

BY LEE GROSSMAN AND PAULO BARROZO



THE NEXT GLOBAL HUMAN RIGHTS Issue

**WHY THE PLIGHT OF INDIVIDUALS
WITH AUTISM SPECTRUM DISORDERS
REQUIRES A GLOBAL CALL TO ACTION**



Background

Identified by Leo Kanner in 1942, autism spectrum disorders (ASDs)¹ are the fastest growing neurobiological conditions in the world. With prevalence numbers rising exponentially over the last six decades, more and more families are living with ASD than ever before. In the United States, one in every 150 American children will have ASD, and it is estimated that figure

treatment and supports. People on the spectrum often cannot communicate the physiological symptoms (such as pain from stomach illnesses or ear infections) that need medical treatments. Too often, people with ASD and their families are told that autism is “untreatable” and that the best option is to prepare them for a life outside of their communities, without independence and services. This happens daily, and it occurs in the United States as often as in Haiti.

Tragically, nations have not yet responded in proportion to the rising rates; in fact, to date there is no global survey or study on prevalence.

is one in every 90 boys. Western Europe and Canada carry similar, if not higher numbers, and we hear daily from parents and professionals in Latin America, Asia, the Middle East and Africa of their rising numbers and the increasing challenges to accessing care.

Tragically, nations have not yet responded in proportion to the rising rates; in fact, to date there is no global survey or study on prevalence. Individuals on the autism spectrum and their families struggle daily to advocate for basic health care, education and community acceptance that should be their natural rights as humans, yet they are systematically discriminated and subjected to global abuses. It is this struggle that formed the Autism Society of America and the hundreds of parent-led autism societies around the world into a powerful advocacy group of concerned citizens.

At ASA, we believe that autism should be viewed by national governments as a medical condition that needs effective

We can no longer accept that a diagnosis of ASD equals hopelessness. We believe that there is a moral and ethical obligation to identify, treat and care for people with autism spectrum disorders so that they can attain their full potential. We believe that the systemic lack of care violates the fundamental human rights of people with ASD, and we as parents and as members of the global autism community must demand action now.

A Condition Without Borders

Despite the lack of prevalence data on autism worldwide, there are emerging trend numbers that suggest that tens of millions of children and adults have ASD. As the numbers increase, the resulting costs of this lifespan condition on national economies rise concurrently; by 2010, estimates of the cost of caring for the estimated 1.75 million Americans with ASD will reach \$90 billion

per year. In countries such as India, Russia and Nigeria, these costs could cripple a nation's health and education budgets within a few years.

While the World Health Organization (WHO) does not maintain global statistics on the prevalence of autism spectrum disorders or appropriate treatments specifically, its 2007 *Global Burden of Disease* report on mental and neurological disorders highlighted the critical situation the world faces with a growing population that includes those with autism. The report demonstrated that traditional epidemiological methods of disease had been greatly underestimating mental and neurological disorders by tracking mortality, not disability rates, which it estimates accounts for almost 11 percent of global disease burden.² Moreover, WHO's 2007 report *Neurological Disorders: Public Health Challenges* highlights this burden by describing "ample evidence that pinpoints neurological disorders as one of the greatest threats to public health."³ The authors of the WHO *Global Burden of Disease* study concluded that the proportionate share of the total global burden of disease due to neuropsychiatric disorders is projected to rise to 14.7 percent by 2020.

International Human Rights Law and Autism

The legal framework and precedence for protecting individuals on the autism spectrum is solidly part of the existing international laws and United Nations (U.N.) conventions that protect human rights.

Currently, three conventions and one draft appeal cover legal issues and policies affecting our community:

- Universal Declaration of Human Rights (1948)⁴
- International Covenant on Civil and Political Rights (1966)
- International Covenant on Economic, Social and Cultural Rights (1966)
- Declaration on the Rights of Disabled Persons (1975)⁵
- Convention on the Rights of the Child (1989)⁶
- Convention on the Rights of Persons with Disabilities (2007)

