

# Special Report

## Autism in the Health Care and Community Setting

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**IBCCES**

**International Board of Credentialing  
and Continuing Education Standards**

*Recognizing Professionals Dedicated to Promoting Quality Care*

“Training will help destigmatize the autism label and help people have more meaningful and satisfactory lives.”

Dr. Bruce Wexler

▶ 1 in 68 U.S. children who are eight years of age have autism

▶ Interactions between health care providers and these patients raise important public health questions

▶ Autism-friendly centers can improve the health of this growing population

## Executive Summary

When a patient with autism spectrum disorder arrives in an emergency room, dentist’s office or other health care setting the challenges for them and their providers can be substantial.

Bright lights, loud noises, and the prodding of strangers can easily trigger anxiety, even to the point of crisis. And it’s happening more and more often.

Autism is the fastest-growing developmental disorder in the country. About 1 in 68 U.S. children eight years of age have autism, according to The Centers for Disease Control and Prevention. Roughly two million Americans carry a diagnosis of Autism Spectrum Disorder (ASD).

Because children and adults with autism have a higher comorbidity rate of other chronic diseases than the general population, they will spend more time in health clinics and their caregivers will spend four to six times more on their medical expenses.

This paper is not about the causes of autism, the advantages of early intervention or new drugs on the horizon. While those are critical issues, the interactions between health care providers and patients with autism are raising important public health questions.

Roughly 77 percent of primary care physicians, nurses and other health professionals across the country who participated in a 2015 Kaiser Permanente study rated their ability to care for someone with autism as poor or fair.

Meanwhile, people with autism and their caregivers routinely report negative experiences with the health system and concerns about the quality of care they receive.

Health care leaders now have the power to create autism-friendly settings and improve the health of that growing population. Professional training and certification is the single most important step in making a commitment to high quality care for people with developmental disabilities. It also makes good business sense, boosting the health center’s competitive edge by improving patient safety, reducing legal liability and decreasing stress for providers and patients.

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“They didn’t treat her the way they should have treated her and there was a huge tantrum.”

Dr. Pamela Rollins

► Overwhelmed in public settings

► Confusion can lead to ritualistic and aggressive behavior

► Unprecedented challenges around autism

## Caring for Patients with Autism

### Why Autism Can be Challenging

Autism is a neurodevelopmental disorder with a wide range of symptoms and impairment levels ranging from mild to severe. No two people with autism will exhibit the same behavioral characteristics.

While researchers don’t know the exact cause, it is generally thought to be related to brain structure abnormalities.

Like everyone, people with autism use their five senses to engage their environment. But they can’t process it as quickly. Therefore, they can become overwhelmed in public settings - like an emergency room or dentist’s office - by the sensory overload and changes to their routine.

They can become withdrawn, uncommunicative and anxious as they struggle with social interaction and misread nonverbal clues. The confusion and stress can lead to compulsive or ritualistic behavior, aggression, or even a complete melt down.

Because the autism spectrum manifests in many ways, professionals might think that if they know one person with autism they understand the disorder, said Dr. Pamela Rollins, an autism expert. She is working with a team of robotics designers on an artificially intelligent robot to interact with children who have ASD.

“There are unprecedented challenges around autism,” Rollins said. “If you’ve seen one autistic person, you’ve only seen one person with autism.”

