

AD

THE AGENDA

ECONOMY

Opinion | Americans With Autism Have Never Had More Support — Except When It Comes to Employment

People with autism often need intensive, one-on-one assistance to find and keep jobs. Here's how the government can help.



Hannah Hess, 26, works at the library at the Monarch School & Institute in Houston in June 2018. | Elizabeth Conley/Houston Chronicle via AP

Opinion by MICHAEL BERNICK
10/04/2021 05:00 AM EDT



MARKET INSTITUTE. HIS NEWEST BOOK, WITH LOUIS VISHNIARU, IS *THE AUTISM FULL EMPLOYMENT ACT*, FROM WHICH THIS ARTICLE IS ADAPTED.

In 1991, when I began as a volunteer assisting adults with autism in finding employment, mention of autism would usually draw a quizzical response or vague reference to the movie *Rain Man*, which had been released three years earlier. Now, such mention usually brings instant recognition: someone saying they have a nephew, niece, grandchild, neighbor or some other connection to a person on the autism spectrum. Popular culture today is replete with autism references and autistic characters.

These shifts have been driven by demographics. The CDC estimates that, as of 2017, more than 5.4 million adults have autism, and the numbers are rising rapidly. As many as 1.1 million young people with autism are expected to turn 18 each year over the next decade. In my state of California, people with autism constituted less than 5 percent of the population receiving services from the state Department of Developmental Services in the 1980s; today, 1 in 3 DDS clients is an individual with autism.

AD

As the population with autism has grown, our society has made great strides in supporting those Americans. Opportunities for children with autism in K-12 education have become far more expansive, as have opportunities in post-secondary education, including colleges and universities. For adults with



Employment rates, though, have been the glaring exception. Statistics are scarce, but the existing data suggests that only about one-third of adults on the autism spectrum work in paid jobs for more than 15 hours a week — and the rate has barely changed since 1991. There is a clear and urgent need to help these individuals find and keep meaningful employment.

This summer, as part of a commemoration of the Americans with Disabilities Act, the Biden administration announced its intention to significantly increase the employment rate of adults with autism and other developmental differences. The White House touted several strategies, including the use of new internet-based toolkits, webinars and job search systems; the designation of the government as a “model employer” for people with disabilities; and a proposal to transition workers with more serious disabilities from alternative workplaces into mainstream employment settings.

These are familiar strategies in Democratic circles, especially the use of technology to deliver services inexpensively and at scale. But in many ways these approaches miss the mark. When it comes to employment for adults with autism and other developmental differences, fieldwork and research show that the answer lies not in technology or big new schemes, but rather in the low-tech, one-to-one, sometimes painstaking process of guiding both job seekers and employers through a job search and providing close support to ensure retention.

Advertisement



These services are already being offered by a network of state and local agencies, which rely in part on federal funding, as well as nonprofits and businesses. But often these entities are short on staff and expertise, leaving families frustrated and hopeless. The priority of the federal government and the states should be to expand and strengthen these networks — in addition to creating more opportunities for adults with autism to work in government jobs, investing in autism-focused businesses and pushing to restructure, rather than replace, alternative workplaces.

Adults with developmental differences and their families should expect the employment services they receive to amount to more than online job boards or tutorials on how to create LinkedIn profiles. I've observed the effectiveness of hands-on, intensive services (as well as the current system's limitations) as part of California's labor department, in volunteer work and in my own family.



the Richmond District of San Francisco. He talks to himself, laughing from time to time, his hands making gestures in space. The man is my son Will, and he is a person with autism.

Will is on his way to an office job with Code Tenderloin, a company that teaches coding in the city's Tenderloin area. He takes considerable pride in this work and in having somewhere to go every day. But the job is fragile. It can end at any time, just as other jobs he has held have ended.

Advertisement

Ad removed. [Details](#)

Since Will graduated with a bachelor's degree from California State University, East Bay in 2013, he has worked steadily, though no job has lasted for more than 14 months. Immediately after college, he had an internship at the energy utility PG&E aimed at adults with disabilities, but it did not lead to a full-time job for him or any other participants. Other jobs followed: data entry,

