



# Newsletter from the Sierra Madre #66

April, 2010



## **PROJIMO Community Based Rehabilitation Program**

run by and for disabled villagers in western Mexico (Coyotitan)

## **HEALTHWRIGHTS**

Workgroup for People's Health and Rights

## **PROJIMO Skills Training and Work Program**

run by disabled youth in rural Mexico (Duranguito)

*This newsletter reflects on the 2nd Continental Congress on Community Based Rehabilitation held in Oaxaca, Mexico, and celebrates the potentially liberating changes that are under way in the concept and practice of CBR. The Congress also provided feedback on programs in different countries where David Werner has facilitated evaluations and workshops in recent years. This includes good news from a boy in Ecuador about his progress after a workshop there last May.*

## **The Evolution of Community Based Rehabilitation: Impressions of the 2nd Continental Congress on CBR**

*by David Werner*

### **The changing face of CBR—new features:**

#### **Trend toward *Inclusive Development*.**

In concept, and slowly but surely in practice, “Community Based Rehabilitation” (CBR) has been evolving in empowering and potentially liberating ways since it was launched by the World Health Organization (WHO) 3 decades ago. Indeed, the politics and social philosophy behind CBR have metamorphosed so radically that Chapal Khasnabis, current CBR wizard at WHO, now shuns the term “*Community Based Rehabilitation*.” Rather he champions “*Community Based Inclusive Development*.”

This conceptual transformation of CBR was strikingly palpable at the 2nd Continental Congress on CBR held in the city of Oaxaca, Mexico, March 3–5, 2010. The Congress was a major event, sponsored by various UN agencies, government institutions, and non-governmental organizations. Most of the 600+ participants are active in non-government CBR initiatives. They came from 16 countries of the Americas and the Caribbean.

**Increased leadership by persons with disabilities.** In keeping with the theme of the Congress “*Hacia el Desarrollo Inclusivo*” (Toward

Inclusive Development), a refreshingly large percentage of the participants, as well as speakers, were people with disability. Leaders from a wide range of associations of disabled people took active part. This strong representation of people with disability was a welcome change from the previous CBR Congress—and many others like it—which have typically been dominated by high-level non-disabled hotshots, with only the showcase inclusion of a few “token crips.”

**Greater focus on human rights—of everyone.** Likewise, in the spirit of inclusiveness, at this Congress in Oaxaca there was strong emphasis on basic human

rights, and the need to struggle for equal opportunities for everyone, including other marginalized groups. Equity-oriented development of the community as a whole was clearly and appropriately highlighted.

**Combating poverty.** In this context, there was considerable emphasis on the vicious causative cycle between disability and poverty, and therefore attention was given to the need for an economic and development model—from the local to the global level—that empowers the poor and guarantees that all people will have the resources to meet their basic needs. In the world today over one billion people (1 out of every 7) are hungry, and the number is growing. Children are hit especially hard by this fact. Community rehabilitation must enable and mobilize all who are disabled, impoverished, hungry or marginalized. Thus “Inclusive Development” has to grapple with the biggest challenges currently facing humanity and the planet in the 21st Century.

**From “training” to empowerment.** The original theoretical design of CBR, back in the 1980s, was for the most part top down. Governments, rehab professionals, non-governmental organizations (NGOs), community leaders, volunteer “local coordinators” and marginalized



In the 2nd Continental Congress on CBR it was good to see how far CBR has moved toward being open-ended and inclusive.

families were all expected to work together to “train” disabled people to function better and “integrate” more fully into the community, which in turn would be educated to accept them. (The first CBR manual was titled “Training Disabled People in the Community.”) These were, as far as they went, laudable goals. What was often lacking was the inclusion of the people with disabilities as equals in the planning and decision making processes. From what I heard at this congress, it would appear that this problem has been recognized and is being addressed.

### Government and NGOs working more closely together (sometimes).

One of the outstanding features of the 2nd Continental Congress on CBR was the participation and building of alliances between government and non-governmental programs. Present and participating at the Congress, at least for the first day, were the heads of the *DIF* (Integral Family Development) programs of Mexico at both the national and state levels. (In Mexico, most government programs and services concerning disability are coordinated by the *DIF*, which are headed by the wives of the current elected president or governor.) The *DIF* directors gave very supportive speeches at the beginning of the Congress. At the close of the Congress, the President’s wife (head of *DIF* for the nation) announced that Community Based Rehabilitation would henceforth become an official nationwide program, promoted by *DIF* working together with NGOs.

### Confronting the institutionalized abuse of power.

Greater cooperation between government and non-government initiatives is, at least in theory, a big step forward. However, in nations or communities where the government has strong ties to an elite minority committed to policies that widen the gap between rich and poor, problems tend to emerge. In most countries, at least in Latin America, governments have dragged their heels in launching CBR programs. Of the few programs spearheaded by governments, most have petered out. With few exceptions, the most vibrant and successful CBR programs have been initiated by NGOs, religious orders, and (more recently) by organizations of disabled persons themselves.