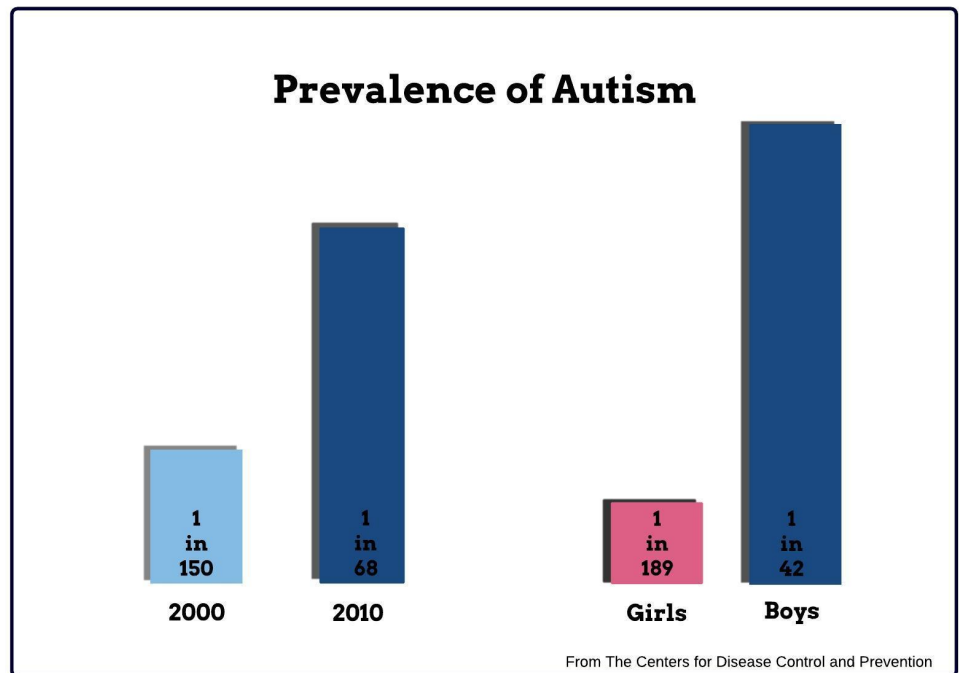
For example, Rollins described an experience involving a girl with high functioning autism who went to see a dentist. Because the girl presented relatively mild symptoms, the dentist and staff didn’t appreciate the nuances of her disorder.

“They didn’t treat her the way they should have treated her and there was a huge tantrum,” Rollins said, noting it took the girl a long time to recover from the experience. “They didn’t treat her with the respect they needed to treat her with.”

► Fastest growing developmental disorder

► First generation of people diagnosed now entering middle age

► Comorbidity is common



### Prevalence, Comorbidity and Aging

Autism is the fastest-growing developmental disorder in the U.S., according to Autism Speaks, an advocacy group that sponsors autism research, awareness and outreach activities.<sup>1</sup>

As of 2010, the CDC estimates that 1 in 68 children in the U.S. have the disorder. That's a rough average of both sexes, since autism is almost five times more common among boys (1 in 42) than girls (1 in 189).<sup>2</sup>

This reflects about a 120 percent increase between 2000 and 2010, a trend that may be influenced by changes in diagnostic criteria. While little is known about adults with autism, the first generation of people diagnosed with autism in childhood are now reaching middle age. The CDC estimates that more than 1 percent of the total U.S. population has autism, but that doesn't include people who have been misdiagnosed, never formally diagnosed or who don't receive services.<sup>3</sup>

Autism takes its toll in other ways, too, due to the likelihood of comorbidity. Adults with autism are more than twice as likely as those without it to have depression, anxiety or bipolar disorder, and to attempt suicide, according to the Kaiser Permanente health study.<sup>4</sup>

They are also more prone to have diabetes, gastrointestinal disorders, epilepsy, sleep disorders, heart disease and high blood pressure.<sup>5</sup>

## Interplay Between Patients with Autism and Health Care Providers

Health care providers who are unprepared to address the special needs of the autistic population in emergency rooms and other patient settings can easily get tripped up.

It has become clear that providers need more education in this area. A Kaiser Permanente survey of nearly 1,000 doctors, nurses and social workers across the country showed that 77 percent of them rated their ability to care for someone with autism as poor or fair.<sup>6</sup> Many providers expressed interest in learning about people with autism and how to better care for them.

“These physicians revealed that they don't know what to do when faced with an individual with autism,” according to the Kaiser study, which was presented at the May 2015 International Meeting for Autism Research.

“Some of them said that they feel uncomfortable around people with the disorder.”

That's not surprising, said Dr. Stephen Shore, an international autism expert, best-selling author, and board member of International Board of Credentialing and Continuing Education Standards (IBCCES). Shore was diagnosed with the disorder when he was

two-and-a-half years old.

“With a little education they can recognize it when they see it,” Shore said. “Otherwise, it's a complete mystery. They don't know what to do. It's like you're speaking another language.”

The lack of autism awareness in health care settings and providers' inability to appropriately assess these patients doesn't bode well for delivering effective care to this population.<sup>7</sup>

Some autistic patients have hesitated to disclose their diagnosis to providers out of fear of discrimination, according to interviews with roughly three dozen adults with autism and two dozen of their caregivers.<sup>8</sup> Almost all of them urged providers to get training on autism.

