

# Autism, Identity and Employment

## *Transcending the Obstacles of the Working World*

artwork: "COMING OUT" BY DONNA WILLIAMS



BY VALERIE PARADIZ, PH.D.

In the winter of 2007, I was on the cusp of a meaningful point in my professional career as an educator. I had moved with my son to a new town in order to begin a job at a large agency that supported individuals with disabilities.

My role was to direct a new training institute as the organization experienced a dramatic expansion of services for people with autism. Ground was being broken for new buildings to be built across the beautiful, rural campus, and there was an atmosphere of exuberance. During my job interview, the CEO was enthusiastic and persuasive. "You are the top person on our list," he told me, adding that having someone with Asperger's syndrome (AS) on staff would be an asset. The chief of staff was also present at the interview. We discussed my responsibilities and felt genuine regard for one another's work. Our philosophies of education were kindred. She was leading a significant research project on nonbehavioral approaches to education and therapy that made me proud to become a member of their organization. A few days later, we negotiated my salary and start date. It felt as if the stars had aligned themselves for doing useful work in an educationally progressive environment.

However, as my first day of work approached, the chief of staff seemed unavailable to my phone calls and e-mails, and I wasn't receiving the guidance and information I had been promised from the human resources office. I became concerned that the agency was changing its mind about hiring me, so I requested

a meeting. It took them several weeks to book a date. When we finally did come together, the CEO was uncomfortably gregarious and difficult to read. However, one thing that was as clear as day was the moment he said that it was problematic for his organization to hire someone with autism. He added that having an individual on the spectrum working with other staff at the agency might undermine their professionalism. Co-workers might feel that whatever the individual with autism might say would be taken as the God-given truth. He ended the meeting informing me that I might be hired part time on contract, probably without benefits, and that it was uncertain if and when I would begin the job.

I drove home, stupefied and hurt. I fretted about how I would pay the bills, not to mention the relocation costs I had incurred to make the move. I hadn't left Woodstock, New York, where I had lived for over 20 years and raised my son, for a part-time job with no benefits. According to the Americans with Disabilities Act (ADA), the actions of this agency toward me were discriminatory and illegal. In fact, during my job interview, when the CEO spoke about my being on the spectrum, he had crossed a legal line. But at the time, I was not as educated about ADA as I am today. I was still adjusting to my recent diagnosis at age 40, and did not know that a prospective employer is not permitted to ask about one's disability during a job interview. Nor was it required of me to reveal my autism, but I had done so, knowing that the chief of staff was aware of my role as an advocate and public speaker.

## Learning about Workplace Discrimination

I turned to good friends on the spectrum for insight, most of them working professionals like me, and was shocked to find

that nearly all of them had experienced some form of employment discrimination. With time, I began to see there was a common thread to our stories. Though we were capable of the work we did, and had the education and experience to show for it, once it was known that we had AS, the image our prospective employers, bosses or colleagues had of us suddenly changed. Our expertise seemed to vanish, and the only identifying factor about us in their eyes was some kind of negative association with disability.

"Don't you hate when that happens?" an African-American friend said to me when I shared my story with her. Clearly, she was a seasoned student of discrimination in the workplace and, in spite of the Civil Rights Act, had endured the same

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phenomenon due to her racial status. Such parallels with other minority groups can be instructive in understanding the challenges individuals with disabilities face in the working community. They might also hold a key for charting the advocacy work that lies before us.

Dr. Irma Ozer, a retired employment discrimination attorney who has AS, feels that "despite the ADA, the general view of disability has been negative." Dr. Ozer is currently writing a book entitled *Asperger's Syndrome and the Public Consciousness*, which views AS through the lenses of personal accounts, findings of psychiatrists, media coverage, and legal and employment issues.

## Employers and Employees Succeeding Together

In January of this year, for the first time in history, the U.S. Department of Labor published employment data on people with disabilities ([www.dol.gov/odep/](http://www.dol.gov/odep/)). The report indicated what many have assumed: Unemployment is more common among people with disabilities than it is among those who are not disabled. In January 2009, the unemployment rate for people with disabilities was in the double digits, at 13.2 percent, compared to 8.3 percent for those who are not disabled.

But there is heartening news too. In the same report by the Department of Labor, the Office of Disability Employment discovered that large businesses that take the initiative in hiring individuals with

disabilities tend to hire even more of us once they see that we are productive contributors and assets to their companies. When employers have the opportunity to discover that people with disabilities have abilities, they are more likely to transcend the unfortunate obstacles of misinformation or prejudice.

Stephanie Creary, a researcher in the Department of Organizational Behavior at Harvard University's School of Business, says that when identity markers such as disability, race or gender affect a person's ability to become employed, we are perceiving "a larger societal issue that has more to do with what our comfort levels are with people who are unlike us." Creary

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## feature / Perspectives from Working Professionals

also works for the Conference Board, a nonprofit organization located in New York City, which seeks to create and disseminate knowledge about management and the marketplace in order to help businesses strengthen their performance while serving society. Finding solutions to the issue of employment discrimination, Creary feels, is a two-way street. Employers and individuals with disabilities need to have forums, such as the conferences and webcasts her organization sponsors, where

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they can learn about each other's needs and priorities. For example, many employers express concern that hiring individuals with disabilities will create an added cost to their businesses. However, the Department of Labor's report also found that accommodating people with disabilities in the workplace costs about the same as it does for nondisabled employees.

