"The Silence that Screams"

Wise writings of a boy who had no voice for 12 years

The dream of inclusion for all

The First International Assembly of the People's Health Movement, Latin America -- held in Cuenca, Ecuador, from October 7-12, 2013 -- was primarily about inclusion: inclusion in the broadest sense, from personal to ecological to cosmic. In a spectrum of interrelated sessions, participants from many countries looked at the role that we human beings play -- individually, collectively, historically and currently -- as a mindful but troubled species on this magnificent but imperiled planet. We looked at Health in terms of connectivity -- or unity through diversity -- within the web of life that sustains us all. And from this perspective, we began to reformulate our long-elusive goal of "Health for All" in terms of the wholeness and unity that binds together every element of the universe, with all its intricate and endless variety, as a cosmic living being in which every element, from microbe to moonbeam, plays a role as a sacred and integral part. In essence, this is the holistic vision of the original peoples of the Americas: that which the inhabitants of the Ecuadorian jungles called Sumac Kausay (Buen Vivir or Living Well).

One voiceless child's struggle to be heard

Given this overarching theme of "inclusion for all," for many of us at the Cuenca Conference, one of the most inspiring sessions was the launching of a unique little book, titled "El Silencio que Grita" ("The Silence that Screams"). This eye-opening event brought the dream of inclusion for all down from the ideological cloud-world to the day to day struggle of one disabled boy to have a voice, and thereby to gain freedom from the "unspeakable" exclusion within which he lived for the first 12 years of his childhood. Yet when this child finally found a voice, the uncanny wisdom and far-reaching insight expressed in his writing fit intimately into eco-humanistic motif of the Assembly.

Matías Cepeda Monsalvo, of Argentina, was born with spastic cerebral palsy so incapacitating that -- in his words, when he finally found a way to communicate -- "I have a body that doesn't let me do anything." The youngster has no voluntary movements of his limbs, body, or mouth. Physically he is totally dependent, and has never been able to speak or use sign language.

Fortunately Matias' family is very supportive. From early childhood, his brother and sisters invented ways to include him in their play, pulled him about in a wagon, and told him stories. The laughter in his eyes told them he understood. But because he had no way of communicating, he often felt frustrated and isolated. Of his early childhood, he later recalls, "I never understood why I couldn't go to school with my brother. Without words, they couldn't know that I had a normal intelligence. If I'd been able to talk, they would have known."
For several years Matias was sent to a "special school," though no one explained to him why it was special. As he reflected later, in his book, "If that school had been more like a class, my time there would have been enjoyable. But if they don't believe you can learn, they can't teach you."

His conclusion is that, "All relations imply respecting the other person as he is, without feeling superior, and between student and teacher this should also be so."

[Toda relación implica respetar al otro tal como es, sin sentirse superior, y entre el alumno y el maestro esto debería ser así también.]

At last, at age 12, Matias says, "I came to a crossroad. . . . I discovered a way to make words, and with that my life turned around."

"Facilitated communication" using a letter board

The manner in which Matias learned to communicate was, *technologically*, refreshingly simple: *a piece of cardboard with letters on it*. Yet, *neuro-perceptively*, it was highly developed: *the sensitive hand and observant mind of an assistant*. One day Matias' parents took him to visit a disabled cousin his age, named Rezno, who likewise had no control of his movements and no voice. But to Matias' amazement, Rezno was learning how to communicate! Some months before, a speech therapist from Canada had taught Rezno and his mother a remarkable method called "assistive communication," which uses a simple letter board, or "tablita." Matias was extremely eager to try this new method. But he had no way of saying so, and to his huge disappointment, nobody suggested they try it with him. His silence was even more painful, now that he knew there might be an alternative.

But then, a few weeks later, at last he was given the chance. One day when his aunt came to visit, she brought a "tablita" similar to the one Rezno and his mother had used. On seeing it, Matias heart pounded with excitement. When his aunt asked him if he knew how to read, he recalls, "I said yes with the voice I had then: a downward thrust of my head and a sound to which they'd given the name of yes."

His aunt held the small "tablita" in front of Matias. On it was printed the alphabet in letters about half-inch high. She asked him to try to make words by pointing to the letters, as he had seen Rezno do.

