

Rural Isolation Affects Availability of Rehabilitation / Therapy Services: Something Extra or A Human Right?

By Shirley J. Novak

My easy-going life has allowed me to take much for granted: a protective roof over my head; food in the cupboard; access to health, healthcare and higher education. And why not? I was born and raised in the US of middle class parents of white European descent. That positive cycle continued when my children were born; I was aware of educational - and therapeutic support - services available should they also want/need them. Over the years, I have come to the realization that *all* of the above are basic human rights - not to be considered *extras* or *services available only* according to the accident of birth locale, skin color, belief system, sexual orientation, physical or mental disability, etc. I've seen the reality first hand in many countries around the globe – that these basic human rights are far from universal. Here I'll share some of what I've learned along the road I've travelled in life.

Many of my colleagues at InterActive Therapy Group are aware of my vacations routinely spent in a remote mountain community, Estancia, El Salvador. These visits extend my volunteer dedication to **Doctors for Global Health (DGH – www.dghonline.org)**, an all-volunteer international, social justice NGO of which I am a founding board member (I currently serve as treasurer). Aspiring to set an example for how medicine should be practiced, DGH promotes **Liberation Medicine**: "The conscious, conscientious use of health to promote human dignity and social justice."¹ The organization is grounded in the concept of **Accompaniment**: "Amplifying voices, responding to invitations, sharing risk and responsibility, being there; working side by side with our fellow human beings to create conditions that demand and facilitate social justice..."² DGH is informed by the **Universal Declaration of Human Rights**, declaring that "recognizing the inherent dignity and worth of the human person, the equal and inalienable rights of all members of the human family, and the need to promote social progress and better standards of life, is the foundation of freedom, justice and peace in the world."³ (^{1,2,3} taken from *10th Anniversary Retrospective*, found on DGH website).

DGH has been partnering with Salvadoran *Campesinos para el Desarrollo Humano* (CDH – Peasants for Human Development) since its inception in 1995 and fosters a near steady stream of volunteer doctors and non-medical others to staff the local clinic and to help carry out community development projects. All volunteers work under and alongside locally-trained health promoters and community leaders. On my first visit in 1993, I fell in love with the country and the people of Estancia. I continue to visit and learn more from my sisters and brothers there with every trip; the connections have become stronger over time. Through annual visits, my Spanish language competency has increased, allowing me to better serve the Latino population here in Syracuse. The cultural exchanges and compassion that I have been able to bring to my professional work have enhanced and impacted my life in so many ways.



Barefooted Jaime exercising at home on new parallel bars

Estancia consists of five *caseríos* (hamlets) spread out over mountain trails, separated by the beautiful Torola River. Electricity is available via solar panels on the community clinic roof; they operate very basic medical equipment, charge batteries and run computers that house both clinic records and systems to manage community development programs. A few isolated homes have solar panels to power a single light bulb, radio and an occasional TV that offers entertainment during long, dark, evenings. Most of the community's houses consist of bamboo lashed together, tile roofs and dirt floors. The "better homes" are made of adobe or cement block with concrete floors. Most *campesinos* survive via subsistence farming - raising their family's own food and a little extra in good harvest years. Selling corn, beans or sugar cane blocks at the local market brings in a little extra money to buy necessities of oil and seeds for the next planting. Women and girls in families weave well-made, sturdy hammocks and

handbags, sold at the market with a profit margin that practically ignores the investment of time taken to create these beautiful, ancestral, hand crafted products.

In 1993, the local two-room school in *caserío* Rodeo only went to third grade; the *caserío* Naranjera school went to second. Now eight schools are spread out over the five communities' "hills" for a total of seventeen classrooms. Beyond 9th grade, a student leaves home to study *if* the family can pay room, board and tuition; students return home on weekends to help out. Not many families can afford school costs or lose their children's help with chores at home. Yet all parents I've met desperately want their children to go to school!

