

Meeting the Global Challenge of Autism Training

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Abstract

Autism awareness, diagnosis and treatment programs are growing exponentially in countries with developed economies, even to the extent they may be taken for granted.

However, these resources barely exist in most developing countries and there is a dire need for trained professionals to provide autism services.

The World Health Organization reached this conclusion in its September 2013 meeting report on autism spectrum disorders, identifying the scarcity of trained and experienced child health specialists as a major barrier to improving access to care.

Two years ago, with the support of more than 60 countries, the 67th World Health Assembly adopted a resolution seeking a global effort to "scale up care" for people with autism spectrum disorders.

The resolution came as professional training and other autism resources were just starting to gain momentum in a few isolated regions. But, as this paper will show, the journey has hardly begun. For many families, these resources are so costly and so scarce they are virtually unavailable.

Dedicated and qualified professionals are key to helping children with autism reach their fullest potential. Without them, these children will struggle to participate in their communities and lead meaningful lives.

As one clinical psychologist, Dr. Neophytos Papaneophytou, put it, "Children on the autism spectrum may have special needs, but they may also have special abilities. It's time to stop pitying special needs children and commit ourselves to discovering their potential."

This paper will explore some of the reasons why developing countries face challenges in dealing with autism, several autism programs that have made great strides and why quality training and credentials are necessary to transform the autism landscape.

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Autism and its Universal Nature

Autism is a complex neurodevelopmental disorder with a wide range of symptoms and impairment levels ranging from mild to severe.¹ It is often characterized by repetitive behaviors and diminished verbal communication and social interaction.

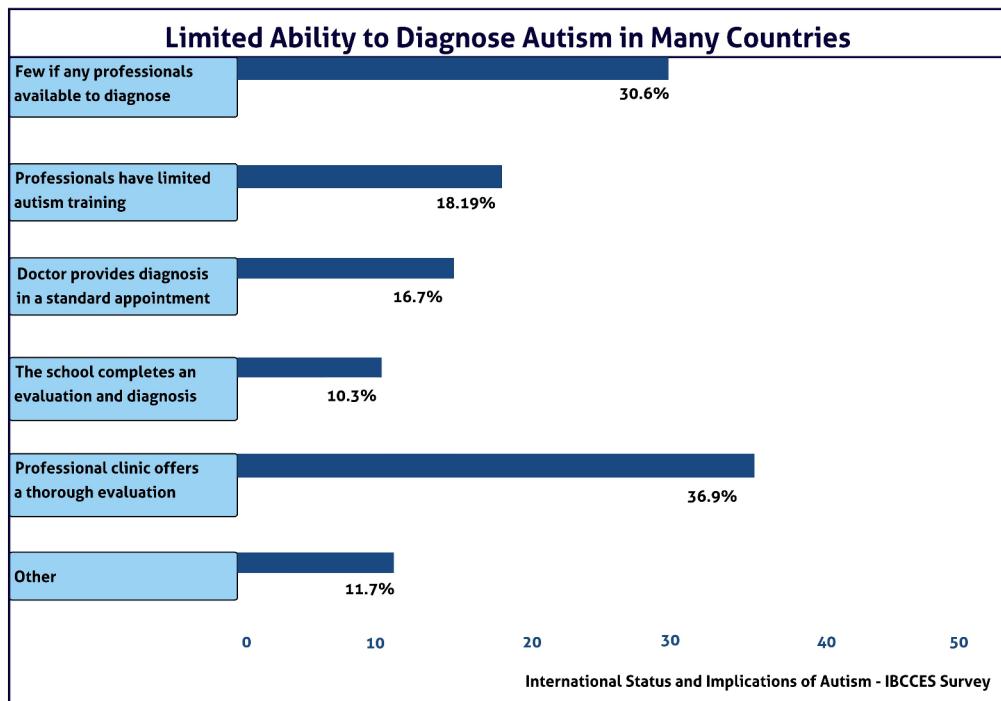
No two people diagnosed with Autism Spectrum Disorder (ASD) will exhibit the same behavioral characteristics. While researchers don't know the exact cause, it's generally thought to be related to a difference in brain structure.

