

A CRISIS IN EMPLOYMENT AMONG PEOPLE WITH DISABILITIES

“Our nation was founded on the principle that anyone who works hard should be able to get ahead in life. People with disabilities deserve the opportunity to earn an income and achieve independence, just like anyone else.” Hon. Steve Bartlett, Chairman of RespectAbility, and, while in Congress, co-author the Americans with Disabilities Act

Between 40 and 57 million Americans are living with a disability. About 17 percent of children aged 3–17 have a developmental disability, including autism, attention-deficit/hyperactivity disorder, blindness, and cerebral palsy. For individuals with disabilities-- our children, parents, colleagues, brothers, sisters and friends--full participation in the social and economic life of the nation depends on equal opportunity for competitive, integrated employment.

Work is no longer simply an option for people with disabilities, as expectations have fundamentally changed. Most young people with disabilities “definitely expect to work” following completion of their education, and a significant percentage of people with disabilities who currently receive means-tested public benefits want to work. For these individuals, work is not just a matter of economic security and independence, but of fairness, dignity and respect—to be seen and valued by peers and colleague as contributing members of society, and to reach their own potential.

Despite more than half a century of laws and policies designed to end workplace discrimination and promote equal access to employment, people with disabilities continue to be widely excluded from the workforce. In 2020, only 17.9 percent of people with a disability were employed, compared to an employment rate of 61.8 percent for persons without a disability. The labor force participation rate-- the percentage of the population that is working, not working and on temporary layoff, or not working and actively looking for work—stood at 32.8 percent in January 2021 for working-age people with disabilities, and 75.5 percent for working-age people without disabilities.

Across all age groups, persons with disabilities were much less likely to be employed than those with no disabilities.

Legislative milestones to advance the ability of people with disabilities to have equal employment opportunity include Title XIX of the Social Security Act of 1965 (Medicaid Act), the Rehabilitation Act of 1973, the Education for All Handicapped Children Act of 1975 (the predecessor statute to the Individuals with Disabilities Education Act (IDEA) of 1997), the Developmental Disabilities Act of 1984, and the Americans with Disabilities Act of 1990 (ADA).

The ADA changed the employment outlook for millions of Americans with disabilities by seeking to end discrimination and guarantee equal opportunity in employment, and promulgating economic self-sufficiency and full participation in the economy as core principles. It marked a

giant step in reversing discriminatory employment practices that contributed to stigma and low expectations, and excluded millions of willing and capable workers from the workforce.

Decades of research since the ADA became law shows that with appropriate services and accommodations, people with disabilities can compete and succeed in any employment setting. The employment of people with disabilities builds self-sufficiency, enhances the wellbeing of families, and strengthens communities. It is good for the business bottom line.

People with disabilities are generally excluded from jobs in the technology-based economy, even though a wide range of accommodations are available. Often, they lack access to training. *"Our latest research shows that vocational rehabilitation is largely funneling people into dying industries that are being replaced by automation or technology,"* said Neil Romano, President of the National Council on Disability (NCD).

For most businesses, the cost of workplace accommodations is negligible. About 59 percent of accommodations cost nothing, and of those with a cost, 36 percent represented a one-time average cost of \$500, according to the US Department of Labor's Job Accommodation Network.

The National Council on Disability, a federal agency that makes recommendations to the President and Congress to enhance the quality of life for Americans with disabilities, outlined four areas that are keys to increasing the number of people with disabilities in the American workforce:

- Services for Transitioning Youth: The need for increased skills training, coordination between systems, and employment-related services and supports available to transition-age youth
- Public Benefits: The need to dismantle disincentives to work present in the Social Security Act and the Medicaid Act
- Federal Employment and Support of Entrepreneurship: Continued challenges to recruiting and hiring people with targeted disabilities and exclusion from entrepreneurship support
- Employer Engagement: Its role in opening government and private sector employment opportunities and highlights of federal and private initiatives to engage private sector employers

The NCD also recommends phasing out of the Section 14(c) program, and in the meantime imposing a moratorium on the issuance of any new 14(c) certificates and strengthening overall enforcement of the 14(c) program.

