

Autism as a Global Human Rights Violation Issue

BY TERI ARRANGA

"There needs to be a global recognition of the fact that autism is a pandemic problem and it doesn't seem to be any particular ethnicity, economic condition, racial background or country of origin that has a higher or lesser degree of autism. It is as much of an equal opportunity condition as the world has ever seen," observed Lee Grossman, President and CEO of the Autism Society of America.

David Humphrey, Vice President of the Autism Coalition for Treatment and Board member of the Autism Society of America and the Autism Research Institute, reports the following estimates on autism in selected Asian countries: China 2,500,000; India 2,000,000; Indonesia 350,000; Japan 300,000; Philippines 250,000; Thailand 180,000. According to Dave, "What is crushing for families in the US - with pretty good resources - is unbearable in countries where families have very limited resources." He continues to say, "Governments in most of these countries virtually ignore the problems of autism because they just can't deal with the enormity of the problem. We were in North Korea on a mission with Mercy Corps and met with government officials. They claimed that there was no autism in North Korea. In a follow-up meeting with Amnesty International, we were told the grim reason: At the first signs of autism, children are taken from their parents to remote 'treatment' institutions where their life expectancy is less than 2 years. Most starve. In decisions to allocate limited food reserves, the autism centres are the lowest priority. Even in 'Second World' countries with strong economies conditions can be horrible - I

have been in autism institutions where these children are literally warehoused in shocking conditions. You are permanently changed from the experience of walking through an institution and seeing children with autism - some tethered to their beds lying in fecal matter as a result of chronic diarrhea and untreated medical problems. Warehoused children are all too common in many countries since families do not have the resources to have one parent stay with the child at home."

Laurie Ahern, Associate Director of Washington DC-based Mental Disability Rights International (MDRI) and co-author of the report entitled *Torment Not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities*, travelled to Serbia and observed the conditions under which institutionalized persons "lived." According to this report: "MDRI investigators found children and adults with disabilities tied to beds or never allowed to leave a crib - some for years at a time." Inhumane and degrading treatment in Serbian institutions violates Article 3 of the European Convention on Human Rights. In a phone call with Laurie Ahern, she related that staff members at the Serbian institutions described the restrained children as

having a variety of conditions including cerebral palsy, autism, Down syndrome, mental retardation, and spina bifida. Laurie observed the many children in these institutions who exhibited behaviors associated with autism. This has not only been happening in Serbia; MDRI has written reports citing the conditions for this population in Kosovo, Turkey, Russia, Romania, Mexico, Peru and Argentina, as well as a host of other countries. Laurie related that these same things are happening to children and adults with autism and other conditions in these countries... the same deprivation and neglect of medical treatment, therapies and any human contact. Even the human contact of personal bottle feeding is too often a luxury not able to be provided, with bottles left propped up on the side of the crib. Neglected children are left to self-abusive behaviors, such as hitting themselves, chewing their fingers, or gouging their own eyes.

Children like these in institutions in Serbia and other countries were observed to be tied to their cribs for years at a time. These children had a variety of diagnoses, including autism. The photos that follow depict a teenage boy (*right*) and a young girl (*left*).



Photos by Marc Schneider, 2007

One of the most compelling quotes reported by an MDRI investigator who visited the Stamnica Institution in Serbia states, "I looked into the crib and saw a child who looked to be 7 or 8 years old. The nurse told me he was 21 and had been at the institution for eleven years. I asked her how often he was taken out of the crib and she said,

'Never, he has never been out of the crib in 11 years.' The lights were off and it was dark in the room in the middle of the day. The smell of urine and feces was overpowering ... There was no stimulus of any kind: no music, conversation, television or radio, only darkness and silence.'

These inhumane conditions result in contorted and atrophied limbs and bones, breathing and other physiological problems, as well as staggering psychological torment.

According to Dave Humphrey, "A member of the parent association, Autism Society of Serbia, reported that a large percentage are children with autism – a very vulnerable group for abuse."

The MDRI report includes the following statements related to the rights that should be afforded to these individuals:

- **All human beings are born free and equal in dignity and rights:**
Universal Declaration of Human Rights, Article 1 (General Assembly of the United Nations, 1948).
- **State Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others ... and their full inclusion and participation in the community:**
Convention on the Rights of Persons with Disabilities, opened for signature March 30, 2007, Article 19.
- **No one shall be subjected to torture or to inhuman or degrading treatment or punishment:**
European Convention on Human Rights, Article 3
- **For the purposes of this Convention, the term torture means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted ... for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.**
UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, article 1(1) (*emphasis added*)
- **State Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.**
Convention on the Rights of the Child, Article 23(1).