The World Health Organization estimates that 1 in 160 children around the world are on the autism spectrum.² Studies in Asia, Europe, and North America have identified people with autism at a rate of 1 to 2 percent, according to the Centers for Disease Control and Prevention.³

However, that number represents a rough average, since detection and reporting vary substantially from country to country and observation and examination is more common in developed countries.

In the last five decades, epidemiological studies have shown the prevalence of autism is increasing globally due to greater awareness, expansion of diagnostic tools and criteria, and enhanced reporting, according to the World Health Organization.⁴

In the U.S., where autism screening is encouraged at an early age, the figure is said to be 1 in 68 children.⁵



Challenges in Access to Care

Autism experts around the globe identified several common barriers to helping children with autism. Those obstacles include a lack of trained professionals and detection services, fear of stigmatization, and the cost of autism services.

Dr. Stephen Shore, an autism expert and special education professor at Adelphi University in New York, reports a shortage of autism resources, even in developing nations with a good record of human services.

"There's such a lack of knowledge of autism," Shore said. "It affects a whole swath of people and nations."

In fact, the scarcity of trained and experienced child health specialists is a major barrier to improving access to care, according to a study published in the Archives of Disease in Childhood, "Improving Access to Care for Children

with Mental Disorders: A Global Perspective."⁶

Similar results were found in a survey, "The International Status and Implications of Autism," published by the International Board of Credentialing and Continuing Education Standards (IBCCES).⁷ Nearly 46 percent of the professionals surveyed said there is a lack of resources and trained staff in their region. Another 27 percent said people with autism and their families had to travel one to three hours, or to another country, to receive autism services.

Shore, who was diagnosed with autism as a toddler, said the process of addressing the issue starts with awareness, then progresses to acceptance and ultimately to appreciation.

"When you work with people with autism you find they have great potential," Shore said. "You learn that many people with autism can do things others can't."

Diagnosis Must Come First

It is generally well accepted that early intervention can produce great intellectual and social benefits and reduce the family's costs.

"The earlier children are identified, the earlier they are able to receive early intervention services," according to research by Autism Speaks.⁸ "Evidence-based early intervention services have been shown to reduce the core symptoms of autism, improve IQ and daily functioning."

In the U.S., the American Academy of Pediatrics recommends that infants be screened for autism during their preventative care visits from ages 9 -to -30 months.⁹

In many developing countries this is where the problem begins. According to the global survey by IBCCES, and experts interviewed for this paper, many governments provide no autism detection services whatsoever and many parents are often too ashamed to seek a diagnosis.

Helen Oshikoya, founder of Nobelova Gradani PsychoEducational Services in Lagos, Nigeria, reports that she started the center's early intervention initiative four years ago due to the utter lack of medical professionals with training to perform developmental surveillance in schools and hospitals.

Without such services, "most children will not be detected in time and will not have the opportunity for early intervention services," Oshikoya said.

The culture in Singapore presents another problem with early detection, said Raymond Marcel Semaun, head of St. Andrew's Adult Autism Services and St. Andrew's Autism Center in Singapore.

When a child is born in Singapore, their developmental milestones are recorded in a medical booklet that follows him or her through life. If there is any indication of autism it's likely to be picked up there.

However, early detection in Singapore is often met with denial by the parents, who will likely delay services because they believe their child will outgrow the problems, Semaun said.

Cross Cultural Differences: Stigmatization, Myths and Misconceptions

Autism detection and interventions can be difficult to standardize across cultures. That's because autism is diagnosed based on behavior and because expectations for social and language skills and developmental milestones differ from country to country, according to a 2013 article in the Harvard College Global Health Review.¹⁰

But if caregivers and professionals don't pick up the symptoms associated with autism, they won't realize those behaviors point to a condition that needs attention.