GOVERNMENT ROLE IN THE EMPLOYMENT OF PEOPLE WITH DISABILITIES

A robust government commitment to helping people with disabilities—decades of laws, over \$400 billion in expenditures and close to 50 programs across multiple agencies-- has failed to close a gap of 40 percent in the employment rates of people with and without disabilities.

Employment services providers struggle with antiquated systems that have not kept pace with fast-changing social, legal, and policy environments. A patchwork of old and new laws creates significant challenges for service providers, as the intended outcomes of many employment funding sources, programs, and services are based on models that predate the ADA by decades, when the economy was manufacturing-based, and employing people with disabilities was considered an act of charity.

Less than two percent of total state and Federal Government expenditures on people with disabilities is committed to improving employment prospects and economic independence; 55 percent of funds are for health care (primarily Medicare and Medicaid), and 41 percent are for Social Security, Supplemental Security Income (SSI) and other government benefit payments. Some see the asset and earnings limitations of means-tested programs as forcing people to choose between work and health care, or trapping those who can and want to work in a cycle of unemployment and poverty.

Millions of Americans with disabilities depend on school transition programs, including special education services under IDEA (Individuals with Disabilities Education Act), the Vocational Rehabilitation Program, and state developmental disability and mental health service systems for help in finding employment. These programs fund the training and services that are provided each year to help millions of Americans with disabilities leave school, enter the workforce, and maintain economic self-sufficiency.

Each year, approximately 400,000 students with disabilities exit the nation's schools. Under IDEA, students with disabilities participate in the transition planning process through the Individualized Education Plan (IEP).

The 100-year-old Vocational Rehabilitation Program serves about 1.2 million youth and adults with disabilities each year to achieve and maintain employment. VR partners and providers of employment services and supports include State Vocational Rehabilitation (VR) programs, community rehabilitation service providers (CRPs), One Stop Career Centers, State and Community level Developmental Disabilities Programs, and Work Incentives Planning Assistance Projects (WIPA) for benefits planning for Social Security Disability benefits recipients.

The Medicaid Home and Community-Based Waiver program provides ongoing employment services to people with disabilities and is the largest federal source of funds for day and employment services provided to people with intellectual and developmental disabilities (I/DD). Nationwide, between 5,000 and 6,000 community rehabilitation providers (CRPs) provide vocational services to people with disabilities in employment service systems in every state, and the majority (70 percent) of those served by CRPs are people with I/DD. According to the Institute for Community Inclusion, total funding for Medicaid reimbursable day and

employment services in 2017 was just over \$9 billion, with about \$1 billion to support competitive integrated employment.

States funding of HCBS programs is optional, and demand far outpaces supply. Over 500,000 people with disabilities are currently on waiting lists for home and community-based long term services and supports. The wait can be as long as 8-10 years in some states.

Employment First, a national movement and framework for systems change, is based on the idea that all individuals with disabilities, are capable of full participation in integrated employment and community life. Under *Employment First*, state policy makers and I/DD service providers commit to the idea that employment-related services and supports should be prioritized over other facility-based and non-work day services, and that people with disabilities should be paid at minimum or prevailing wage rates.

While there is no federal mandate that states adopt *Employment First*, the initiative has been supported in policy statements by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP),), the Centers for Medicare and Medicaid Services' Home and Community-Based Services waiver program (2011), the Department of Justice (2014), and the Workforce Innovation and Opportunity Act (2014).

HIRING PEOPLE WITH DISABILITIES IS GOOD BUSINESS

"Being honest about where you stand can be a hard—yet crucial— first step toward becoming a more inclusive company. Accountability and creating an environment of trust where employees feel comfortable self-identifying as having a disability are true measures of inclusion." – Chad Jerdee, General Counsel & Chief Compliance Officer and Persons with Disabilities Sponsor, Accenture

Research from Accenture, in partnership with Disability: IN and the American Association of People with Disabilities (AAPD), shows that companies that embrace best practices for hiring and supporting people with disabilities outperform their peers.

