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FEATURE

Despite the ADA, equity is still out of reach

Psychologists are intensifying efforts to improve health care, justice, employment and more for people with disabilities

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Signed into law 30 years ago, the Americans With Disabilities Act (ADA) has significantly improved the lives of the 1 in 4 Americans with disabilities. This civil rights law is designed to ensure that people with disabilities have the same

rights and opportunities as everyone else by prohibiting discrimination in employment, education, transportation and other aspects of public life.

But true equality remains elusive, especially for people of color with disabilities and for those whose socioeconomic position makes access to health care and other services more challenging. People with disabilities face systems that were not designed to accommodate all people, ranging from the health-care system to the criminal justice system to employment and education.

And the likelihood of having a disability is not evenly distributed. For example, 2 in 5 non-Hispanic American Indians and Alaska Natives have a disability, according to the Centers for Disease Control and Prevention (CDC) (https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html) , well exceeding the rate in the general population.

Recognizing the many barriers faced by people with disabilities, psychologists are pushing for research-based solutions to make health care more accessible, the criminal justice system more equitable and the ability to receive social and career supports easier.

“Disparities are not fair or necessary, and solutions are within reach,” says Susan Havercamp, PhD, a clinical psychologist and director of the Health Promotion and Healthcare Parity Program at the Nisonger Center for Excellence in Developmental Disabilities at The Ohio State University (OSU).

Barriers to health

People with disabilities have high rates of co-occurring health conditions and often have more health-care needs than people without disabilities, Havercamp says, but they face barriers getting the care they need.

A study of Ohioans with developmental disabilities co-authored by Havercamp and Jessica Prokup, MD (then a medical student), illustrates the problem. It found disparities among all age groups, particularly in delayed care and difficulties getting enough time with physicians (*Annals of Family Medicine*, Vol.

15, No. 5, 2017 (https://www.ncbi.nlm.nih.gov/pubmed/28893818)). People with developmental disabilities were less likely to report having a physician who explained things well, particularly in the 65-plus age group, in which only 83% of respondents with disabilities said they were satisfied with their doctors' explanations. (By comparison, 95% of adults over age 65 without developmental disabilities said their doctors explained things well.)

Unconscious bias by health professionals likely plays a role in the ways people with disabilities are treated. A literature review on implicit attitudes toward people with disabilities found moderate to strong negative implicit attitudes toward people with both physical and intellectual disabilities (Wilson, M.C., & Scior, K., *Research in Developmental Disabilities*, Vol. 35, No. 2, 2014 (https://www.ncbi.nlm.nih.gov/pubmed/24316588)). These findings included the implicit attitudes of health-care professionals.

Such misperceptions are likely due to the limited training medical residents receive about disabilities, Havercamp says. "They assume people with disabilities are really different from anyone else."

To address this problem, psychologists are working to improve training for health-care providers. Among their most far-reaching efforts is their work as part of the Alliance for Disability in Health Care Education, a nonprofit dedicated to integrating disability content into health-care training. The alliance has developed a set of core competencies to guide health-care programs in establishing this content (Core Competencies on Disability for Health Care Education, 2019 (https://nisonger.osu.edu/wp-content/uploads/2019/08/post-consensus-Core-Competencies-on-Disability_8.5.19.pdf)). About 27 health, education and disability organizations have endorsed the competencies, says Havercamp, an active contributor to the group. As of January 2020, nine had adopted at least some of the disability competencies, and 15 had disseminated them to their members or to the public.

Individual schools are also increasing their commitment to people with disabilities. At OSU, for example, medical students now get education on

disabilities every year, thanks to a program developed in part by Havercamp and funded by the WITH Foundation, the CDC and the Health Resources and Services Administration. In addition to lectures, the four-year program includes simulated patient encounters with individuals with disabilities as well as panels whose members discuss daily life and health care with a disability. In the third and fourth years, students can choose community service placements at organizations serving people with disabilities and take an advanced competency curriculum on developmental disabilities.

"The students love it," Havercamp says. "They will share how they never knew this information and how it has affected the way they think."