But suddenly the boy felt frightened. It seemed so impossible! Although he'd learned the alphabet at the special school, he had no control whatever of his spastic arms or hands. Nor, for that matter, did he have any control of his feet -- as did Christie Brown, the prize-winning author who was similarly limited by cerebral palsy, and had used his toes to write his inspiring autobiography, called *My Left Foot*.

So when Matias' aunt suggested asked him to point to letters on the *tablita*, it seemed like a cruel joke. He knew his limitations and was scared he would fail. Even his mother, sensing his anguish and doubting the method could work, became upset and wanted to call off the experiment.
But his aunt wisely said to Matias, "Don't be afraid. I'll support your hand." Holding the *tablita* in front of Matías with one hand, with her other she firmly took hold of his right hand and extended the stiff index finger. "I'll help your hand to move where you want it to," she explained. "Just try to reach out with your finger, and touch the *tablita*, letter after letter, to form the words you want to say."

His excitement overcoming his fear, Matias strained to make his unruly hand obey his will. The spastic extremity writhed this way and that. But somehow, supporting his hand, his aunt managed to interpret where he was trying to move it. And following his lead, she helped the finger to touch the letter he had chosen. And then another letter. And another.

In this way, his aunt was able to help filter out the uncontrolled movements from the voluntary motion he wanted to make. And astonishingly, he discovered he could actually reach out and touch the letters of his choice. He began to create words! The boy was ecstatic. As he later declared in his book, at that moment a whole new "*giro de vida*" (turn of life) opened up for him. Of course a lot of practice and refinement would still be needed. But after 12 years of silence he had discovered a way to speak! He felt liberated.

But life, it seems, is never straightforward. As it turned out, there were still some huge barriers to overcome. First was convincing other people -- above all his mother -- that the letters and words his finger touched were his own, and not just the wishful thinking of his well-intending aunt.

Again, long days went by. For whatever reasons, none of his family followed though with this new breakthrough in communication. And without it, Matias had no way to tell them his desperate desire. Of this painful interim he states in his book:

"The silence continued. But now it wasn't the same, my silence was full of words. I didn't understand why the silence continued in my life. As the days passed, I thought that, like this, I didn't want to live. The opportunity had passed to insert myself into the new turn of life, and they didn't let me enter. . .

Why didn't my mother try it? Why didn't my mother believe it? Without a voice I couldn't tell her that it was *me* who was speaking!

Life has mysteries no one understands. Why is it that some adults find it so difficult to believe in simple things? ... I felt that the spark in my eyes had begun to fade."

And then it happened! One afternoon -- Matías wondered why -- his mother sat down next to his wheelchair with the *tablita* and took hold of his hand. Clearly she still had doubts that the method actually worked, but she'd decided to give it a try. It took many days of trials and frustrations until his mother learned to support his hand to the right extent, in a way that could help him move it where he wanted. But at last she was convinced that the choices behind "the moving finger" were his and not hers. He kept pointing out things that took her by surprise. At last she said to him, "... Yes, it is *your voice* that is speaking to me!"
But still, the road ahead was difficult. It took a long time until family and friends who were used to Matías' silence began, as he puts it, "to accept my voice." But little by little, others in the family learned how to converse with him using the *tablita*. Being able to express his thoughts and declare his wishes opened up a whole new and joyful world for him.

Matías was still only 12 when he had the bright idea of writing a book. I have a hard time imagining how he did it, using the method of facilitated communication with his mother literally "holding his hand" in one of hers, holding the letter-board in the other, and somehow writing down all the words he pieced together. But however they managed it, *El Silencio que Grita (The Silence that Screams)* is clearly a work of love and joy as well as deep commitment.

The book is Matías' narrative of his childhood without a voice, of his devoted family, and of his impression of what he calls his "mundito" or world that surrounds him. The small book is at once a moving work of art and a gem of human insight. With remarkably wisdom, it is a clarion call for a healthier, fairer, more caring world. What makes it even more remarkable is that Matías wrote this book when he was between 12 and 15 years old. Truly an age of transformation and wonder.