“I hope training will help destigmatize the autism spectrum disorder label and we can do something to help people have more meaningful and satisfactory lives,” said Dr. Bruce Wexler, professor emeritus of psychiatry at Yale School of Medicine.

“We can train health care providers so they are more comfortable themselves, which will make for more humane interactions,” Wexler said.

"Physicians revealed that they don't know what to do when faced with an individual with autism."

Kaiser  
Permanente  
Study

- ▶ DSM-5 created autism spectrum disorder
- ▶ New ICD-10 insurance codes take effect Oct. 1
- ▶ DSM-5 lists both the old and new codes

# DSM-5



Diagnosis

## **DSM-5 and its Relationship to Autism**

To improve the accuracy of diagnosing of people with autism-related disorders, changes were made to the Diagnostic and Statistical Manual of Mental Disorders, culminating in the release of the DSM-5 in 2013.

The DSM-5 created the autism spectrum disorder, combining what previously had been four separate disorders, including Asperger's, into one broad category with different levels of severity.<sup>9</sup>

The upcoming Oct. 1, 2015 deadline for the next DSM-5 revision specifically targets coding changes for insurance claims. Use of these new codes, known as the International Classification of Diseases, 10th Revision (or ICD-10), will avoid delays in reimbursement for clinical services.

According to the American Psychiatric Association, most practitioners won't need additional training since the DSM-5 manual lists both the old code and the new code, making a smooth transition to assign valid, HIPAA-compliant ICD-10 codes to psychiatric diagnoses. But it may behoove clinicians to train administrators, information technology specialists and coding professionals. .



## **Business Opportunities in Serving this Treatment Market**

### **The Economics of Training Health Professionals**

Training health care providers can be the single most important step in showing a commitment to high quality care for people with autism and their caregivers.

With professional and convenient online training and certification programs like IBCCES, there now exists an opportunity to do good for people with autism and generate profits, too. Specialized training boosts the health facility's reputation and credibility, which in turn grows the customer base and sets it apart from competitors, a big advantage in a crowded marketplace.

"It's something we jumped on," said Jacksonville Speech and Hearing Center President Michael Howland, who hired IBCCES to train and certify his entire workforce, including front office staff. "Because of the growing incidence of autism and the real need that is out there."<sup>12</sup>

In fact, the physical and emotional hardships for children and adults with autism generate significant economic costs.

### **The Unmet Health Care Needs of People with Autism**

A comparison of health care experiences shows that children and adults with autism are more likely to have unmet health care needs and that adults with autism use the emergency room twice as often as those without the disorder.<sup>10</sup>

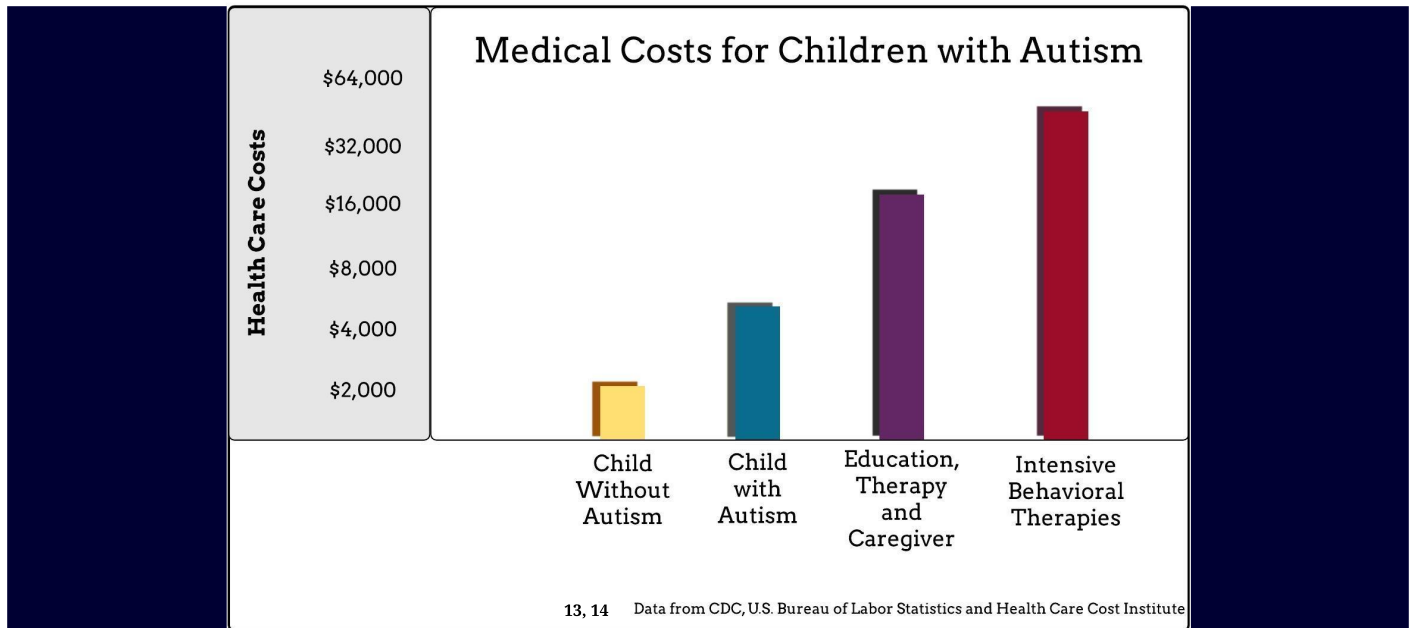
This study – the first to obtain input from adults with autism – also showed disparities in patient-provider communication, lower patient self-efficacy, and lower usage of preventive services.