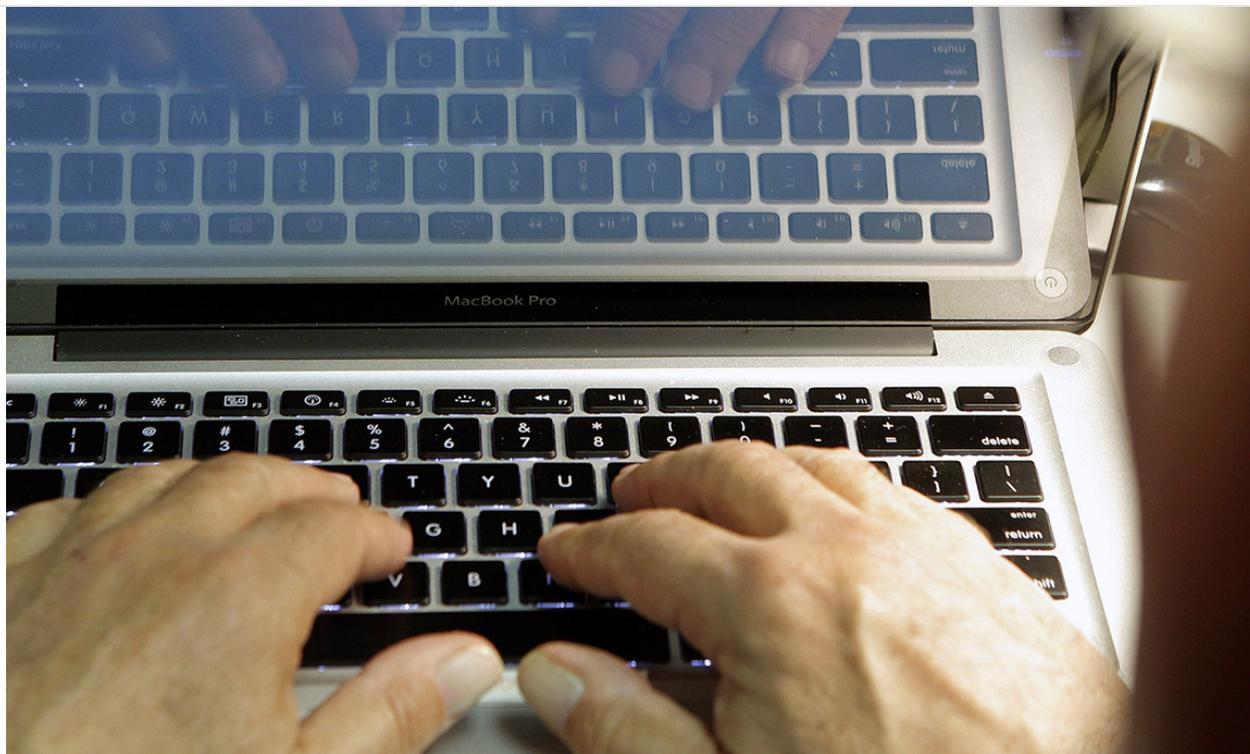


a hotel that housed homeless people during the early days of the pandemic.

He is willing to do any job, at any location, and is preternaturally upbeat and positive. But he also has behaviors that employers and co-workers find disconcerting. He talks loudly to himself and laughs to himself, often walks around with a greasy Starbucks bag and old coffee cups and plastic forks, and has a series of severe obsessive-compulsive behaviors, including a compulsion to hide old food and papers in various locations. Will has little understanding of money or any ability to manage it. If you asked him to write a check to you for \$5,000, he would do it (he has done it before). He retains some of the prodigious memory skills he had in childhood, but he has not found any real use for them in the job world.

Will's desire to work and his difficulties so far in finding a long-term job are shared by other members of AASCEND, an adult autism job club in the Bay Area that I facilitate. During the pandemic, more than half of our 40 or so members were out of work. At our monthly Zoom meetings, they talked about how much they missed having somewhere to go every day. But, for most, getting and keeping a job has been a challenge even in good economic times.

For Will and others with autism to secure stable employment, they first must find or carve out positions where they can add value. In the mid-2010s, there was a popular notion that adults with autism were especially competent at tech jobs, and for a time I thought this might be the case for Will. But over time he displayed no unusual tech skills. Time has shown, too, that only a small percentage of the adult autism population — 10 to 15 percent — has an unusual level of tech competence. We should not expect tech jobs to be an easy way out.



Time has shown that only a small percentage of the adult autism population has an unusual level of tech competence. | Damian Dovarganes/AP Photo

Adults with autism also need to find workplaces that truly want them and recognize what they have to offer. “Autism-friendly” workplaces are usually described in terms of physical elements: noise reductions, special lighting, quiet spaces. But these physical elements rarely get at the core needs for successful employment. The true autism-friendly workplace is one that incorporates flexibility and patience, giving the worker time to learn skills and develop any needed workplace behaviors they might lack.

AD



requirements: what's worked best for VWH and other ASCEND members is unglamorous, intensive, one-to-one placement and retention services. In California, these are offered by DDS and the Department of Rehabilitation, as well as regional agencies that work with nonprofits such as ARC, Goodwill, Best Buddies and Pomeroy Center. This network, when operating effectively, can guide workers through the employment process by identifying job leads, negotiating with employers, informing employers about government wage subsidies and on-the-job training funds, and providing ongoing job coaching and problem-solving support.