In the early years of CBR, the focus was primarily on alleviating the child’s disability, with too little attention on the basic poverty-related needs of the child and family. Today, CBR—with its increasing focus on “Inclusive Development”—tries to help the whole family and community live in more empowering, less disabling circumstances. While in practice there is still a long way to go, this new conceptual framework is encouraging.

It remains to be seen how much the CBR goal—based on equitable inclusion of marginalized groups—translates into effective praxis.

### The need for experienced welfare program chiefs, rather than first ladies.

In each round of national, state and municipal elections, new presidents and governors come into power, and their wives become the new heads of *DIF* at the different levels. In this congress these women were quite supportive and were clearly making a strong effort, and with good luck they will continue to. Nevertheless, these directors are not chosen to head these important family services because of their qualifications, interest or abilities. Furthermore, they often dismiss the experienced former staff to employ their personal friends, and replace successful programs with untried new ones, often with more emphasis on appearances than demonstrable benefits.

A suggestion which was widely discussed in whispers at the Congress was that governments should reassess the tradition of putting the “first wives” of top politicians in charge of public-service institutions. Instead, they should enlist the services of experienced persons who have a track record of compassionately working for the rights and empowerment of the disadvantaged. Although many participants at the Congress thought this was a good idea, I was told it would be virtually impossible to change such an entrenched tradition.

Equalization of power is more easily dreamed of than achieved.

**Toward a broader, more flexible definition of CBR.** Another positive trend that became clear in the Congress is an increased flexibility in defining what CBR is. The original designers of the CBR concept—mostly European rehab professionals—instituted a fairly rigid definition of CBR. To qualify, a program had to fit into a specific box, with detailed dos and don’ts. If a program did not conform to the official recipe, it could not be called Community Based Rehabilitation—and was therefore excluded from the club.

The rigid prescription for CBR of course contradicted the underlying vision of diversity and inclusiveness. To those of us with disabilities who worked in community programs, these inflexible recipes for inclusion struck us counterproductive. If

CBR were to evolve into a liberating process, there needed to be a wide diversity of approaches. No preordained model should be upheld as the right one. Programs needed to be able to innovate and be creative: to experiment and adapt to local needs and possibilities. Some improvisations would work out well and some not. By networking, we could all learn from each other’s mistakes and successes. Through trial and error CBR could improve and evolve. The quest for inclusion would remain an adventure, not a prescription.

### FREEDOM OF CHOICE



When CBR was first promoted, it was fairly rigidly defined by professionals. Local communities had little “freedom of choice” to change or adapt the prescribed model. Now things are changing: **from top-down to bottom-up.** People with disabilities are increasingly becoming leaders, or subjects, of the CBR process, rather than meekly remaining recipients, or objects. (Cartoon from a talk, at the Congress, on “Sustainability,” by Olmedo Zambrano.)





Dr. Chapal Khasnabis (center), now the lead advocate of CBR at WHO, has stressed the importance of a Human Rights approach that promotes **Inclusive Development for All at the Community Level**. He advocates a more flexible approach, adapted to the needs and possibilities of each community.

**The central role of organizations of people with disability.** Disabled activists have advocated for open-ended diversity in the implementation of community programs for many years. Many were highly critical of CBR. They resisted “rehabilitation” according to other people’s rules. They didn’t want to be “normalized” into an unfair and hierarchical society. Rather, they wanted to change society: to make it more inclusive, more equitable, and more welcoming of diversity. As Joshua Malinga, the South African dis-

abled activist said, “It’s society that needs to be rehabilitated!”

**Professionals on tap and not on top.** This groundswell from below—from the disabled community and their advocates—has had a transformative influence on CBR. The new movers and shakers for the process in WHO and other UN organizations—as represented by Chapal Khasnabis of WHO—have become outspoken champions of diversity within CBR, and advocate for the exploration of a wide variety of models. They encourage greater leadership by people with disabilities and their family members, and insist that service providers and pro-

fessionals be on tap and not on top. Today the promoters of CBR not only use the rhetoric of empowerment, but are beginning to stand to one side and let people organize and innovate on their own terms.

Of course this process of empowerment and inclusion is still far from complete, and it will remain so as long as we live in such a stratified society.

**Social Justice from the bottom up.** What I found most exciting about the CBR Congress is the spirit of change. People on the bottom are no longer willing simply to be trained to fit in. They want to join with other marginalized peoples in the struggle for a fairer, more inclusive, more egalitarian society.

For all its organizational foibles, I found the Oaxaca Congress exhilarating. Who knows?—Perhaps humanity has a small chance of surviving after all!