Other psychologists are working to increase preventive care for people with disabilities. A perennial problem for patients with disabilities is that disability-related medical issues take center stage when they do see a doctor, leaving little time for attention to general preventive care and more universal issues such as reproductive health care. For example, a study led by CDC researcher Jacqueline Miller, MD, FACS, found that women with disabilities were less likely than those without to have gotten a mammogram in the previous two years (*Journal of Women's Health*, Vol. 20, No. 9, 2011 (https://www.liebertpub.com/doi/abs/10.1089/jwh.2010.2609?rfr_dat=cr_pub%3Dpubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&journalCode=jwh)). The disparity could not be explained by financial barriers alone, suggesting that issues such as transportation and positioning for people with mobility limitations might play a role.

"The other part of it is that if I have a disability and I live with something that is really bothering me, it's not going to be my priority to get a mammogram, either," says Gloria Krahn, PhD, MPH, a psychologist at Oregon State University who studies ways to improve health services for people with disabilities. "It takes so much effort to get to one medical appointment that you have to parse out your energy and resources."

Prenatal and postpartum care can also fall into the access gap for people with disabilities, says Kara Ayers, PhD, a psychologist at the University of Cincinnati Center for Excellence in Developmental Disabilities at Cincinnati Children's Hospital Medical Center and co-founder of a peer-support and research network studying the experiences of parents with disabilities. Not only may women with disabilities need specialty care that is only available in a few areas, they may face barriers to supports like lactation consulting. Lactation consultants may not have experience working with mothers who have upper-body-strength or mobility issues, for example. Worse, Ayers says, parents with disabilities are at risk of being reported to child protective services (CPS) without just cause. In one 2010 case in Missouri, a nurse reported a breastfeeding mother who was blind after her baby struggled to breathe during a breastfeeding session. The mother told ABC News (https://abcnews.go.com/Health/missouri-takes-baby-blind-parents/story?id=11263491) that she had noticed the problem and asked a nurse for help. Soon after, the newborn was removed from the parents for two months during the investigation.

More education of the public and professionals to reduce bias against people with disabilities could prevent these traumatic situations, Ayers says.

Justice and disability

When parents with disabilities are called before CPS, they often find that the process of investigation isn't accessible, Ayers says. CPS often opens investigations soon after birth, while mother and baby are still in the hospital, based on the presumption that a disabled person won't be able to parent safely, she says. The parent may be asked to demonstrate that they can lift and change the baby using a standard hospital bassinet, which is not designed for people with physical disabilities, ignoring adaptations that parents may have prepared in their home nursery. The process may require reading or answering hypothetical, abstract questions, which can be unfair to people with intellectual disabilities.

This sort of inaccessibility permeates the justice system, as do structural barriers to justice for people with disabilities, who are vastly overrepresented among incarcerated populations. According to a Bureau of Justice Statistics report, 32% of prisoners and 40% of jail inmates reported at least one disability, which is three to four times the rate in the general population (Bronson, J., et al., 2015 (https://www.bjs.gov/index.cfm?ty=pbdetail&iid=5500)). Two in 10 prisoners and 3 in 10 jail inmates reported having a cognitive disability.

In many cases, these impairments are mild, and defendants are reluctant to admit to them, says Marc J. Tassé, PhD, a psychologist and director of OSU's Nisonger Center for Excellence in Developmental Disabilities. Defendants often work to mask their impairments out of a desire to be seen as neurotypical and competent, he says. While intellectual disability can be a mitigating factor in sentencing, without a comprehensive psychological evaluation, a judge may not realize the depth of a defendant's disability.

Meanwhile, incarcerated individuals with intellectual disabilities are at high risk of victimization within jails and prisons, according to the California Policy Research Center (https://eric.ed.gov/?id=ED465905) . They are also at risk of serving lengthened sentences because of infractions made while incarcerated —infractions against rules they may not comprehend.

Disability intersects with race and socioeconomic status in criminal cases as well.