The 1948 U.N. Declaration on Human Rights lays forth the right to "the highest attainable standard of health—often referred to as the right to health" as a basic human right for everyone. While the spirit of the enactment was in the aftermath of the atrocities committed during World War II, the declaration has a history of thoughtful application to more "subtle activities that also have severe and longlasting effects on health and human rights such as absence of basic health-care systems ... and tolerance of discrimination against groups such as injecting drug users, people with mental-health disorders, illegal immigrants, or homeless people."⁷

In August of this year, the British journal *The Lancet* laid out an eloquent case for how, and why, the principles of human rights can be put into practice to attain adequate health care for those in need. Using the success of the HIV/AIDS advocate community's efforts of the late 1980s to illustrate this point, the authors demonstrate that "although this strategy was partly motivated by moral outrage at

Chart A: Estimated Number of Individuals with Autism in Selected Nations, 2007

(calculated from prevalence rates in some cases)

COUNTRY	NUMBER	DATA SOURCE
China	1,100,000	Peking Health Science Center (estimate based on official 2005 rate of 1.1 in 1000 children affected)
India	2,000,000	Action for Autism India (based on an estimated rate of 1 in 250), 2007
United States	1,500,000	U.S. Centers for Disease Control and Prevention ADDME Study 2007 and Autism Society of America, 2007
United Kingdom	650,000	National Autistic Society 2006 (based on rate of 1 in 100)
Mexico	50,000	Based on 2005 estimates by Ministry of Health of 2 to 6 per 1000
Philippines	500,000	Autism Society of Philippines, 2007
Thailand	180,000	Estimate of the Minister of Mental Health, 2006

abuses suffered by people living with HIV, the inclusion of human rights was primarily because evidence was emerging that showed that discrimination was driving people away from prevention and care programmes.”⁸ Groups were not being treated because of their disorder, even though the presence of their condition necessitated access to health care.

The Lancet also highlighted that the activism of the HIV/AIDS community included the health-care professionals who served the community. The organizations Medecins Sans Frontieres (Doctors without Borders) and Medicines du Monde (Doctors of the World) applied their founding principles that doctors have a duty to treat, and mobilized their health-care colleagues to join with the affected groups and call for change. As the authors point out, “although not initially intended as the launch of a health and human rights movement, the emergence ... of these groups ...

The United Nations estimates that 650 million people in the world living with disabilities—about 10 percent of the world’s population—lack the opportunities of their mainstream peers.

has drawn attention to the universal value of health and the duty of care providers ... and the international community to intervene when human rights are ignored.”⁹ The critical importance of early identification and treatment of autism spectrum disorders underscores the necessity of the health-care workers act—not treating constitutes harm.

The United Nations estimates that 650 million people in the world living with disabilities—about 10 percent of the world’s population—lack the opportunities of their mainstream peers. For persons with autism spectrum disorders, the U.N. Declaration on the Rights of Disabled Persons (1975) also provides essential protections that go beyond health care and into essential human rights. For this reason, ASA strongly supports the full participation

ASA'S DECLARATION ON THE HUMAN RIGHTS OF PERSONS WITH AUTISM SPECTRUM DISORDERS

Access to the health care, educational opportunities and social inclusion required to live a full and meaningful life is a fundamental right of all human beings. This right has been recognized and upheld in every legal culture of the world, in the several codifications of the international community's recognition and commitment to fundamental human rights, and in the bills of rights of virtually every country. But with autism spectrum disorders, pervasive discrimination exists on a global scale. Proper and timely access to medical diagnosis and treatment are typically not available and, in many nations, may be discouraged or simply withheld. When available, services are often within economic or geographic reach. Regardless of ethnicity, economic status, nationality, religion or country, individuals on the autism spectrum and their loved ones are systematically discriminated against and left to fend for themselves to locate the most meager of supports and interventions.

The numbers of those diagnosed with autism are at rates that international organizations typically consider pandemic, and continue to rise unabated. When confronted by the seriousness and consequences of the condition, by the numbers of affected individuals and families, and by the scale and pervasiveness of the discrimination they suffer in the access to proper and timely health care and services, we call on the international community of nations to issue a declaration that people with autism spectrum disorders are entitled to the protection of fundamental human rights.

We call on each and every country and on the international community of states to adopt the following principles into domestic and international law and policies, and to encourage the attitudes and undertake the concrete actions necessary to make them a reality.