Of the 16 countries that participated in the Continental Congress on CBR, Colombia had by far the largest number of programs represented. In the closing ceremony the contingent from Colombia gave a rousing salute on stage.

## Theater of Liberation: The Voices of Suki

For me the most inspirational event of the Oaxaca Congress was a theater skit on the second evening. It was performed by a troupe of disabled actors who called themselves *El Tren de Duermevela* (The Train of Sleep-Waking). All the actors have spastic and/or athetoid cerebral palsy. The youngest is 12 years old, the oldest 22. They are members of ConNos/Otros, the Center of Conductive Education in Jiutepec, Morelos, Mexico.

The play, titled “*Las Voces de Suki*” (The Voices of Suki), was written by Ekiwah Adler Beléndez who also has cerebral palsy. In the opening scene, Suki, a young man with cerebral palsy, sits despondently in a tall-backed wooden therapy chair at center stage. Around him in the shadows sit the draped figures of his various moods, or Voices: Anger-and-Desperation, Fear, Shadow, the Injured-Child, the Spirit-of-Silence, the Voice-of-the-Heart, Will-

power, and Hope. Another disabled actor plays the Therapist. Some of these Voices of Suki perch in wheelchairs, most huddle on the floor. Anger-and-Desperation struggles to hold herself upright with a walker.

power, and Hope. Another disabled actor plays the Therapist. Some of these Voices of Suki perch in wheelchairs, most huddle on the floor. Anger-and-Desperation struggles to hold herself upright with a walker.

The various Voices take turns visually and verbally vying for Suki’s attention. However, many of the actors have difficulty forming words because of their oral spasticity. At one point Anger-and-Desperation gets into an argument with Hope. The rest of the Voices vote on which has the better, more reasonable view. They decide in favor of Hope. Then

the Voice of the Heart begins to speak, the actor’s body contorting with spasticity. His distorted words are almost impossible to understand, but after each phrase an unidentified voice repeats clearly what he says. And it is pure poetry, beautifully exploring the passions of the human heart, and is a cry for understanding, acceptance, freedom and love.



In the play, Suki (in chair), a young man with cerebral palsy, is surrounded by his diverse voices, or moods—all acted by other young people with cerebral palsy.



most transformative of all, the faces and bodies of the actors, for all their distortions, begin to radiate a sense of joy, acceptance, and pride in who they are. Glorious and absolutely shameless! They thrive and delight in sharing with the world at large their vital artistry—with all its wonders and struggles, challenges and pain. The production was a wondrous, liberating experience for everyone, off stage and on. At the finale, the audience (or at least all who were able to do so) rose in a standing ovation. And the actors—empowered by the current of connection, their untamed bodies twisted with excitement—



At the close of the play the actors—especially the 12-year-old boy, Omar—were thrilled to be seen for their abilities rather than their disabilities.

took their bows and, in their own strange way, beamed like a mist-melting sunrise.

I'll never forget the exuberance and pride on the face of the youngest actor—a nerve-damaged but strangely beautiful 12-year-old boy—unable to walk yet in spirit able to soar! How fortunate he is to have as his peers such creative and liberating role models! ... We all came away more bonded and less bound.

To contact the theater group, *El Tren de Duermevela*, or to make contributions, write to Mágara: [Sermara@aol.com](mailto:Sermara@aol.com).

## Feedback on workshops and evaluations facilitated in other countries

As is usually the case in big international conferences, while many of the presentations were excellent, a great number of repetitive generalizations were delivered by a long parade of speakers. The most worthwhile part of such conferences often is the informal meeting of people and exchange of ideas that takes place in the intermissions and hallways. And this Congress was no exception

For me, one of the most valuable aspects of the Oaxaca Congress was the chance to reconnect with friends and representatives from countries and programs I've previously visited throughout Latin America and the Caribbean. Through such encounters I was able to get updates and feedback on CBR initiatives where I have facilitated workshops or evaluations over the last decade. These included consultations and evaluations in Honduras, Guatemala and Cuba, and Assistive Technology Workshops in Columbia, Peru, Ecuador, Bolivia and Brazil.

On the whole, the feedback I got in this way was very encouraging. I will mention a few examples:

**Cuba.** I met with the new coordinator, for Handicap International Belgium, of the first Community Based Rehabilitation program in Cuba, located in the Province of Granma. She told me that the participatory evaluation I'd facilitated there in May 2004 (see Newsletter 52: <http://healthwrights.org/Newsletters/NL52.pdf>) had led to a number of substantial improvements. For example, among my recommendations, I had suggested that the families of children with intellectual disability have stronger representation and leadership in the program. Now, she said, this is happening. Among other things, the program has organized a campaign for the mainstreaming of such children in schools. Likewise,

Child-to-Child activities have been introduced, so that schoolchildren will be more welcoming and helpful to a child who is different. The new coordinator urged me to come back for a visit and to conduct a participatory technology workshop.