Parents are desperate to find qualified health care providers who are sensitive to autism and know how to interact with their children.

Yet these services and providers are woefully inadequate, according to advocates for people with autism.

"Currently there are waiting lists to access autism services all across the United States, largely due to a dearth of experienced providers," according to the Center for Autism Research, a research institute at the Children's Hospital of Philadelphia.<sup>11</sup>





Diverse opportunities exist for a wide range of health issues commonly related to autism, especially in the fields of neurology, gastroenterology, cardiology, and diabetes. That doesn't include treatment options for autism's core symptoms, which often require speech, language, occupational, and physical therapy.

"While research on causes and cures for autism is vital and will make for a better future, services for those who live with the disorder are essential today," said Anne S. Holmes, chairperson of the Autism Society's Panel of Professional Advisors and IBCCES board member.

"Among the most pressing concerns is the lack of attention given to the needs of these children once they become adults and continue to require support and specialized services."

## Patient Safety – Reducing Liability

Hospitals, health providers and therapists have a professional duty to provide a high standard of care for their patients. But providers who don't understand the unique nature of people with autism may fall short of that goal.

Patient incident reports bear that out. When it comes to patient safety, the potential for serious harm is three times greater for patients with ASD than with the general population, according to the Pennsylvania Patient Safety Authority's study of patient incident reports over a 10-year period.<sup>15</sup>

The Pennsylvania Patient Safety Authority reviews scientific evidence to help health care systems improve safety practices and the delivery of care. The Authority found that patient safety standards tend to overlook patients with autism.

It concluded that the top risk reduction strategy is to train all staff - healthcare providers and allied health professionals - on the characteristics of ASD, the challenges faced by patients with ASD and their families in the acute care setting, and methods to improve these interactions. Training is another word for prevention and it can go far to reduce medical liability.

"Anything to reduce that is good," said Shore. "Thousands of dollars are spent on litigation and that's money that could have been spent on helping kids."

### **Compassion: The Autism-Friendly Medical Model**

An Internet search of the phrase autism-friendly displays a long list of schools, restaurants, cruise ships, theaters, and workplaces. But the list contains few hospital emergency rooms or community health settings. This is unfortunate. Creating an autism-friendly environment, or Certified Autism Center, means patients with autism will feel welcomed and they'll be calmer and better able to relate to others.

This is huge relief for parents and caretakers.