"A lot of the folks I see never received a comprehensive evaluation at any point in their lives, and we're kind of scrambling now that they're in trouble to say, 'No, actually if you look back at the records, they were showing developmental problems from an early age,'" says Joette James, PhD, a clinical neuropsychologist who consults on criminal forensic cases. Some people facing the death penalty have records replete with evidence of undiagnosed developmental disabilities, as well as of abuse, trauma, discrimination and poverty, James says.

Even defendants who do have diagnoses have often been misdiagnosed, says Elliot Atkins, EdD, a forensic and consulting psychologist in New Jersey. Many defendants on the autism spectrum have been labeled with attention-deficit hyperactivity disorder, a misclassification that can change both the outcome of a criminal trial and the type of mental health treatment the person receives. Correcting those diagnoses is an important part of forensic psychologists' work.

The symptoms of some developmental disabilities can make some defendants look less sympathetic to law enforcement officers, judges and juries. A person with autism may not show empathy or remorse after committing a violent act in the same way a neurotypical person would; a person with a low IQ might behave in unexpected ways at a crime scene.

Contextualizing the actions of defendants with developmental disabilities is one important role for forensic psychologists. Another is explaining defendants to their own lawyers. Understanding a client's cognitive ability can help lawyers work more productively with him or her, Atkins says. Psychologists can also help lawyers get their clients into a mental health court, if appropriate. These courts aim to treat clients with cognitive disabilities or mental health diagnoses rather than simply incarcerating them.

Advocating for defendants with disabilities can also draw attention to the need for reform in the criminal justice system, James says. When she describes the trauma her clients have experienced, laypeople are often shocked. Many of her clients have suffered extreme poverty and familial instability. Most have had limited access to quality education and mental health care, yet these factors are often not considered when her clients are charged with a crime. "The criminal justice system is so broken," James says.

During and after incarceration, people with disabilities find themselves in a system that neglects their needs, with many county jails failing to provide simple accommodations for inmates with physical disabilities, according to a report by Amplifying Voices of Inmates With Disabilities, an affiliate of the advocacy group Disability Rights Washington

(https://www.disabilityrightswa.org/reports/access-denied/) . In Washington state, for example, the group found that inmate showers were a step higher than the surrounding floor, outdoor recreation areas were inaccessible due to steep staircases, and deaf inmates were unable to communicate within the jail or with those outside the jail due to inadequate technology. Therapy, religious services and classes inside jails are also frequently inaccessible to those with disabilities.

Supporting employment

Though the ADA forbids discrimination in employment on the basis of disability, people with disabilities are less likely to be employed than people without disabilities. In 2019, for example, the unemployment rate for people without disabilities was 3.5%. For people with disabilities, it was 7.3%, according to the Office of Disability Employment Policy.

The disparities begin within the education system, which is not set up for equity or diverse learning styles, says Ivory Toldson, PhD, a professor of counseling psychology at Howard University. The impacts are worsened by the effects of systemic racism. According to a 2020 Government Accountability Office (GAO) report, 40% of allotted special education service time was either undelivered or went unrecorded. Meanwhile, the GAO has also found that students with disabilities are disproportionately disciplined. Although students with disabilities make up 11.7% of the school population, they make up 25% of students suspended out of school, 23% of those expelled from school and 27% of those arrested at school (GAO, 2018 (https://www.gao.gov/assets/700/690828.pdf)). The situation was most dire for Black students with disabilities, who make up about 19% of students with disabilities but 36% of students with disabilities who are suspended from school.

Psychologists have a role in pushing back and reducing stigma around disability in the school system, Toldson says.

"Psychologists have to be social justice advocates as well as being professionals," he says. "I'll make the audacious statement that if you're a psychologist in the traditional school setting and you have no complaints or critiques about the way the system is functioning, you're not being a good psychologist."

Other psychologists are working to address the transition from school to adulthood, when school-based accommodations and individualized educational plans melt away. "It's almost as if society thinks [students with disabilities] can magically be independent now that they are adults," says Connie Sung, PhD, an associate professor of rehabilitation counseling at Michigan State University (MSU).