These services draw on the main elements of the Individual Placement and Support model, an approach developed by a team associated with Dartmouth Medical School in the 1990s that emphasizes intensive, individualized assistance in job placement and retention. (The model was originally targeted at people with mental illnesses but has been adapted for other populations with high unemployment rates.) In a report issued last December, MDRC, the leading national employment research entity, documented the value of the ISP model across the majority of the programs studied, citing examples of what success looks like: rapid job searches, follow-along support, coordination between program staff and mental health professionals and, most of all, small caseloads of fewer than 20 job seekers.

The problem right now is that, among intensive job search programs, the quality of services can be quite uneven. Job counselors and job coaches often come to their positions with little training or direction. They often are given caseloads of 60 to 70 job seekers. They might have four to five hours a month to spend on each worker — not nearly enough to assist in any serious way. Without knowledge of the job placement process, more than a few job counselors today will default to online job boards, which for most adults with developmental differences are black holes, where applications go to disappear.

Funding for this system is split between the federal government and state governments, with programs operated by states and regional entities. To really help adults with autism, the Biden administration and state governments need to prioritize improving and professionalizing this existing intensive employment services system. That will mean different things in different areas. To serve their clients better, some states will want reduced caseloads, improved staff wages and additional training. The role of the job counselor or coach should be valued and decently compensated, and candidates should have a strong sense of mission and craft.

Technology has a role to play in disability placement and retention. In fact, some of the existing tools — such as those developed by the Stanford Neurodiversity Project, Cornell’s Institute on Employment and Disability, Life Sherpa and Meristem — are quite good. But they are no substitute for human-to-human support. The type of employment assistance needed by most workers with developmental differences must be high-touch and in person.

A key part of an individualized approach to autism employment is matching each person to the right workplace, whether in the public or private sector, in a mainstream setting or an alternative one. But even as many employers have stepped up and committed to hiring more adults with disabilities, the results so far have been modest, especially in the public sector and among universities and large nonprofits.

Right now, the private sector is leading the way when it comes to autism employment. In recent years, a subsector of workforce intermediaries has emerged to help support state and regional services with placement and



started by people with private-sector backgrounds who know the hiring process, while also understanding how individualized and high-touch services for people with autism need to be. These entities — including Integrate, Autism Speaks Employment, NEXT for AUTISM, NeuroTalent Works, EVOLVE, Autism Workforce, Zavikon, Uptimize, Potentia, SourceAble and Evolibri — work primarily to help place people with autism in private-sector jobs, spanning a range of industries, occupations and geographic areas.

AD

For example, Integrate, established and led by Marcia Scheiner, a former bank and financial services executive, begins with an employer's hiring needs, identifying positions that it might have difficulty filling. The organization then helps train supervisors and staff at the company, educating them about what autism is, the range of skills and behaviors it includes, the success of previous autism employment initiatives and the problems that these programs have encountered. Nobody is required to take the training, though Scheiner notes that attendance usually is high, since so many people today have a connection to autism. Once a position or positions are identified as appropriate for an adult with autism, Integrate connects with local autism groups and disability agencies to assist in recruitment. If a placement is made, Integrate holds weekly check-ins with the department managers about the employee.

While workforce intermediaries have been active primarily in the private sector, they and other providers should have more opportunities to partner with public sector entities to identify and set out specific jobs, assist workers in



... requires a strong commitment from the government.

The Biden administration says it will promote public-sector hiring by designating the federal government a “model employer” for people with disabilities, with specific hiring goals and reasonable accommodations in place. More than 20 states have enacted “model employer” designations over the past decade. These states have established alternative processes for workers with developmental differences to get on hiring lists, and have even reached out to government departments about why they should hire these workers. Data is limited, but employment specialists throughout the country report few long-term hires through these programs. In California, no more than a handful of the clients of local employment programs for adults with developmental differences have been hired through LEAP, the state government’s alternative hiring process for adults with developmental differences.

AD

If governments want to see real results from “model employer” designations, they will need to ensure that their programs are structured in a way that is transparent about hiring numbers, and that incorporates intensive placement and retention services. Other large employers exempt from market pressures also should increase their hiring of adults with developmental differences as well — particularly universities that receive millions of dollars in government autism research funds and nonprofits that are generously funded with government social services funds.



with more intensive support. The past decade has seen the rise of “autism-focused” small businesses, which have the explicit goal of employing adults with autism. A number are in tech or data analytics; others are in low-tech fields, including petting zoos, farmers markets, car washes and even artisanal chocolate making. These businesses will always be a niche market, but they ensure a welcoming and patient workplace with a higher level of individualized support than mainstream employment settings.