Initially to address the trauma young children experienced during the 12-year Salvadoran civil war (1980-1992), five integral child development centers were established in 1994. Locals were trained to provide stimulation and early education to children who ranged in age from 2-7 years; the "teachers" continued their own studies each Saturday until they earned their high school diplomas. Through an agreement with the Ministry of Education, government teachers now instruct the older children while the local, lesser-trained *educadoras* teach the younger ones. It is with these impressive "teachers" that I have been humbled to share my time, training and expertise working with young children. I provide periodic workshops and site visits (walking an hour or two) to offer up-close, hands-on suggestions for these folks with limited resources. Favorite activities have been to bring fabric and art supplies, creating unique educational materials: simple hand-made puzzles; "*cinco patitos*" sticks to accompany the familiar children's song, "Five Little Ducks"; classroom board books; and picture posters to cue desired behaviors. Often I'm presented with their most challenging kids and asked: "What should I do?"



Preschooler manipulating blocks in kinder

The schools, preschools and community clinic all operate under extremely tight budgets with scarce resources. The government has historically provided little help to this community, although this is slowly beginning to change, due to a progressive government party now in power. CDH (sometimes with DGH collaboration) carries out a variety of health, community development and educational projects outside of the clinic. Included are: annual dental campaigns (via DGH volunteer dentist from Ohio); micro-credit lending; exercise and special medical attention to the elderly; Reach Out and Read for preschoolers, who each receive four books a year, and literacy activities for parent and child; community gardens; "*Siete Semillas*" (7 grains), nutrition supplement prepared for children at highest risk of malnutrition; latrine building; clean water and sanitation projects. CDH recently attained funding from a foundation in Spain to build a bridge that connects two of Estancia's *caseríos*. Now school children can safely cross during rainy season rather than swim the dangerously high river, supplies can be carried in and out more easily and safely, and sick patients have quicker access to the local clinic or nearest hospital an hour drive away.



Health Promoter mixing nutrition supplement's toasted seeds

As long as they don't live too far away to safely walk, early childhood and elementary school education is now more readily accessible to children in Estancia who fall into the "normal" category. "Special needs" children, however, are a different reality. Kids who generally can't leave their houses and are not, therefore, able to go to school or social events have a tough life. In this isolated community where even basic services are a commodity, special therapies to accommodate these children's individualized needs are practically unheard of.

Consider Juan Carlos who sat on a stump just inside his house for most of the day before he was "noticed" and given special attention. He could not get around the community but longed just to sit on the edge of the soccer field near his house. During their ten months of volunteering in Estancia with DGH, volunteers Don and Caitlin got fired up to work with him, as well as Jaime, Milton and Estela. As a result of their persistence, taking their medical work into the community, now Juan Carlos can watch those games in a donated wheelchair.

Milton, who suffers from Spina Bifida, can be pushed to school in a jogging stroller donated by a Syracuse family and taken to Estancia last summer, as a piece of my luggage. Suffering from Cerebral Palsy, Estela lacked sufficient control over her muscles to allow for good head control. Don worked with one of the local elders, Buenaventura, to construct and then cover a chair that helps her sit in a better position for breathing. The children received basic "PT" from DGH volunteers, who taught family members to do the exercises, too.



Estela's unfinished chair

Jaime is another success story. With his winning smile, DGH volunteers first began visiting him at home, bringing a few crayons, books and toys to get an idea of what he might be able to do. When he showed promise, if just given the chance to learn, Jaime was soon on their list for regular house calls. Don worked with Jaime's dad first to construct a board that he could be strapped against, holding him in a standing position, to enable his manipulation of toys on a table surface. Soon a set of simple parallel bars were constructed that allowed Jaime to stand, strengthen his legs and eventually walk.