As mentioned earlier, these horrific situations are not limited to Serbia. Laurie Ahern related to me that while she was in Uruguay, she found children in cages because, "... according to staff, they had autism."

According to Dave Humphrey, "This mistreatment of children with autism is found in many countries where the sheer number of children with autism is overwhelming the systems and limited resources. Furthermore, in many countries,



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such as China and Japan, autism carries a terrible social stigma. This results in the family being shunned by the community and the child not receiving basic human rights. In Thailand up until recently this resulted in many children in rural areas being locked in cages with 'superstitious treatments.' Thanks to the dedicated work of Princess Ubolratana, whose son Khun Poom Jensen had autism and recently died in the tsunami, many of these children with autism in the rural villages have been moved to excellent treatment facilities. The Princess has demonstrated that these terrible conditions can be corrected and children with autism can be treated with effective therapies and with compassion."

Dave continued, "My good friend Ellsworth Culver, co-founder of Mercy Corps (the largest international emergency relief agency), went with me to Asia and investigated the devastating effect of autism. He got very involved with the unbelievable neglect he saw. He told me with great sorrow that if he were not working for Mercy Corps he would devote his life to autism. He said that the children were raised in silent terror and ignored by those who should be helping. He said this caused him more pain than disaster victims who do get help. He died last year at 78 with most of his work undone."

THE AUTISM SOCIETY OF AMERICA HAS ISSUED THE FOLLOWING STATEMENT ON AUTISM AS A HUMAN RIGHTS VIOLATION:

"The health care indispensable to a full and meaningful life is a fundamental right of all human beings.

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 essential health care has been recognized as a fundamental human right.

But with autism, there is a pervasive discrimination on an equally global scale. Proper and timely access to medical diagnosis and treatment are typically not available and where they are, they are discouraged or simply withheld. Services, virtually non-existent, are typically inadequate and inappropriate when available. Regardless of ethnicity, economic status, nationality, religion or country, individuals with Autism and their loved ones are systematically discriminated against and left to fend for themselves to provide the most meager of supports and interventions.

The numbers of those diagnosed with autism are incredibly high, already of pandemic proportions, 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 must recognize that autism is becoming the most important human rights health issue in the world. Indeed, undisputed facts and greater moral maturity compels the world to see in the predicament of individuals with autism and other mental disabilities the new human rights frontier of our time."

How are individuals with autism discriminated against in the United States? I talked to Lee Grossman and to Robert Krakow, Chairman of the Board of Lifespire and co-founder of Autism United.

Lee reported, "I don't know of any place in the world where people with autism and their families aren't being discriminated against. We know that there are some human atrocities happening. We know that some people with autism are being institutionalized ... put in cages ... But at the same time, you have the developed countries, such as the US, where such a small minority of people who have autism are getting looked at appropriately by physicians, for example. So we have yet to identify anyplace in the world where people, just because of their diagnosis, aren't being discriminated against."

I asked Lee how the "handling" of autism differs from other conditions. Lee cited the example of HIV, "... where there are worldwide efforts and public policy initiatives in many, many countries in the world to deal with conditions such as HIV, and, for the most part, the media and communities have dealt aggressively and positively in providing treatment and a more wholesome environment for people affected by HIV or AIDS. You can't say the same thing for autism. There are no national public policies that deal specifically with autism. There are no communities or cultures that seem as if they are really responding to this epidemic. We've done the same thing for cancer, diabetes and other chronic medical conditions, but this has yet to be done for autism. And not only has it yet to be done for autism, but there is a conversely proportional amount of negativity given towards the autism community. Again, they're systematically being discriminated against: They're not provided adequate healthcare, not provided appropriate or adequate services in terms of education or behavioral services, and

families are left to fend for themselves in trying to get the meager services that are out there. I would say that not only is this happening in Third World nations, but in the most developed nations, such as our own.”