There are 15.1 million people of working age living with disabilities in the U.S. Based on the research, companies that embrace disability inclusion will gain access to a new talent pool of more than 10.7 million people. Workers with disabilities who are employed are also consumers; the GDP could be boosted by as much as \$25 billion if just one percent more of persons with disabilities joined the U.S. labor force.

Results of the study are based on an analysis of the financial performance of 140 companies that averaged annual revenues of \$43 billion and participated in the Disability Equality Index, an annual benchmarking tool that objectively rates company disability policies and practices. Forty-five of the participating companies excelled in key DEI categories--as well as in measures

of profitability and value creation. They achieved on average 28 percent higher revenue, double the net income, and 30 percent higher economic profit margins over a four-year period, and were twice as likely to outperform their peers in terms of total shareholder returns.

Key best practice areas measured by the DEI include culture and leadership; community engagement and support service; employment practices; enterprise-wide access and supplier diversity.

Employing people with disabilities provided multiple tangible benefits to employers in the study, including innovation. As natural problem solvers who must creatively adapt to the world around them, people with disabilities are often skilled in problem-solving, persistence, forethought and a willingness to experiment—all essential for innovation. Staff turnover was as much as 30 percent lower in the companies with a well-run disability community outreach program in place.

Inclusion provides shareholder value and proven ROI--regulators and investors increasingly monitor diversity and culture, and disability inclusion is a key metrics.

A survey undertaken by the National Business and Disability Council in 2017 found that 66 percent of consumers will purchase goods and services from a business that features persons with disabilities in their advertising, while 78 percent will purchase goods and services from a business that takes steps to ensure easy access for individuals with disabilities at their physical locations.

Companies that are proactively inclusive of people with disabilities often earn their loyalty and patronage, according to the Workplace Initiative 2017 report. People with disabilities represent the third-largest market segment in the U.S., a market segment that expands when family, caregivers and others who seek goods and services that are disability-friendly are included. A 2018 study estimated the total after-tax disposable income for working-age persons with disabilities is about \$490 billion. Persons with disabilities tend to be more brand loyal and also make more shopping trips and spend more per trip than the average consumer, according to a Nielson study.

EMPLOYING PEOPLE WITH AUTISM SPECTRUM DISORDER (ASD)

Among American adults with Autism Spectrum Disorder (ASD), 80 to 90 percent are unemployed or underemployed. Most work part-time in low-paying jobs, at or below the minimum wage. The situation is similar in the UK, where research by the National Autistic Society (NAS), shows that just 16 percent of adults with ASD were in full-time work, despite 77 of people who were unemployed saying they wanted to work.

Each year, close to 100,000 children with ASD in the U.S. turn 18, but only about 58 percent of them will work in a paid job before the age of 25, compared with 74 percent of young adults

who have an intellectual disability, and nearly 99 percent of all high-school graduates. Approximately 85 percent of college graduates with ASD are unemployed.

About 1 in 54 children in the United States has ASD, according to Centers for Disease Control and Prevention. ASD is often characterized by impairments in social interaction, difficulties in communication and the presence of repetitive or restrictive behavior patterns, such as repetitive motor movements, inflexibility with regard to routines, restricted interests, and unusual reactions to sensory input. It affects individuals in different ways, with different barriers and challenges, and occurs in all racial, ethnic, and socioeconomic groups. ASD is four times more common among boys than girls.

Parents of children with ASD are highly concerned about the life-long supports their child may need to live an independent life--nearly 80 percent of parents in Easterseals Living with Autism study said they were extremely or very concerned about their children's independence as an adult, compared to only 32 percent of other parents. Areas of greatest concern for parents were for their child's financial independence, quality of life, social and interpersonal connections, and employment and housing opportunities.

These concerns are well-founded—most young people are eager and able to work, but are excluded from employment for reasons including systemic challenges around services and supports, longstanding biases and stereotypes, and hiring policies that don't account for or prioritize neurodiversity.

An overview of current research about youth and young adults with ASD, their parents, services providers, and other stakeholders confirms that many young adults with ASD experience poor transition outcomes in postsecondary employment, higher education, health care, social connectedness, and independent living. Although employers described people with ASD as dependable, punctual, conscientious, and consistent, parents felt that their children were steered toward jobs that were underpaid, and for which they may be overqualified.