"For patients with autism and for their families or caregivers, this can be a nightmare experience," said Dr. Olga Goldfarb, director of the Autism Program at Capital Health's Institute for Neurosciences. "They have problems interacting and approaching other people. It can be very scary for those with autism."<sup>16</sup>

## **How to Improve the Health Outcome and Experience for Patients with Autism:**

- ▶ **Avoid triggering sensory overload. Some people with autism may be hypersensitive to changes in sight, touch, smell, taste, and sound.**
- ▶ **Usher patients to a quiet, more dimly-lit room with less equipment**
- ▶ **Treat the patient in a manner that is as minimally disruptive as possible.**
- ▶ **Communicate with the caregiver or family member to get an effective medical history.**
- ▶ **Stick to questions that require only a "yes" or "no" answer.**
- ▶ **Let patients see and touch instruments and materials that will be placed on their bodies.**
- ▶ **Be direct and factual: Realize that your body language or social cues may not be picked up.**

Goldfarb works at one of the country's two autism-friendly emergency rooms: the pediatric emergency room at Capital Health Medical Center in Hopewell Township, N.J., which opened in October, 2014. The only other autism-friendly emergency room in the country is at Columbia Memorial Hospital in Hudson, N.Y., which also opened last year.

### **Why Staff Certification Through IBCCES is the Best Solution**

Reputable online certificate programs can deliver credentialed practical skills in a convenient and cost-effective manner, saving employees and employers the time and expense of traditional university classes.

The International Board of Credentialing and Continuing Education Standards (IBCCES) formed in 2001 for that very reason. With its quality education partners and high standards, IBCCES ensures that those it certifies provide the highest quality of care for people with autism.<sup>17</sup>

IBCCES is the leading credentialing organization for professionals in the field of autism and others who work with people with autism. Students achieve certification only after passing a rigorous exam administered by an online proctoring system.

The exam is developed by a highly credentialed board of content experts and it's independently verified, removing conflict of interest and assuring credibility.

### **IBCCES Offers Three Certification Options:**

#### **► Certified Autism Specialist**

**Applicants with a master's degree in special education or related field, plus two years of experience with special needs students and 14 continuing education hours.**

#### **► Autism Certificate**

**Applicants who work in a setting where they are likely to have contact with people with autism. They don't need a master's degree, but are required to have 14 continuing education hours.**

#### **► Certified Autism Center**

**Facilities ranging from hospitals, doctor's offices and speech and physical therapy clinics to Boys and Girls Clubs and tutoring centers with highly trained employees who are fully equipped to serve people with developmental disorders.**

**► The Autism Certificate fee is \$295.**

**► The Certified Autism Specialist fee is \$495.**

**► Fees don't include training or continuing education courses, which are available through IBCCES' educational partners.**

▶ IBCCES is more affordable and faster than college courses or a degree

▶ Certification proves an employee is qualified to work with people with autism

▶ Parents are searching for providers who understand autism

It offers a great way to meet health professionals where they are, so they can take advanced or specialized courses of study without completing college prerequisites.

“IBCCES is filling a real need, a gap,” said Shore. “It’s educating people already in the field who do not have time or who need the credits. It provides a nice, streamlined way of getting it. It will make them so much more efficient in working with people on the autism spectrum.”

Once 80 percent of the staff at a center is trained and certified, the center will be eligible to become a Certified Autism Center. The designation will differentiate the center from its competition, position it for explosive growth and improve the way it cares for the fastest growing population of developmental disorders. The Autism Certificate is significantly more affordable and faster than a series of college courses, or a degree that can cost thousands of dollars.

A few organizations make other options available. Autism Training Solutions offers a library of videos, reports, and studies for continuing education and self-study.<sup>18</sup>

A Pennsylvania emergency room doctor and three professors developed the “Assess Communicate Treat for Autism (ACT)” training manual and DVD to help emergency room clinicians deal more effectively with patients on the autism spectrum.<sup>19</sup> But neither of these resources offer certification that proves the employee is truly qualified to work with people with autism.

Until more recently, “the training has not been widely available or distributed,” said Wexler, who is also an IBCCES board member.

### **Return on Investment**

Employees are health care systems’ greatest asset and key to their competitive edge. Investing in autism training will attract new customers, increase referrals, raise productivity, improve patient safety, and reduce liability.

It’s not hard to justify the costs. From a market perspective parents are desperately searching for health care practitioners who understand autism.

▶ Certified Autism Centers stand above the competition

▶ Autism training keeps health centers out of court

▶ Autism certification shows a commitment to high quality care

“Who’s the good doctor, who’s the good dentist who will understand our children so we don’t have bad experiences,” Rollins said.