People with autism have the fundamental human right to:

- Live an autonomous, independent and meaningful life
- Self-determination and direct involvement in decisions affecting their lives
- Accessible and appropriate education, housing, assistance, care and support services as well as sufficient income
- Freedom from threats, discrimination, social exclusion, and cruel and abusive treatment

Indeed, the data on exclusion, the lack of treatment, identification and access to appropriate care and education that families face requires a new way of thinking. The inadequacy of accommodations, treatment and education for autism in all countries makes assuring rights for those with autism the new human rights frontier of our time. Our societies' reaction to the predicament of those directly affected by autism needs to rise to a greater scale of moral maturity.

Adapted in part from the Charter of Rights for People with Autism, European Parliament, May 1996.

of nations in this declaration and is working to have the United States join the 118 countries who are party to this convention.

Our Call to Action

People on the autism spectrum are entitled to human rights, and nations of the world have a moral obligation, backed by international law, to protect and deliver on those human rights. The lack of adequate health care, the disarray of education and service options, the almost complete absence of employment options, and the scattered, often non-existent, supply of services and supports for the estimated 15 million humans with autism highlight that these rights are violated daily in countries everywhere.

At ASA, we join with partners of the United Nations around the world to educate and inform, believing that education and awareness are the key to securing a community that respects the human rights of all people. But we also join with our partners to declare that the time is now to demand those rights—we cannot tolerate another year of systemic neglect.

With these principles as our guidelines, we call for members of the international community to adopt the following declaration (see declaration on page 11).

Give us Hope

The success of humanity's struggle for human rights is largely due to moral outrage at the discrimination, oppression and exclusion of individuals and groups, and can be measured by the change in attitudes and concrete actions they have inspired to overcome what is unrighteous and cruel. However, today the struggle continues. And as we take stock of the progress achieved in the past and the extraordinary challenges that still lie ahead, the plight of individuals suffering with autism and other disabilities confronts us as the next frontier for human rights in the world.

ASA, autism groups from around the world and partners in the delivery of services to autism have begun working on a global advocacy movement that calls on each respective government to make fundamental policy changes to improve the lives of all affected by autism. The success of our efforts will be easily measured. We know we have succeeded when the autism spectrum becomes an accepted part of the human condition. While this goal may take a generation to achieve, the global community should aim for nothing less. The long-term effects on all nations of not treating and

educating all children to reach their full potential far outweigh the short-term costs of providing adequate services.

To the global community, we simply say, “We have the solutions...give us hope.”

ABOUT THE AUTHORS

Lee Grossman is the President and CEO of the Autism Society of America (publisher of the Autism Advocate). **Paulo Barrozo** is a lecturer at Harvard University in Cambridge, Massachusetts. Both authors have sons with an autism spectrum disorder.

ENDNOTES/REFERENCES

¹ Autism Spectrum Disorders are defined in the United States by the *Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV* and the Autism Society of America as autism, Pervasive Developmental Delay-Not Otherwise Specified, Asperger's Syndrome, Rett's Syndrome and Childhood Disintegrative Disorder.

² *Global Burden of Disease Report*, 2007, World Health Organization, http://www.who.int/mental_health/neurology/en/.

³ Neurological Disorders: Public Health Challenges, 2007, World Health Organization, http://www.who.int/mental_health/neurology/neurodiso/en/index.html.

⁴ *Universal Declaration of Human Rights*, United Nations General Assembly resolution 217 A (III) of 10 December 1948, <http://www.un.org/rights/>.

⁵ Convention on the Rights of the Disabled, United Nations General Assembly resolution 3447 (XXX) of 9 December 1975, Office of the United Nations High Commissioner for Human Rights, <http://www.ohchr.org/english/law/disabilities-convention.htm>.

⁶ *Convention on the Rights of the Child*, adopted and opened for signature, ratification and accession by General Assembly, resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with article 49, <http://www.ohchr.org/english/law/pdf/crc.pdf>.

⁷ “History, principles, and practice of health and human rights,” *The Lancet*, vol. 370, p. 449, August 4, 2007.

⁸ Ibid.

⁹ “History, principles, and practice of health and human rights,” *The Lancet*, vol. 370, p. 451, August 4, 2007.