Poor outcomes are influenced by factors including a lack of coordinated, comprehensive care. This service deficit is especially harmful to youth and young adults with ASD who have intensive mental health needs, because federal and state systems tend to be siloed--providing educational services, disability supports, or mental health services—and are thus unable to support individuals with complex, multifaceted needs. Over half of youth with ASD aged 15–17 have also been diagnosed with co-occurring conditions, including attention deficit disorder (53 percent) and anxiety (51 percent). Nearly one-quarter had depression, and 60 percent had at least two concurrent conditions. Other common co-occurring conditions include sleep disorders, intellectual disability, seizure disorders, and gastrointestinal ailments

Because ASD often presents a wide range of barriers and challenges across multiple areas of functioning, standardized solutions are not possible and can even be harmful. Instead, a broad range of supports, services and individualized transition plans are needed to effectively address the needs of transitioning youth with ASD—a coordinated, comprehensive approach not necessarily found in siloed services focused on health care, housing, transportation, social services, or education.

There is limited research and no broad consensus as to when transition planning should begin. While IDEA requires that transition plans be in place by the age of 16, many feel that planning should begin as early as age 10 and perhaps even at birth, continuing through adulthood and independence.

Individuals with ASD are challenged by poor person-environment fit, which refers to the match between the needs of people with ASD and their surrounding environments in high school, college, the workplace, and community service systems.

Another significant barrier to successful transition is access to existing services. Effective transition from school to employment requires an understanding of an array of state and community agencies, organizations and services, each with different rules, regulations, eligibility guidelines, and procedures. Families of individuals with ASD report that identifying, accessing, and paying for work transition services involves working through a complex public and private service system—a task made harder given the widespread service and program closures due to COVID-19.

A growing number of employers are embracing neurodiversity and revising HR practices to accommodate neurodiverse talent, including people with ASD.. Among them are SAP, Hewlett Packard Enterprise, Microsoft, Ford, Caterpillar, Dell, Deloitte, IBM, JPMorgan and Chase. Although the programs are still in the early stages, managers reported productivity gains, quality improvement, boosts in innovative capabilities, broad increases in employee engagement, and reputational enhancement.

Prioritizing a neurodiverse workforce requires companies to reimagine established practices like the job interview, and to embrace non-traditional approaches to training and work. People affected by ASD, as well as dyspraxia, dyslexia, ADHD, and social anxiety disorders often have higher-than-average IQs and special skills in pattern recognition, memory, or mathematics. Yet these individuals often struggle to fit the conventional profiles sought by hiring managers. Neurodiverse people sometimes exhibit behaviors that run counter to traits sought in job interviews—good communication and socialization skills, being a team player, emotional intelligence, persuasiveness, outgoing personalities, the ability to network, and the ability to conform to standard practices without special accommodations.

During interviews, neurodiverse people may not understand the nuances of questions or answer questions the way employers expect. They may share too much information, or answer

an open-ended question with a “yes” or “no.” Some struggle with making eye contact, or may take a long pause before answering a question.

In this way, neurodiverse people are frequently screened out after interviews, their unique skills and talents lost to employers. *“For the most part, [the low employment rate] is not because of the lack of ability among adults with autism to perform jobs—it’s mostly due to their challenges with social interaction and communication,”* says David Kearon, director of adult services at Autism Speaks, an autism science and advocacy organization.

For the many companies that prize innovation and outside-the-box thinking, this talent pool is too important to lose—and they are doing something about it. Having people who see things differently and who might not fit in seamlessly *“helps offset our tendency, as a big company, to all look in the same direction,”* said Silvio Bessa, SVP Digital Business Services for SAP.

SAP’s groundbreaking Autism at Work program, launched in 2013, focuses on hiring employees that are on the autism spectrum. The program—which SAP said was one of the first to place an intentional emphasis on hiring candidates that are differently abled--has been a huge success. Each participant in the program is assigned a mentor from within the company. The retention rate for employees with ASD is about 90 percent.