"I sometimes have to ask for accommodations," says Dr. Rachele Jones, speaking of her job at Premier High School of Texas, located in Lubbock. Rachele holds a doctorate in special education and has Asperger's syndrome. In her job as a special education teacher, she must be able to communicate effectively with co-workers. Before she sends important e-mails out to colleagues, Rachele has a "go-to" person in the office who reviews her first drafts before they're sent out. "This helps me fit better into office politics," she says.

### To Disclose—or Not

During an interview for her current job, Rachele felt it was necessary to reveal her

disability. She did what Stephen Shore, assistant professor of education at Adelphi University and an individual diagnosed with autism, calls "partial disclosure." Rachele told the interviewing committee she had a "communication disability" and that she had strategies for coping with it. It was a risk she felt she had to take. In her previous position as director of special education at Lubbock Christian University, she had been laid off from her full-time position and demoted to an adjunct role

for reasons that were not clear. In her new job, she did not want possible misunderstandings about her communication style to affect her employability. Once she was formally hired, she disclosed her diagnosis fully. This process gave her confidence about making requests for accommodations at work and has won the respect and admiration of co-workers. "I'm really lucky," she says about her colleagues. "They are really, really good people." Not only is Rachele accepted for her communication differences, she is also valued and needed for her expertise. This is the first time on the job, she says, "where people actually call me 'Dr. Jones.'"

Another person I interviewed for this story asked to remain anonymous. A software engineer working in the Boston area, he chose not to reveal his identity out of concern for losing his job, were his employer to find out that he has AS. When I asked him about his thoughts on disability, identity and employment, he turned to the analogy of race as a means of uncovering important issues. "It's like

the African-American news commentator who only gets assignments about Martin Luther King Day, in spite of the fact that his background is in economics or political analysis." He views his own experience of social and sensory difference in the corporate workplace in such cultural terms. For him, being on the spectrum at work is like being "a member of an almost invisible minority in a host culture or society." In our depressed economy, with corporations eliminating thousands of jobs each week, his very livelihood is at stake on a daily basis. Disclosing his disability in such a setting would be a liability.

I also spoke with Karl Wittig, a retired engineer who worked in research and development for a large electronics corporation for 25 years. Karl's work was integral to the development of high-definition video, something nearly every citizen in the country benefits from in some fashion today. "When I started out on the job, I felt so at home," Karl says of his former workplace. "It was a kind of hold-out for eccentric scientists," a place where "there was nothing unusual about people having personal peculiarities." Karl never self-disclosed to supervisors. To begin with, he hadn't known about the autism spectrum for most of his working life. At age 44, only a few years before his retirement, he was diagnosed with AS. "I did tell a couple of co-workers," he says, humorously adding, "but they were people from the former Soviet Union who knew how to keep a secret."

At the time of Karl's diagnosis, new management had come in that was more conscious about business than about research and development. "I felt my personal way of being didn't fit in the way it had in the past," he says. It's possible that because of his social eccentricity he

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was fine. She was more than fine; she was great. When I picked her up, she explained to me that one of her new friends said hello by beeping his machine, moving his head back and forth, and smiling. (In reality, her nonverbal friend would get so excited when he saw her that his oxygen machine would beep.) As Lindsay spent more time in the classroom, she would come home to explain that some of her friends would “freak out” (have tantrums) sometimes, but that was because they needed to learn to “use their words.”

I know that Lindsay's exposure to these friends will stay with her for many years. She accepts these children as her friends, as she should. She understands that some kids have legs that don't work and others have ears that don't hear. She understands that some kids “freak out” when there is too much noise, some need to be reminded to use their words, some like to twirl toys because it helps them calm down, and others need extra help, like having an adult with them when they

are on the playground. She also understands that some people communicate through sign language, which she has learned to do quite well.

### Dis-integration

When Lindsay attends kindergarten next year, some of these same students will be in her class and others will be in a self-contained class. Thanks to this integrated school, with its fantastic staff, she will have the advantage of having learned from these children, as they have learned from her. I wonder, though, if some of her friends are enrolled in self-contained classes, how I will explain to Lindsay why they are no longer in her class. How will I explain this “dis-integration”? She and her friends, disabled or not, will be transitioned (or de-transitioned) into classes that may not include the children she has befriended who have taught her so many valuable things. Explaining this may even prove to be more difficult than discussing why some kids do not

communicate the way that she does. Right now, these friends are part of her classroom; they are part of her school. I wonder: When they all get to third grade, will these same children go from being “the friends in my class” to “those kids that go to specials with my class?”

Having had this experience with my daughter strengthens my belief that all children, regardless of their ability levels, can benefit from some type of integration. Recently, I was able to participate in circle time with Lindsay and her friends. As she sat in my lap, I watched one of the students who is not as verbal as Lindsay imitate the way that my daughter was singing the greeting song. Need I say more?

### About the School

Whispering Pines is a private preschool with three locations in Upstate New York that provides educational and therapy services to young children with special needs, as well as a preschool early learning experience for typical children. The program encourages building relationships for growth in social-emotional, movement, language and cognitive areas. For more information, visit [www.wppkids.com](http://www.wppkids.com).

### About the Author MICHELLE DEFELICE HAVERLY

*Michelle DeFelice Haverly is a special educator and mother of two who has worked with individuals on the autism spectrum for over 10 years. She is currently working as a consultant to provide in-service training to professionals working with all types of students with special needs.*