**The book launching in Cuenca**

As fortune would have it, Matías' grandfather, Julio Monsalvo, is a pediatrician and a health activist who for years has been a leader in the People's Health Movement in Argentina. When Matias completed "*El Silencio que Grita,*" Julio was so impressed with the young writer's wise intimations for a healthier co-existence, that he shared the manuscript with colleagues in the PHM. From this, the proposal arose to arrange the official launching of Matias' book at the 1st International Assembly of the People's Health Movement--Latin America (PHM--LA), held in Cuenca, Ecuador, October 7-12, 2013.

The two key speakers recruited for the book launching were Julio Monsalvo and myself. I was picked, I suppose, because of my long history in community health and disability work, and my activism in the empowerment of marginalized and disadvantaged peoples -- especially children. Also, my own newest booklet -- on *The People's Struggle for Health and Liberation in Latin America* -- would be formally launched at the same Assembly.

(Ironically, as it turned out, due to a glitch in the complicated programming of the myriad presentations and events, the launchings of Matía's book and my book were scheduled at the same time, in different venues. So I opted out of my own book-launching to take part in that of Matías -- a decision for which I am thankful.)

For the launching of *El Silencio que Grita*, I had hoped very much that Matías would be able to attend in person. But the logistics of flying the extremely spastic young man (who had just turned 18) from Argentina to Ecuador were too daunting. Instead, it was decided that Matias, with the facilitating hand and voice of his mother, would create a video which would be presented on a movie screen to the audience at the launching.
While this seemed like a good idea, I was worried by what I thought would be the snail's pace of Matias' presentation. "It will be so painfully slow," I said to myself, "that the audience will get bored, no matter how stimulating the content."

How mistaken I was! At the launching in Cuenca, after Julio and I had given our lauditory addresses and the big screen was lowered to show Matias and his mother, the audience sat spellbound for the full hour that Matias "spoke." Three-quarters of the screen was filled with Matias -- his uncooperative body strapped awkwardly into his wheelchair -- and his mother, who sat beside him holding the cardboard tablita and Matias' contorted hand. In the lower left corner of the screen was a separate image with a close-up of the tablita with the alphabet, showing the letters and Matias' hand, held by his mother. And as the boy's arched finger moved from one letter to another, his mother calmly spoke the words he spelled out.

What totally amazed me -- apart from the clarity of Matias' words and thoughts -- was the speed with which his finger moved from letter to letter. It was hard to believe that this rapid action was a duel effort, with his mother's stabilizing hand allowing his voluntary movements to find their way past his spastic discord to the desired letters. Yet, for all those competing impulses, he was able to "type" on the letter-board much faster than I can with my partially paralyzed hands, on my laptop! I marveled more than ever at the adaptability of the human mind -- or, in this case, of two human minds working together -- to overcome challenges that seem insurmountable.

I'm sure the entire audience of nearly 300 people felt the same way. Everyone was on the edge of their seats, gaping in wonderment -- both at the boy's ability to find a voice, and at the clarity, confidence, and humility with which he expressed himself.

The audience was largely made up of people in the field of rehabilitation and disability rights, including many students. Also present was a group of about 30 disabled adolescents, many with cerebral palsy, some of whom, like Matias, were unable to speak. Matias was surely an enormous inspiration and role model for them.

Adding to the power of his presentation was the glow in Matias' eyes, which punctuated and energized his key messages. One of these messages, also vividly expressed on his website, is that the greatest joy in life comes from reaching out to help others:

"It gives me strength to know I can be useful to others, this is the objective of my life. I would like my life to serve that many people find peace in their souls."

[Me da fuerzas saber que puedo ser útil a los demás, ese es el objetivo de mi vida. Quisiera que mi vida sirviera para que muchas personas encuentren la paz en su alma.]

(From Matias' site: http://www.altaalegremia.com.ar/secciones/Diversidad_entre_las_Personas.html)
In the video viewed at the Assembly, Matias expressed a flood of thoughts and feelings that he’d had bottled up inside for so long. After more than a decade of silence, this was his big chance, to address hundreds of enraptured listeners, and he was clearly thrilled with the opportunity.

