snapshot about the state of disability equity and access in America. It is to be used as a reference point to help guide thought leader discussions around priority areas of focus, and it serves as a baseline to collectively identify additional opportunities to impact policies, programs, and empower the disability community.

Easterseals and The Coelho Center collaborated to compile and summarize the most current data available from the most reliable, credible sources to reflect on the impact the COVID-19 pandemic has had on the lives of people with disabilities; identify urgent and evolving needs; and, wherever possible, highlight innovative approaches to advance access and broad inclusion in education, employment, healthcare and transportation.

EASTERSEALS

Easterseals is leading the way to full equity, inclusion, and access through life-changing disability and community services. For more than 100 years, we have worked tirelessly with our partners to enhance quality of life and expand local access to mobility and transportation, healthcare, education, and employment opportunities. And we won’t rest until every one of us is valued, respected, and accepted. Through our national network of Affiliates, Easterseals provides essential services and on-the-ground supports to millions of people each year – from early childhood programs for the critical first five years, to autism services, medical rehabilitation and employment programs, veterans’ services, and more. Our public education, policy, and advocacy initiatives positively shape perceptions and address the urgent and evolving needs of the one in four Americans living with disabilities today. Together, we’re empowering people with disabilities, families, and communities to be full and equal participants in society. Learn more at www.easterseals.com.

THE COELHO CENTER
The Coelho Center for Disability Law, Policy, and Innovation

The Honorable Anthony "Tony" Coelho has spent his entire adult life helping advance the lives of people with disabilities. He calls this his "ministry". Diagnosed with epilepsy when he was 22 years old, Tony's ministry is marked by significant milestones: primary author and sponsor of the Americans with Disabilities Act (ADA) – the most important piece of civil rights legislation in the last 30 years; advocating for the ratification of the U.N. Convention on the Rights of Persons with Disabilities; and persuading President Bill Clinton to establish the Office of Disability Employment Policy at the U.S. Department of Labor. Tony continues to advocate for civil rights for individuals with disabilities. He persuaded President Barack Obama to issue an executive order enforcing Section 503 of the Rehabilitation Act of 1973 requiring federal contractors and subcontractors to hire people with disabilities – something they have been doing since 1973 for women and minorities.

In 2018, Tony founded The Coelho Center at Loyola Law School to continue his legacy. The mission of The Coelho Center is to collaborate with the disability community to cultivate leadership and advocate innovative approaches to advance the lives of people with disabilities.

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Our differences make us stronger. Celebrating our differences is the foundation of a great place to work. Choosing to include is the next step in the creation of an environment where each person feels comfortable to bring their whole self to work and be authentic. Inclusion is diversity in action.

Special Thanks

CHANGE FOR BALANCE

The full-service strategic communications and production agency is on a life-long journey to change this world for the better. Change for Balance helps clients conceptualize creative ideas, solve problems, forge new relationships and work collectively toward a brighter future.

The agency works to cast disability in a new, genuine light by leveraging its deep roots in entertainment. Change for Balance advances disability inclusion, breaks down misperceptions and stigmas, and makes certain people with disabilities are authentically represented and their stories amplified.
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But First, Stigma:

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