Autism certification will build the facility’s reputation and the community’s confidence in its ability to provide the best care for people with developmental disabilities.

Becoming a Certified Autism Center will help facilities differentiate themselves from their competitors and position them for the growth that’s inevitable with this fast growing population of developmental disorders.

From a human resources perspective, upgrading employee skills makes good business sense, as it has been proven to attract and keep good employees, reduce turnover, and boost job satisfaction.

From a medical liability perspective, autism training can help keep health centers and their staff out of court and save hundreds of thousands of dollars in malpractice costs. As previously noted, the Pennsylvania Patient Safety Authority pointed to autism training as the top risk reduction strategy for health facilities in that state. And for good reason: The average award for healthcare mistakes in the outpatient setting is roughly \$290,000, according to a four-year study of legal settlements and jury awards published in the Journal of the American Medical Association.<sup>20</sup>

## **Conclusion**

It is now clear that professional training and certification can be the single most important step in showing a commitment to high quality care for people with autism and their caregivers.

For a population with a history of difficult health care experiences, training and certification will go far to eliminate disparities and improve access to care.

Considering medical liability, the growing market of people seeking providers who understand autism and many providers’ discomfort with the topic, health care leaders are confronted with a powerful argument to get their entire staff trained.

## **Authors**

### **Caren Burmeister**

After 21 years in newspaper journalism, Burmeister left the industry to pursue her own business and freelance writing career. She has a bachelor's degree with a double major in journalism and sociology from the University of Miami.

### **Dr. Bruce E. Wexler, M.D., Neuroscientist at Yale School of Medicine, leading autism researcher**

New Haven, Conn.

Wexler is professor emeritus of psychiatry and senior research scientist at Yale School of Medicine and director of the Neurocognitive Research Laboratory at the Connecticut Mental Health Center.

Wexler's 35 years of research has helped advance the understanding of brain plasticity. His proprietary research led to the development of Activate, a cognition assessment and cross-training program for children with ADHD and other disorders.

He has published more than 100 scientific papers and articles. His book, *Brain and Culture: Neurobiology, Ideology, and Social Change*, has received international attention.

Wexler has received several prestigious research grants, including a \$4 million Director's Office Grant from the National Institutes of Health for "paradigm changing medical research."

### **Anne S. Holmes, M.S., CCC, BCBA, CAS, Board Directors of Autism Society of America**

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A Board Certified Behavior Analyst with a master's degree in speech pathology and 35 years' experience in the field of autism, Holmes is the chairperson of the Autism Society's Panel of Professional Advisors.

Formerly the chief clinical officer of Eden Autism Services, where she oversaw standards of care, staff development, and student outcomes, Holmes is now the vice president of KDH Enterprisers, a Division of Autism Spectrum Disorders Consulting Services in Robbinsville, N.J. She serves as a primary consultant to families, schools and agencies across the nation and has published numerous articles on autism.



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Rollins is an associate professor in the School of Behavior and Brain Sciences at The University of Texas at Dallas Callier Center for Communication Disorders. Rollins has dedicated more than 30 years to understanding, identifying and treating children with Autism Spectrum Disorder, culminating in the book, *Facilitating Early Communication, Language and Social Skills: From Theory to Practice*. In 1995, Rollins received the American Speech-Language-Hearing Foundation's New Investigators Research Grant. She is also a four-time gubernatorial appointee to the Texas Council on Autism & Pervasive Developmental Disorders.

Rollins is presently working with a team of experts and robotics designers on *Robots4Autism*, a humanoid robot that helps elementary and middle-school-age children understand emotions and expressions and the appropriate social behavior and responses.

**Dr. Stephen Shore, Ed.D., CAS, Professor at Adelphi University, best selling author, International speaker, autism expert**

New York City, N.Y.

A professor at Adelphi University and best-selling author, Dr. Shore is one of the world's most respected speakers and voices for self-advocacy. Diagnosed with autism at two-and-a-half years of age, the support he received from his parents, teachers, and wife helped launch his career in research. Shore is the author of *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*; *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*; and the critically acclaimed *Understanding Autism for Dummies*. He also created the DVD *Living Along the Autism Spectrum: What it Means to have Autism or Asperger's Syndrome*.

He is also a former board member of the Autism Society and president emeritus of the Asperger's Association of New England.



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