The Harvard article found that "stigma and cultural norms, along with poor diagnosis or medical infrastructure, could be undermining prevalence rates, masking the amount of children that have autism in developing countries."¹¹

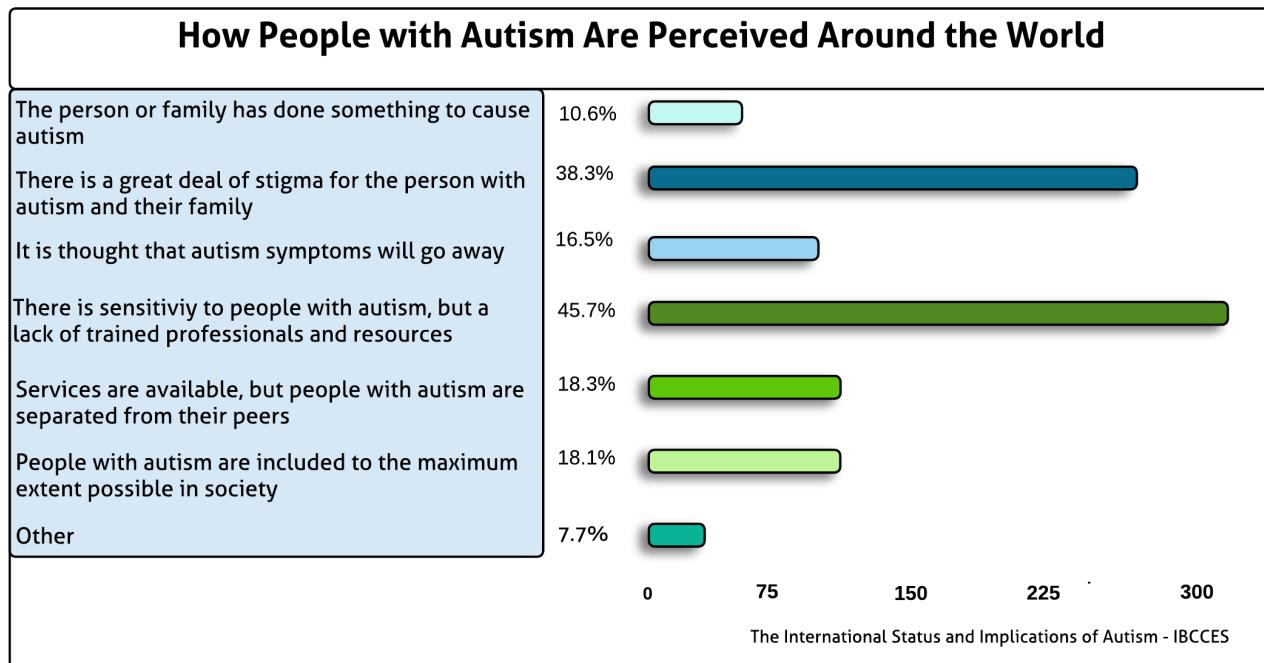
This is confirmed by autism professionals who took the global survey, roughly 40 percent of whom said there was a great deal of stigma for the person with autism and their family. Only 18 percent of them said people with autism are included to the maximum extent possible in society.

Oshikoya reports that stigmatization is one of the reasons why most parents don't bring children in for diagnosis.

"We are slowly breaking this barrier with the introduction of autism screening in some selected hospitals, but the advocacy for screening is still not enough," she said.

Misconceptions arising from religious beliefs sometimes aggravate the problem, Oshikoya said, noting that many people in Nigeria still view autism and other neurodevelopmental disorders as a spiritual problem.

"As a result, parents are unwilling to share information about their child's difficulties or seek advice from qualified professionals," she said. "Thus, most parents are left with no choice but to seek out diverse spiritual houses to heal their children."



In Singapore, denial by parents and siblings is also very common, said Kelvin Ong, project manager of St. Andrews Autism Center and Eden Center for Adults.

"They don't go to the doctor for assessment," Ong said. "There is shame and embarrassment, too."

Papaneophytou has witnessed similar behavior in his native country of Cyprus, where he is organizing an International Conference on Autism Treatment and Research in November, 2016.