Several universities have developed pilot programs that prepare students with autism for the workforce, and potentially serve as models for larger initiatives. In 2017, researchers at Virginia Commonwealth University in Richmond recruited 81 high school seniors with ASD to work in jobs at four hospitals — stocking supplies, sterilizing instruments, scanning documents and even cleaning. A teacher and a teaching assistant from the school district taught the students how to do their jobs while a job coach showed them how to interact professionally with their supervisors and coworkers, and how to accept feedback without getting upset. A year later, more than 70 percent of the students were working about 20 hours a week, earning more than minimum wage.

THE EMPLOYMENT OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (I/DD)

The stigma of low expectations and other systemic challenges continue to exclude people with I/DD from the workforce. Only 20 percent of working-age adults supported by state I/DD agencies are employed in a paid community-based job, and only 15 percent held an integrated job, according to the 2018 National Core Indicators survey. The majority of those employed

hold entry-level positions with low income and limited benefits. Individuals in supported jobs worked an average of 13 hours per week, earning an average weekly salary of \$117.

It is important, and encouraging, to note that the stigma of low expectations is not one shared by the vast majority of transitioning adults with I/DD—86 percent expect to be employed after graduation. The employment disparities are rather a product of systemic failures, despite decades of legislative efforts, scientific breakthroughs in understanding I/DD, and passionate commitment by advocate and service providers in communities across the nation.

Interagency collaboration is a predictor of employment outcomes during transition, yet inadequate linkages between the education, rehabilitation, and adult IDD systems are primary factors in the low employment outcomes of youth with I/DD. Young people in special education transition programs often perform menial, manual tasks that do not prepare them for integrated employment. They rarely have access to technologies such as computers and PDAs that improve performance and employability, and are often a prerequisite for competitive, integrated jobs.

Employment disparities persist despite the fact that the conditions that facilitate the employment of people with I/DD that are well known. These include the ability to work and increase earnings without losing eligibility for public benefits; opportunities for post-secondary education, including college and vocational training; ongoing planning to promote job advancement and career development; fair wages and benefits; self-employment options, and the ability to explore new career directions over time.

Family and caregiver support is also essential for youth with I/DD who are transitioning from a system of education-based services, to which they are legally entitled, to an adult service system based on eligibility requirements. Family members' role modeling and expectations contribute to positive employment outcomes for individuals with IDD.

An evolving set of best practices—including person-centered career planning, supported employment, job creation, and self-employment—have been shown to help people with I/DD prepare for, find and maintain employment, but widespread adoption has been slow. Reasons include inconsistent policies, uncertain funding mechanisms, limited professional staff development, limited outreach to private employers, and variable allocation of resources to CRPs. Research suggests that service and philosophical variation among providers hinder the creation of a unified vision for service delivery.

A major barrier to successful organizational transformation to further the employment of people with I/DD is insufficient state and federal resources dedicated to integrated employment. Community rehabilitation providers (CRPs) are being asked to deliver more services that lead to competitive, integrated jobs and less facility-based work, but doing so requires a significant change to their business models and related costs. Research by the U.S. Department of Health and Human Services shows that only nine percent of CRP staff is

dedicated to employment, and that direct support staff experience confusion about their roles and feel unprepared to help.

State IDD agencies are the primary source of long-term funding and service coordination for adults with IDD. They provide, fund, and monitor a wide range of day and employment services. Funding for state IDD agency day and employment services comes from two main sources: Medicaid and state general revenue funds, with Medicaid the largest federal source of funds, primarily through Home and Community-Based Services (HCBS) waiver authorities that allow states to provide flexible supports in community settings.

Most long-term day and employment supports are administered by state IDD agencies and delivered by community-based providers under contract. State VR agencies provide services to over one million people annually, closing approximately 550,000 case records per year. CRPs and their staff are the primary source of day and employment supports for people with IDD. Between 5,000 and 6,000 CRPs nationwide offer vocational services to individuals with disabilities, 80 percent of whom are people with IDD

The Social Security Administration (SSA) supports employment participation through several programs including work incentives targeted at individuals who receive Supplemental Security Income or Social Security Disability Income, the Ticket to Work program, and the Work Incentive Planning and Assistance program. SSA work incentives, such as the Plan for Achieving Self-Support, Impairment-Related Work Expenses, and the Student Earned Income Exclusion, support employment by allowing individuals to exclude money, resources, and certain expenses from total earned income.