Several times during the long recording, when he paused, his mother asked him if he was finished, and he repeatedly answered, NO! He expounded for nearly an hour. And everyone present marveled at how a person so young, who spent his first 12 years without a voice, had gathered such profound understanding of humanity and the world surrounding him.

In his book, Matias sheds light on this inclusive view:

"I am one part more among all the parts that form mi mundito (my little world), and if I harm one of those parts, my world won't be the same, and for that I won't be the same. If I want to be happy I should try to make every part of mi mundito happy. If every part is happy, mi mundito will be happy.

When I speak of "mi mundito" I feel I belong. I don't say this from superiority, but from belongingness, since I am no more than the other parts. All the parts are important.

Elsewhere in his book he equates happiness with Paz Interna or Inner Peace:

Inner Peace is the harmony between what we are, what we believe we are, and what we would like to be. That harmony is the result of an equilibrium very difficult to achieve. And without the capacity to keep very silent quite often, that Inner Peace will not be so easy to achieve and maintain.

Because my silences are necessarily long, I can keep quiet and look at my life and at that of those around me. This is where I feel my life has importance, because observing I can analyze, analyzing I can learn, and learning I can help.

What is surprising, given his enormous challenges, is that for the most part Matias finds a joy in being alive, and his deepest meaning in his desire to serve others.

After the presentation of the prerecorded video, Matias came onto the screen "live", via Skype. With his mother facilitating he was able to communicate directly with the audience and answer questions. This was the high point of the event, both for Matias and everyone present.

Some people reading El Silencio que Grita or attending Matias' presentation may think it incredible that someone so incapacitated in terms of his body and voice could become such a perceptive, caring, and wise person. But, on the other hand, we could argue that the young man's outstanding insight and empathy developed, not in spite of his enormous challenges, but in some ways because of them. Suffering and joy are two sides of a sphere, as are longing and compassion. Like day and night.
Of himself and people like himself, Matias speaks of their isolation, and of their potential liberation, as follows:

"There are persons in situations of confinement. My body is a jail for me. The body of people like me does not respond to the orders we give them. We're locked into the prison of our body, with the orders in our mind and no way to realize them. This produces a permanent disequilibrium in our Internal Peace.

The feeling of lack of Liberty interferes with our Internal Peace... If we can understand that ideas and feelings are not prisoners, this is where we are free.

In his writings -- both his book and website -- Matias expresses a view of life that is surprisingly consistent with the worldview of the original peoples of Amazon Basin of Ecuador, whereby people aspire to live in harmony with one another and with the natural environment. And for all life's suffering and contradictions, keeping in touch with that larger harmony -- with that spirit of oneness through diversity -- Matias has found a way to rise beyond his incapacities and enjoy the wonder in his miraculous mundito, universe, and existence.

**Helping others imprisoned by silence find a voice**

As Matias explains, one of his foremost ambitions in life is to help others in "the prison of silence" find a voice, and in finding their voice, their freedom. In this Matias has much in common with those of us who are activists the pursuit of Health and Dignity and Social Justice for All. As such, it is very fitting that Matias words, thoughts, and example were honored in the First Assembly of the People's Health Movement--Latin America.

For me, communicating with Matias has lifted my spirits. Since the event in Cuenca, we have been corresponding by email. I asked him for photos to include in this newsletter, and he has welcomed me to freely use any of his writings or materials that might help others in silence find a voice.

Matias is especially eager to help more people in his situation, who are desperate to communicate but can't do so because their bodies don't allow it, find a voice. He would like to see everyone who could benefit from the "tablita" (letter board) and the method of "facilitated communication" learn about it and use it with their loved ones.

To this end, we encourage anyone reading this newsletter -- especially those working in the fields of rehabilitation or alternative communication -- to help spread the word. Clearly the method will not work for everyone with profound cerebral palsy or other speech-limiting disabilities. But for those like Matias, who have a good mind locked into an unresponsive body, the method can be truly liberating. There are many thousands of such persons dying to find a voice.
A lot of people, like Matías' own mother at first, are very skeptical about this method of "facilitated communication." But reading Matía's book or watching the video presented en Cuenca can help dispel their doubts. Matia's mother, Liliana Monsalvo, now has become an instructor in the methodology, teaching other voiceless persons and their family members how to use it. Clearly the technique is an art as well as a science. It depends on a partnership that requires both patience and love. But when the human chemistry is right, the method can be liberating.