To address that gap, in 2016, Sung and her colleagues launched Spartan Project SEARCH at MSU, part of an international program that helps transition-aged youth with developmental disabilities overcome employment obstacles. MSU is the first large public university to be a host site. Each year, eight to 10 young adults with disabilities come to MSU for a vocational training program to learn job- and work-related social skills and work on campus for nine months. They learn to take public transportation independently and navigate in the community safely with strangers (Price, R., *Behavior Analysis in Practice*, Vol. 11, No. 1, 2017 (https://www.ncbi.nlm.nih.gov/pubmed/29556448)).

"So far, over 80% of the graduates have stayed at MSU and become employees, which is a tremendously high employment rate compared to the usual rate for people with developmental disabilities," Sung says.

Sung and her team are also experimenting with virtual reality technologies to help individuals with autism spectrum disorder gain skills. Participants undergo simulated interactions with an avatar to learn and practice. So far, the researchers have found that participants enjoy using the technology to learn new skills and report few negative effects such as visual disturbance or anxiety (*Annual Review of Cybertherapy and Telemedicine*, Vol. 14, 2016 (https://uwe-repository.worktribe.com/output/913467/the-potential-of-virtual-reality-technologies-

to-support-people-with-an-autism-condition-a-case-study-of-acceptance-presence-and-negative-effects)).

Such technology offers a huge opportunity for overcoming many of the access and transportation issues that individuals with disabilities face, says Leonard Abbeduto, PhD, the director of the University of California, Davis's MIND Institute. Abbeduto and his team have developed a language intervention for children with fragile X syndrome delivered entirely through videoconferencing (*Developmental Neurorehabilitation*, Vol. 21, No. 1, 2018 (https://www.ncbi.nlm.nih.gov/pubmed/28956679)).

"The sorts of things we could think about would be doing job coaching at a distance for adults in the workplace, or doing check-ins with people at home to give advice about independent living, or we could use virtual reality to train people at a distance," Abbeduto says. "Technology holds so much potential for reaching more people than we can do in one-on-one or group therapies. We need to think creatively."

Meanwhile, a growing number of universities are offering programs for young adults with developmental disabilities. At the University of North Carolina, for example, the TEACCH School Transition to Employment and Postsecondary Education program helps students with autism with a high school degree transition to jobs or postsecondary education with skills instruction delivered at community colleges throughout the state. At the University of Iowa, students with intellectual, cognitive or learning disabilities can receive support through the Realizing Educational and Career Hopes program, which offers vocational counseling as well as support for inclusion in campus life. However, there is an urgent need for more capacity, say advocates in the field. According to the Bureau of Labor Statistics (https://www.bls.gov/news.release/pdf/disabl.pdf) , only 19.3% of people with disabilities were employed in 2019, compared with 66.3% of people without disabilities.

For Sung and her colleagues, the next step is a grant-funded expansion of their program to use virtual reality to train workers with disabilities on how to address nuanced social situations beyond interacting with co-workers, such as

dealing with customers. Every success in training shows hiring managers and other employees that people with disabilities are capable, Sung says. She cites a case of a young man with autism in the program who was very quiet. The staffers he worked with assumed he couldn't understand the work instructions because he preferred not to engage. In fact, he was incredibly efficient at the work and finished tasks in half the time of other employees. The department ended up creating a position for the young man after his time in Spartan Project SEARCH ended.

"He still works there," Sung says. "He changed this department's perception of people with disabilities."

Further reading

Building Skills, Confidence, and Wellness: Psychosocial Effects of Soft Skills Training for Young Adults With Autism (https://pubmed.ncbi.nlm.nih.gov/30879257/)
Connor, A., et al., *Journal of Autism and Developmental Disorders*, 2020

Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives
Drainoni, M.L., et al. *Journal of Disability Policy Studies*, 2006

National Health Surveillance of Adults With Disabilities, Adults With Intellectual and Developmental Disabilities, and Adults With No Disabilities
Havercamp, S.M., & Scott, H.M., *Disability and Health Journal*, 2015

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