Estela at home with her parents

It should be noted that each Doctors for Global Health volunteer brings to his/her own experience a variety of interests, talents and strengths. While Jaime, Estela, Juan Carlos and Milton do not appear to have been singled out for special attention by previous DGH volunteers, others have. About three years ago, five year old Alba and her mother were accompanied by a DGH volunteer to the capital, San Salvador, several hours away from Estancia. The purpose of their trip was for Alba to undergo a comprehensive hearing examination. Born deaf with facial deformities that necessitated repeat surgeries, she had been attending the local preschool since two years of age. The *educadora* however, clearly untrained to teach a child with this severe disability, was finding it more difficult to work with her each year - impossible to give Alba sufficient attention while dealing fairly with the rest of the class of little ones. CDH managed to find money in the budget to purchase hearing aids for Alba, but the hot, dusty climate made them unusable after a short time. Living in a dirt floor house with no indoor plumbing didn't help! What was successful for a time, though, was enrolling Alba and her mom in a special school for the deaf to learn sign language. This was a huge family commitment since it took Alba's mom away from the family for long periods of time; the school was in the closest big city, a trip that took 1½ hours to walk from house to the nearest bus stop, then another 2½ hours via two buses. Tuition and travel expenses for those regular trips were covered by CDH, in part by a large donation from the DGH volunteer who had already invested her time and her heart.

These few examples from El Salvador relate just some of the many needs in rural, isolated communities in underdeveloped countries around the globe. It will not be a surprise to many readers that these inequities exist in developed countries as well, including pockets around the US. I believe that education and health care - and therapies for "special needs" children - are a human right. Imagine how these children in Estancia could soar if only provided services like those available to kids in CNY, serviced through Early Intervention and ITG! My volunteerism through DGH accompaniment is a small attempt to help bridge these injustices.

As stated in its Mission Statement, Doctors for Global Health strives: *To improve health and foster other human rights with those most in need by accompanying communities, while educating and inspiring others to action.*

Stated well by Dr. Jack Geiger, keynote speaker at the 2002 DGH General Assembly: "What we are really saying to the people we work with is that their lives are as worthy as our own; that their lives are as worthy of life as everyone else's; that all life is equally valuable. And what we demonstrate, by our presence and our work, is a commitment to the idea of equity, not as an abstraction, but as something that has to do immediately and directly with the lives of the people we work with."

Dr. Geiger continues, "Every community we accompany has unique strengths and needs, but they all share a common thread: the health inequities they face are symptoms of larger social, economic and political injustices. Malnutrition, poverty, preventable death and violence all violate basic human rights. As global citizens, we must name and challenge these injustices." You're invited to join Doctors for Global Health we chip away at that huge but hugely important challenge. As a result, we'll all be better global citizens.

PHOTO GALLERY

Additional photos from the Estancia community.



Milton in his new jogging stroller



Juan Carlos inside dirt floor, bamboo house; outside with his mother, in his new chair



Milton's parents get him to school



Jaime in doorway of house, with Don, DGH volunteer



Jaime exercising on parallel bars, outside his bamboo house



Women's Cooperative: showing off their hand-crafts for sale



Educadoras – lay “teachers” in Estancia’s preschools, after August 2009 workshop



Health Promoter, Etelvina, preparing natural medicine, CDH's version of "vicks"



Health Promoter, Silvia, checking weight of baby at kinder, site of monthly weighing of preschoolers



Post-earthquake, running the pharmacy on health brigade, 2001



Preschoolers share lunch at the kinder

Four short videos that might be of interest.

The videos labeled **Intro to Rehabilitation Center, Santa Marta (El Salvador)** and **Part 2** should be of special interest to clinicians. They show a dynamic rehabilitation center in action, narrated by Isabel Quintero, DGH volunteer to Santa Marta and current board member. Isabel is a physical therapist from Spain. Meet also the two young women who have been trained to work with diverse populations in Santa Marta needing their help. DGH recently fostered an exchange that put Health Promoters from Santa Marta and Estancia together to share experiences and knowledge.

<http://www.youtube.com/watch?v=Kj8kjqJbIR4&feature=channel> Ten minute intro to Doctors for Global Health.

<http://www.youtube.com/watch?v=HZpxtA-NXfQ&NR=1> Intro to Rehab Center, Santa Marta, El Salvador.

http://www.youtube.com/watch?v=UZBrR0MI-SQ&feature=player_embedded Part 2 of the above.

http://www.youtube.com/watch?v=dDg_jllcqdE&feature=channel DGH – Rehab & Art as Healing, Santa Marta