The beauty of the method is that the technology is extremely simple and, monewywise, virtually cost free. The only equipment needed is a homemade letter-board. No electricity. No special gadgets. Just time, enthusiasm, and love.

More information and materials

For the Ecuadorian edition [Click Here.](#)
For the Argentinian edition [Click Here.](#)

Matias Cepeda's email address: mcepeda10@yahoo.com.ar
Matias Cepeda's mother's email: Liliana Monsalvo: monsalvoliliana10@gmail.com

David Werner's talk at the launching of Matías' book. Currently in Spanish only:
"El espíritu de luchar para el buen vivir de todas y todos: Lo que podemos aprender de Matías Cepeda"
In Spanish: [Click Here.](#)

This Wikipedia article on Facilitaded Communication ([http://en.wikipedia.org/wiki/Facilitated_communication](http://en.wikipedia.org/wiki/Facilitated_communication)) reviews the ongoing controversy over Facilitated Communication, where some people swear to its validity while others claim it that the facilitators actually control or express what the disabled "client" says. The later is probably true in some cases -- especially for "clients" with limited mental capacity. But in certain cases there is strong evidence that Facilitated Communication really does work. Examples exist where a formerly "silent" person has learned to write, sometimes very lucidly, without the assistance of a facilitator. For such persons Facilitated Communication can be truly liberating.

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From October 7-12, 2013, in Cuenca Ecuador, the
Latin American regional branch of the People's Health
Movement held its first continental assembly, with the
overarching theme: "Towards a fulfilling life and
harmony between humanity and Mother Earth!" This
visionary theme is based on the holistic, all inclusive
world-view of the original peoples of Latin America,
is expressed the term "Sumac Kausay," which
translates as "Buen Vivir" or "Living Well." The
theme for the conference is a response to the global
threat to humanity and to all life on the planet posed
by the current globalized economic system that puts
the short-term economic growth of the rich before the
health and well being of all. In the indigenous
concept of Sumac Kausay, the tribal people's saw
themselves as an integral part of nature, in which the
well-being of all things, animate and inanimate, was
linked part of a single living being, and the good of
any part of that being was linked to the good of all.

In this sense, the Assembly had an overarching view
of the place of humanity in the world that was
mystical -- or spiritual in the broadest, all-embracing
sense. Speaker after speaker embraced, from a broad
spectrum of perspectives, the need for a new social
economic and philosophical paradigm that is based
not on personal competition and acquisition, but on
caring and sharing: a vision that celebrates oneness
through diversity, and which respects the rights and
inclusion of all things, great and small.

But under the umbrella of this overall universal vision of "the
rights and health of all" -- the spectrum of presentations and
forums at the Assembly were, for the most part very practical
and down-to-earth, focusing of the struggles of marginalized or
oppressed peoples to protect their lives, their health, and the
natural environment from the greedy abuses of transnational
corporations, global imperialism, and neo-colonialization. From
Ecuador and neighboring countries, there were well-documented
presentations of how powerful foreign oil companies and mining
consortia -- backed by the US government, the CIA and, when
necessary, the military, ruthlessly plundered the forests, the
rivers, the livelihoods, the health, and the lives of indigenous
populations, savaging their cultures and driving many of them to
disintegration or virtual extinction.
What became distressingly clear in the two twin assemblies -- of PHM and of ReAct -- is that the biggest threats to the future of humanity and the ecosystems we depend on come from the current "neoliberal" capitalist system that calls for endless economic growth and puts private profit before the public good.

The big question in the PHM Assembly, of course, is what to do about this inequitable, unsustainable, and now totally globalized economic system. The need for radical change was apparent, and proposals for action were widely discussed. No one doubted that struggle for change would be an uphill battle. The concentration of wealth and power behind the dominant system is formidable. Not only does the world's ruling class controls the social and pecking order, but to a very large extent it dictates the content of public education and the mass media, both of which are aimed more at social control than at awareness-raising or collective mobilization for change.