Papaneophytou struggled to find autism resources several years ago for his nephew who lives in Cyprus. While he has seen progress in the last few years, he said that shame and a refusal to accept reality is still quite evident.

"Many families avoid diagnosis and they tend to live in denial," Papaneophytou said. "Those that try their hardest to get help are faced with the insurmountable issues of daily life, survival, familial fatigue, and a general lack of support."

Economic Disparities and the Role of Parents and Advocates

Family support can play a powerful role in providing advocacy and affordable services for children with autism, Shore said.

He notes that Autism Speaks, a leading autism advocacy group in the United States, was founded by family members of a child with autism.

"Often it's the parents that get these centers going," Shore said. "It tends to start there, and hopefully they get the government's attention and support."

Nearly 46 percent of professionals who took the global survey said autism treatment and educational services were available, but only if the family could afford them.

However, many families in developing countries simply don't have the money to hire speech-language pathologists, private psychologists or applied behavior analysts.

Papaneophytou reports that Cyprus offers little public school support for children with autism and that parents usually have to pay for therapy out of their own pockets.

Trained and experienced autism professionals are also scarce, he said. Children with autism may receive speech therapy a few hours a week, but spend most of their time drawing pictures or doing very basic school work in a room with children with other disabilities.

"Children on the autism spectrum may have special needs, but they may also have special abilities," Papaneophytou said. "But there is no system in public education to enhance that ability. They are always regarded as 'special needs' kids and the attitude is one of pity. No one is interested in discovering any potential."

For many, the situation isn't much brighter in Singapore. The few schools that accept students with autism there are often full, and most private services are too expensive for families, Semaun said.

"There is a waiting list for public and subsidized services, and when it comes to the private sector all the costs add up," he said.



Our Sunny World is a Moscow-based non-profit that provides development, rehabilitation, and adaptation services for youth and young adults with autism.



Our Sunny World, Moscow



Our Sunny World, Moscow

Models of Success

Shore, who has participated in autism conferences in 41 countries, has observed some resourceful autism advocacy programs.

In one tiny room in Beijing, China, he reports that workers used sensory integration activities and a cognitive developmental approach, known as the Miller Method, to close the gaps in the children's development.

"They used plywood and duct tape to build a playground and hacked together quite a good program," Shore said. "Maybe they bought books or attended a workshop. That's how it starts. What I find is, wherever I go there are always pockets of best practices."

Here are four outstanding projects that demonstrate how helping people with autism reach their highest potential is possible, even in impoverished countries.

Lagos, Nigeria: Nobelova Gradani Psycho-Educational Services.

Named for the "noble citizen," this center opened in 2011 and presently has 50 children in its early intervention program.¹²

The team of psychiatrists, psychologists, behavior analysts, occupational therapists, and neuro-developmental assessors emphasize the use of applied behavior analysis, a scientifically validated approach that uses positive reinforcement and intensive step-by-step instruction to build useful skills and socially appropriate behaviors.

In partnership with seven hospitals and 32 school health programs, Nobelova Gradani has provided thousands of autism and developmental screenings. In addition, it offers teacher training in early autism intervention and educational support in connection with the Department of Behavioural Studies at Lagos State University Teaching Hospital and IBCCES.

According to Oshikoya, "Many of our children are now achieving significant developmental milestones and are engaging in more appropriate behavior."

Singapore: St. Andrew's Autism Center

Operating under the premise of person first, autism second, St. Andrew's Autism Center is a comprehensive program for the education, training, care, and spiritual needs of children and adults with autism and their families.

A service of St. Andrew's Mission Hospital, the center launched in 2005 with a focus on students and clients with moderate to severe autism.¹³

It operates an Autism School for children ages 7 to 18. Using a multi-disciplinary approach, teachers work closely with one another and educational psychologists, occupational therapists, speech therapists, and social workers to customize students' education and services. The curriculum includes functional numeracy and literacy, personal care and daily living skills, community-based learning, adaptive physical education, and expressive arts.