According to Robert Krakow, “In this country, we’ve come a long way. For education, we have the Individuals with Disabilities Education Act. What we see now with a lot of families and children is the way that that’s not implemented due to lack of resources, so the public schools take a position adverse to families and sometimes resort to bullying tactics or retaliation. That’s discrimination. But we have a mechanism here to assert our civil rights for our children in education. What it comes down to, then, is resources, because who has access to a lawyer who can manipulate that system for the family better than they could do it themselves? Because we know the schools, in many cases, are doing that. So then, it’s access to justice in that system. So I see it as a continuum. I wouldn’t make any kind of artificial distinction. People with disabilities are subject to being denied access to society. In some places it’s worse than others. In some places kids are tethered to cages; in some places they’re hidden in the back of the apartment. I’m sure there are many children with autism who are hidden in poorer communities in New York City – I’ve seen this. They don’t go to school. Schools don’t even know they exist. They’re denied basic civil rights: the right to participate in their society and get services. Then there’s the denial of insurance coverage. It’s all a matter of a gradation of deprivation. We all would try to aspire to an ideal where every person with a disability is integrated fully into the society and whatever accommodations are necessary are made. In a poorer society, that may be more difficult, although that depends on the culture. You could have a culture with even scarce resources that still respects individuals who are less-able than other individuals.”

Bob continued, “In the health field, there’s no question: non-pharmaceutical biomedical intervention is very scarce – rare. Very few families can really participate in that because insurance does not cover most of it, so it’s out-of-pocket. Why should that not be available to certain kids if it can help them? That’s a social decision we’ll have to make, because if it can truly help them, then

“All people are valuable, deserving of respect, and can participate in society and a family with appropriate supports.”

Elizabeth Bauer, former Executive Director of the Michigan Protection and Advocacy Service, elected member of the Michigan State Board of Education, and Board member of Mental Disability Rights International

as a society we should make it available. That’s a civil rights issue – the right of a child to have access to healthcare to recover. A child should have the same access as any other to be healthy. Very few kids get the kind of intervention that would give them the opportunity to lead a productive life. Providing appropriate medical care – not just drugs – the opportunity to get the most appropriate medical interventions to lead the most productive life – is a civil right, and that’s being violated every day and our society is just not coming to grips with it. It’s been maybe 15 years since we’ve seen an upsurge in the diagnosis of autism, and I think it’s a real increase in numbers, and the United States is just not dealing with it – it’s just not responding adequately. It’s a monumental problem – it’s a civil rights problem, and it’s also a social problem that we have to respond to. When these kids become adults, there aren’t enough group residences or other types of interventions. When these kids get in institutional settings as adults, the opportunities for abuse are just horrendous, and this is where the civil rights aspect of this comes into the best focus, because in New York -- and other places, too -- but in New York, there was a place called Willowbrook where abuse was rampant. They lived in filth, had no education, were abused physically and every other way. And finally people – parents mostly – responded to that. The result of that, and a long struggle – a famous struggle – was the closing of Willowbrook and a court order in New York that appropriate settings be funded by the State, and that was an example where the legal system was the effective mechanism to getting that done. And there’s a court order that’s in place today – for the last 25-30 years – that requires the State to provide for children in an appropriate way. And we’ve got many more group homes and other kinds of settings, and day centers, rehab

centers, and work centers that are a result of that. And you don’t have the widespread abuse that we used to have. There’s still abuse, and there are still violations, and there are still bad settings and bad actors, but it did have an institutional and societal response that was historic, and it happened in other places, too. So those battles still have to be fought, because now we’re going to have many, many more adults that need a setting in which they can live, and some of them will need 1-to-1 assistance. Is that a civil right? I would argue: “Yes.” Is it a civil right that our country is going to be willing to pay for? That’s in very serious doubt – we have cut-backs going on in Medicaid right now, and that’s how it’s funded. So we have to find new ways to respond to that and fulfil the obligations we have so that each individual can fulfil their potential and lead a productive and safe life where they’re not abused and they have an opportunity to thrive.”

Lee added, “Individuals with autism, when they receive the appropriate interventions, improve significantly. To me, that’s the whole idea behind the global human rights violation: If they’re not getting any services, you can’t expect them to improve. The hope is that we can maximize their potential and provide them with opportunities so that they can live a much more productive life. That’s what we’re robbing of people right now who have autism, and we’re robbing it from the families, too, because their families have to go into debt, they have to sometimes be shunned from society; the burden is placed on the family because of the crisis they’ve been thrown into – of not receiving any assistance and their kids being discriminated against because they have autism. We’re robbing the families and the individuals of opportunities and the chance to maximize the individual’s potential.”