Most participants agreed that the momentum for radical change must come from the bottom if humanity is to advance toward "health for all" by taking effective action against global warming, escalating bacterial resistance, world hunger and other approaching manmade tsunamis. A critical mass of people must become aware of the major problems we collectively face, and concerned enough to take effective collective action. In turn, for this to happen, we need alternative "people-centered" methods of education and information sharing, which can gradually replace the current top-down systems of brainwashing and dumbing down.

With this in mind, in my presentation at the Assembly, I put a lot of emphasis on the methods of "Education for Liberation" or "Education for Change" that have been developed in Latin America and widely used in Community Based Health Care. Likewise I stressed the empowering possibilities of "Discovery-based Learning" used in the so-called "Child-to-Child" approach where school-aged children learn to help with health need in their homes and communities.

This paper I presented in Cuenca is titled "People's struggle for health and liberation in Latin America: a historical perspective." In the paper I give an historical overview of the key role that community-based health programs and health workers played in the grassroots mobilization of disadvantaged people in the organized action and popular resistance that led to the overthrow of oppressive regimes, and their replacement (at least temporarily) by more egalitarian leaders.

A more extensive, illustrated version of my paper -- which was published as a booklet for distribution at the PHM Assembly -- is available online. To read the English version, click here. For the Spanish version, click here.
The 1st International Assembly of the People's Health Movement--Latin America in Cuenca was held jointly with the 2nd Regional Seminar of ReAct (Action on Antibiotic Resistance.) At first glance, a seminar devoted to Antibiotic Resistance may seem very specialized and extraneous to the universally holistic theme of the PHM Assembly. However, the theme of the React seminar -- "Recuperate the Health of the Ecosystems in Order to Combat Bacterial Resistance" was approached by speakers in a way that tied the global escalation of bacterial resistance to antibiotics to the profit-hungry abuses of corporations. This was seen as part of the same capitalistic exploitation that triggers the transnational plundering of rainforests and corresponding genocide of indigenous peoples. The destructive activities of the powerful extraction industries, Big Pharma and Big Agro were highlighted. And the driving force behind the deadly practices of all these giant transnationals is the free-market pursuit of unbridled economic growth, regardless of the human and environmental costs.

In terms of human and environmental costs, the flagrant overuse of antibiotics -- in everything from billions of prescriptions for the common cold (where antibiotics do no good and kill beneficial bacteria) to the routine inclusion of antibiotics in the feed of live-stock, to stimulate growth, [see note below] is leading to potentially genocidal levels of resistance. If the current irresponsible pattern continues, with poor governmental regulation due to the powerful lobbies of the multi-billion-dollar industries, many infectious diseases may become totally resistant even to the newest and most costly antibiotics. As a result, vast sectors of humanity may die prematurely, as was the case in times past with such horrific epidemics as the Black Plague, or measles with native Americans in the days of colonization.

Pertinent links:

David Werner's booklet titled The People's Struggle for Health and Liberation in Latin America, a historical perspective, October 2013, HealthWrights. English: [Click here.](#)

In Spanish: La lucha de los pueblos por su salud y liberación en América Latina: perspectiva histórica, por David Werner, published for and by The People's Health Movement Latin America, October, 2013. Spanish, [Click here.](#)

People's Health Movement--Latin America: (in English and Spanish) [www.phmovement.org/en/node/8047](http://www.phmovement.org/en/node/8047)

The First International Assembly of the People's Health Movement--Latin America was held jointly in Cuenca with an international meeting of ReAct, a global initiative to combat the overuse and misuse of antibiotics. This perilous overuse, promoted by Big Pharma and the Big Livestock Industry, is causing the escalating emergence of resistant strains of bacteria. This pending global crisis may soon put humanity back into the times of mass epidemics and high mortality from infectious diseases that once again become incurable. To learn more about ReAct and its mission, see:


ReAct en America Latina: [https://www.facebook.com/ReactLatinoamerica](https://www.facebook.com/ReactLatinoamerica)