The center also has an adult autism services day program for clients age 19 and older. It stresses greater independence by teaching skills for daily living, recreation, vocation and home and community living. To strengthen family relationships, it also offers a parents support group and siblings programs.

"The center brings them out of the home and into the community," Ong said. "We do advocacy so they are more comfortable in the community and expand their horizons with arts, dancing, and musical performances and help them participate in employment."

Moscow: Our Sunny World

This non-profit center was founded in 1991 by specialists and parents of children with autism and other developmental challenges.¹⁴

Our Sunny World was one of the first Russian organizations to provide development, rehabilitation, and social adaptation services for youth with autism. It relies on methods such as applied behavioral analysis, somatosensory (touch) therapy, physical therapy, speech therapy, productive activity, art therapy, and music therapy.

The center also introduces computers and tools, such as a Picture Exchange Communication System (PECS), to help children communicate. In addition, it offers an annual summer camp for children with autism and a project that teaches independent living skills for adults with autism.

Tokyo: Musashino Higashi Gakuen

This private school east of Tokyo integrates students with autism with their regular peers. Opening in 1964, it emphasizes Daily Life Therapy, which focuses on physical education, intellectual and artistic stimulation, and emotional regulation.¹⁵

Its structured educational program stress physical stamina building to regulate mood, concentration and awareness of surroundings; emotional stability and trust through group dynamics and a close bond with teachers; and intellectual stimulation through an age-appropriate curriculum of literacy, math, science, social studies, technology, and the arts.

The school's regular students socialize and make friends with their peers who have autism, inspiring them to push their own limits as they witness students with autism make tremendous strides.

The school has been so successful it launched a satellite in the U.S., The Boston Higashi School, in 1987.

About a third of its students have autism, said Shore, a member of Boston Higashi School's Advisory Board of Education.

"They're just included with everybody else," Shore said. "Theirs is the only approach that simultaneously teaches regular education along with autism. They pay attention to the strengths of the person with autism."

Dire Need for Trained Autism Professionals in Health and Education

All the experts interviewed for this report cited a dire need for professional autism training in the developing countries where they work.

In Cyprus, an island country of about 1.1 million people, "the lack of professionally trained experts remains a huge need," said Papaneophytou.

Presently in Lagos, the largest state in Nigeria with nearly 5.2 million people, Nobelova Gradani is the only autism service provider offering diagnosis and early intervention services, Oshikoya said.

Through self-funding, Nobelova certified four new autism specialists in 2016 and has 30 students in training. But it's still not enough, Oshikoya said. She is on a campaign to convince the Nigerian government that professional training is essential to the success of people with autism.

"We still need more individuals trained to support the children that we are diagnosing every day," Oshikoya said. "At the moment, Nobelova is overwhelmed with parents who cannot afford treatment."

IBCCES Training and Certification Programs:

1. Certified Autism Specialist – For professionals with a master's degree in special education or related field and two years experience with special needs students.

2. Autism Certificate – For professionals who are likely to have contact with people with autism. A master's degree is not required, but the applicant must have 14 hours of continuing education.

3. Certified Autism Center - Officially recognizes schools and facilities such as hospitals and speech and physical therapy clinics that have highly trained staff and are fully equipped to serve people with developmental disorders.

4. Advanced Autism Certificate - For professionals with an Autism Certificate who want to increase their knowledge and expertise in applied behavioral analysis therapy. It's designed to help master educators and licensed professionals use applied behavioral analysis in the home, center, school, or community.

5. Advanced Certified Autism Specialist
For professionals who have a Certified Autism Specialist Certificate and want to increase their knowledge and expertise in the field of applied behavioral analysis therapy.

How IBCCES Can Help: Credentials and Standards

Farida Saba Aslam of Karachi, Pakistan obtained her autism credentials through IBCCES to open a holistic therapy institute for people with autism and other developmental disorders.

Having more confidence in herself as an autism expert with those credentials, Aslam plans to seek advanced certification and start an autism awareness campaign in Pakistan, train mothers and therapists, and promote inclusive schools for people with disabilities.