Even more intensive services have been available for years at what are known as alternative workplaces, such as those offered by PRIDE Industries in California. A nationwide movement to eliminate alternative workplaces has been gaining speed for some time, on the grounds that they segregate workers with developmental differences, and the Biden administration appears to be embracing this movement. Nobody in the disabilities employment field disputes that, whenever possible, mainstream employment should be the goal. But many families with severely impacted adults currently employed in alternative workplaces regard them as indispensable.

AD

Jill Escher is the president of the National Council on Severe Autism and the parent of a severely impacted son and daughter. She and other members of the council have pushed back against the drive to end alternative workplaces. As she explains it: “Many adults with severe disabilities will be incapable of competitive integrated employment, understood as employment in mainstream settings. It is fruitless and misleading to pretend otherwise.” Instead, Escher

There is nothing discriminatory about jobs that protect the severely disabled from being fired or from the vicissitudes of the free market,” Escher says, pointing to family members linked to her council who are “nonverbal, cannot follow even simple directions without continual guidance and exhibit an array of disruptive behaviors. It is not just unlikely, it is impossible, that they would ever be hired for competitive wage jobs.”

Alternative workplaces provide the highest level of one-to-one supports and work structure — precisely what some adults with developmental differences need. These workplaces might need to be restructured in some ways — to ensure minimum wage pay, when possible, and to regularly reassess employees for possible transition into mainstream opportunities — but they certainly should not be eliminated.

When adults with autism and their families first come to our AASCEND job club, they usually are bewildered by the job search process. Maybe they’ve read something about the Autism at Work programs at Microsoft or SAP, but they soon recognize these jobs are few in number and located far from where they live. Maybe they’ve applied for jobs online and wonder why they’re not getting any response. Family members want to help but often don’t know where to start. They worry their sons or daughters or siblings might never be employed.

AD



market for them, but that they and families need to take responsibility and take action, joining with others in the autism community for mutual support. We also make sure they know there is an extensive system of government-funded employment services, as well as nonprofit assistance, available to them at little or no cost, including when they lose jobs and need new ones.

Still, our job club families have learned that this system at times can be maddening to access and navigate, and sometimes offers only cursory or amateur services. Even I, as someone who has worked in the employment field and has spent years on this issue, am often stymied. Strengthening this system — to support intensive, individualized services in a range of settings — should be the center of any government disability program going forward.

As for my son Will, although his job at Code Tenderloin has carried him through the pandemic and given him somewhere to go every day, it probably is not a long-term answer. While continuing in that job, he and his Department of Rehabilitation job counselor are actively applying for other positions, with a focus on larger employers that can offer stability — city and state governments, major health care and educational institutions. Eight years into his job journey, I know it might take additional time and jobs to get the right fit.

I've seen people in our AASCEND group go through their own job journeys over the course of years and eventually find some employment stability — as a librarian, administrative assistant, data analytics specialist, a grocery checker and in the state architect's office. I know that, with the right approach and the right people, it's possible for people with autism to find work, and the fulfillment that comes with it.

FILED UNDER: OPINION, EMPLOYMENT, JOE BIDEN, JOE BIDEN 2020, AUTISM, THE AGENDA

National Security Daily

From the SitRoom to the E-Ring, the inside scoop on defense, national security and foreign policy.





INDUSTRY

Select Industry ▼

* All fields must be completed to subscribe.

SIGN UP

By signing up you agree to allow POLITICO to collect your user information and use it to better recommend content to you, send you email newsletters or updates from POLITICO, and share insights based on aggregated user information. You further agree to our privacy policy and terms of service. You can unsubscribe at any time and can contact us here. This site is protected by reCAPTCHA and the Google Privacy Policy and Terms of Service apply.

SPONSORED CONTENT

By

YourBump

[Gallery] Shaq's New Yacht Is Literally A

Definition

[Pics] She Never Got Married, And Now We know

bonvoyaged.com

Worst Colleges In America (California Is

Post Fun

[Photos] Jackie Kennedy's Granddaughter Is

Definition

[Gallery] Always Place A Toilet Paper Roll Under

Definition

[Pics] Pour Vinegar On Bread And Leave It In

StyleBistro

This Is Why You Should Cut Your Hair After 50

Lonny

Look Inside The Obama's Post-White House

It's Rosy

Rare Photos Of Camilla Reveal The Truth

Assisted Living | Search Ads

How Much Does It Cost To Hire A 24-Hour Live-In Carer

[About Us](#)

[Advertising](#)

[Breaking News Alerts](#)

[Careers](#)



FAQ

Feedback

Headlines

Photos

POWERJobs

Press

Print Subscriptions

Write For Us

RSS

Site Map

Terms of Service

Privacy Policy

Do not sell my info

Notice to California Residents

© 2021 POLITICO LLC