COVID-19 AND PEOPLE WITH DISABILITIES

"People with disabilities have been disproportionately affected by the coronavirus and its economic consequences." Carol Glazer, President, National Organization on Disability

The COVID-19 pandemic has had a devastating impact on the employment people with disabilities. One in 5 workers with disabilities has lost employment since March, 2020, compared with 1 in 7 in the general population. About one million U.S. workers with disabilities have lost their jobs since March, according to the U.S. Bureau of Labor Statistics.

When the pandemic hit, people with disabilities, at greater risk from exposure to COVID-19 than the general population, were furloughed or left their jobs in large numbers, especially those working in fulfillment centers, grocery stores, health care settings, and the restaurant, retail and hospitality sectors—where large numbers of people with disabilities are employed, and which may be slow to rebound.

Many of these individuals lost access to essential services and supports, as agencies that provide disability employment services cut back programs and services or closed altogether, due to cancelled government contracts, city and state budget cuts, fewer referrals from vocational rehabilitation agencies, and unanticipated costs related to the pandemic.

In a July, 2020 survey of 191 organizations serving people with intellectual and developmental disabilities, 77 percent shut down or discontinued programs—mostly employment services and day programs-- as a result of challenges related to COVID-19. Sixteen percent of the shuttered programs are unlikely to reopen. The closures could curtail access to those services for people with developmental disabilities over the long term, especially in parts of the country where there are few service providers. The survey was conducted by the American Network of Community Options and Resources (ANCOR), a national trade group representing disability service provider

While the long-term impact of the pandemic on employment is unknown, history shows that in a post-recession economy with rising employment rates, people with disabilities lag behind the general population in hiring. Current research bears this out. Between March and October 2020, individuals without disabilities were almost twice as likely to rebound to pre-pandemic employment levels as individuals with disabilities.

A recent survey by the National Organization on Disability of 200 organizations that collectively employ 8.7 million people found that many employers do not have adequate accommodations or processes for on-boarding people with disabilities. Post-recession, employers are unlikely to prioritize hiring people with disabilities.

Workers with disabilities face the long-term loss of essential services that support employment.

A recent survey of thousands of families of those with ASD found that the COVID-19 pandemic caused symptoms to worsen, and led to “significant, ongoing disruptions to therapies.” Most caregivers reported disruptions in services including special education and speech, physical, occupational and applied behavior analysis therapies. The majority said their loved ones with ASD in all age groups did not receive online or adapted services in place of in-person services. Among those who did, families indicated that benefits were minimal.

Children with ASD under age five were most severely impacted by service disruptions related to COVID-19 because they generally did not respond as well to telehealth. Sixty-four percent of caregivers said that the pandemic’s impact “severely or moderately impacted” their child’s autism symptoms, behaviors or other related challenges.

Over 3,500 parents and caregivers of individuals with autism participated in the survey funded by the Simons Foundation Autism Research Initiative

The upsurge in remote work during the pandemic may benefit people with disabilities by opening up more employment opportunities. According to the Society for Human Resource Management, 82 percent of businesses are adopting a more flexible work-from-home policy for all employees, which is seen as a reasonable accommodation for people with disabilities. Five percent of organizations are more likely to hire individuals with disabilities than before the pandemic began, according to SHRM.

"Remote work has experienced an increase and universal uptake in some sectors as a result of the pandemic," said Wendi Safstrom, Executive Director of the Society for Human Resource Management Foundation. "People with disabilities are our most-practiced innovators, they spend most of every day solving problems, removing barriers and inventing ways of doing things. With the success of remote work thus far, it's likely that there will be increased opportunities for individuals with disabilities."

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Many of these workers lost access to essential in-person care and support. Others with preexisting conditions were forced to leave jobs due to the danger of infection, particularly those with front line jobs in fulfillment centers, grocery stores and health care settings. Job losses have been steep in the retail and hospitality sectors, where many people with disabilities are employed.

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