"I love to share my knowledge, and I feel good when people practice what they learn from me," Aslam said. "This motivates me to learn more myself."

Pakistan is one of 31 countries where IBCCES trains educators and licensed professionals in evidence-based autism treatment strategies.

Reputable online certificate programs like those offered by IBCCES are an affordable and convenient way to gain credentials with or without an advanced degree. This is particularly true in countries with limited access to professional development options.

Formed in 2001, IBCCES is the leading credentialing organization for professionals in the field of autism and the first to develop industry standards. Building comprehensive training in partnership with 240 or more universities around the world, IBCCES provides interactive online knowledge and strategies that exceed physical, occupational, and educational goals for children and adults with autism.

IBCCES Training and Credentials Cover These 10 Areas:

- Autism overview
- Behavioral competency
- Communication competency
- Social skills competency
- Environment competency
- Emotional awareness and bullying competency
- Sensory awareness competency
- Program development competency
- Motor skill competency
- Medical and health considerations

Conclusion

It will take a highly trained, qualified force of teachers and health professionals to scale up care for people with autism in developing countries around the world.

Without it, the potential of people with autism will go unrecognized. Many will continue to be excluded from their communities and struggle to perform the basic activities of everyday life.

As the four models cited in this paper have shown, providing a trained autism workforce can be achieved, including countries with limited resources.

Affordable online autism training and certification programs like those provided by IBCCES can turn a caring autism advocate into an expert with the skills and evidence-based treatment strategies to help people with autism succeed.

Authors

Helen Oshikoya, M.S. Lagos, Nigeria

Chief Executive Officer of Nobelova Gradani Psycho Educational Services, Oshikoya founded the center in 2011 to provide autism and developmental screenings and teacher training in early autism intervention and educational support. She has been one of the foremost advocates for children in Nigeria, particularly for children with autism.



Oshikoya is a member of the Nigerian Bar Association. She is also a Certified Autism Specialist, a certified training partner of IBCCES and a certified child development clinician.

Neophytos Papaneophytou, Ph.D., New York

Papaneophytou is an assistant psychology professor at City University of New York and has a clinical psychology practice, the HealingMind Center, in Manhattan, N. Y. and Hoboken, N.J.

A native of Cyprus, Papneophytou is organizing an International Autism Conference in Pathos, Cyprus in November, 2016.

He has written two children's books and created the non-profit, Magic Always Happens, which promotes awareness, education, and scholarships for people of all ages on the autism spectrum.



Raymond Marcel Semaun, B.S., Singapore

Semaun is the head of St. Andrew's Adult Autism Services and St. Andrew's Autism Center, which are part of St. Andrew's Mission Hospital operated by the Anglican Church.

He is a certified consultant for Applied Behavioral Analysis Therapy. Semaun has two decades experience with children with autism and has been a guest lecturer at autism seminars in Indonesia, China, Russia, and Australia.



Authors

Stephen Shore, Ph.D., New York

Shore is an assistant professor of special education at Adelphi University in Garden City, New York, where his research focuses on matching best practice to the needs of people with autism.

Diagnosed with autism as a toddler, Shore has the real life experience that has made him a well-recognized international speaker on the subject.

He has written numerous books on autism, including "College for Students with Disabilities" and "Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome." He is a board member of Autism Speaks, president emeritus of the Asperger's Association of New England, and an advisory board member of the Autism Society of America.



Other Contributors

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Aslam is a Certified Autism Specialist at DHA Medical Center in Karachi. She also has certificates in cognitive behavioral therapy, speech therapy, and behavior analysis therapy and is a registered behavior technician. She worked 29 years with the Pakistan Center for Autism, eventually becoming its senior director.

Kelvin Ong, B.Ed., Singapore

Ong is project manager for St. Andrew's Autism Center and oversees the Eden Center for Adults, a day activity center that is supported by the Autism Association of Singapore.

Caren Burmeister, B.S., Jacksonville, Fl

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

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