**Colombia.** At the Congress I had a good discussion with Estella Ortiz, coordinator of nearly 40 local mediators for Stichting Liliane Fonds in Holland, in the southern part of Colombia. Estella participated in a CBR Assistive Technology workshop I facilitated in Monteria in 2008 (see Newsletter 62: <http://healthwrights.org/Newsletters/NL62.pdf>). She told me since my visit she has organized a number of similar workshops with groups of mediators and families of disabled children, and that these have helped participants take a more participatory, innovative approach to problem solving and assistive technology.

**Brazil.** It was my great pleasure to meet at the Congress a young woman by the name of Gloria Pimentel, from Recife. Gloria has just graduated with a degree in "Public Service" from the Catholic University in Pernambuco, where her thesis was on Community Based Rehabilitation. Gloria's infatuation with CBR can be traced back 14 years to a workshop on CBR that I facilitated in Recife in 1996 for CORDE, a disability service program of the Brazilian government. (See Newsletter 34: <http://healthwrights.org/Newsletters/NL34.pdf>)

Gloria had been raised in a home for abandoned children started by one of the participants in the Recife workshop. This was Father Eduardo Figueroa, a Catholic activist whose life work with the poor and oppressed reflects his ties to the Theology of Liberation. Some of the children in the home Padre Eduardo ran were disabled, and he wanted to help them become included in the community.

At the time Father Eduardo attended my CBR workshop, Gloria was just 5 years old. As an infant she had been abandoned by her parents—whom she had never known—and Father Eduardo had taken her in. So Gloria grew up in the children's home at the time when Padre Eduardo was experimenting with aspects of Community Based Rehabilitation in the surrounding communities. As a child she had read my books *Disabled Village Children* and *Nothing About Us Without Us*. Since she grew up in company with the disabled children in the Home, it was only natural that CBR became a part of her life and her dreams.

In her thesis, on "The Contribution of Social Service to the Efficacy of Community Based Rehabilitation" Gloria advocates an empowering approach where CBR addresses the underlying questions of equity and equal opportunity, not just for those who happen to be disabled, but for everyone. The ultimate objective of CBR, she asserts, is "*uma construção de uma nova sociedade, mais justa e igual*" (the construction of a new society, more just and equal.)



Gloria Pimentel of Brazil and David Werner at the CBR Congress in Oaxaca



## Ecuador—Feedback on a CBR Participatory Technology Workshop: A message from Jeferson



Jeferson's uncontrolled movements made it hard for him to stay seated in his wheelchair.

At the CBR Congress, the most heart-warming feedback from my sojourns in other countries came from Elizabeth Terranova, coordinator of a grassroots CBR program in Guayaquil, Ecuador. In April, 2009, I had facilitated an assistive technology workshop there. One of the children whose home we visited was a 13-year-old boy, Jeferson, who has cerebral palsy. A group of participants, together with his family, had made assistive devices for him during the workshop. The combination of spasticity and constant uncontrolled movement (athetosis) impedes the boy's control of his body so much that his mobility, hand-use, and self-care skills were extremely limited. He was unable even to crawl, and struggled to stay upright in his wheelchair. Although he has some trouble with speech, he is intelligent and perceptive. Despite his struggles with his unruly body, he has a wonderful spirit. He is eager to try anything that might help him do more for himself and become more independent. I took a liking to him at once, and the feeling was mutual.

We found that Jeferson's inability to do much for himself was greater than need be, in part because his very loving family did almost everything for him. Our challenge was to help him find ways to do more for himself.

In our exploration of Jeferson's wishes and possibilities, the two things he said he wanted most were to *get dressed* and to *go to the bathroom by himself*. At present, his mother had to carry him across a gravel patio and place him on the toilet. As he got bigger she began to develop a back problem.



Jeferson's mother had to carry him across a gravel patio to place him on the toilet.

But a possible solution was at hand. Although the boy couldn't lift himself onto a standard toilet, while crouching on the floor he could lift up his butt.



While crouching on the floor Jeferson could lift up his butt. Then perhaps he could sit on a ground-level commode.



They put the sawed-off legs of the improvised commode in sand-filled bottles so the added weight would give stability.



Jeferson's group presents their ideas at the workshop.

So in the workshop he and his group designed a "low-rider commode." They cut a hole in the seat of a plastic chair, sawed off the bottom 2/3 of its legs, and for stability put leg stumps into sand-filled plastic bottles. With a bit of help from his mother, but no heavy lifting, Jeferson could get onto the commode and use it. He was determined to learn to do it without help. Also, with practice he hoped he could learn to take off and put on his clothes.



With a minimum amount of help the boy could sit on the commode.



Jeferson sits happily on his new commode.



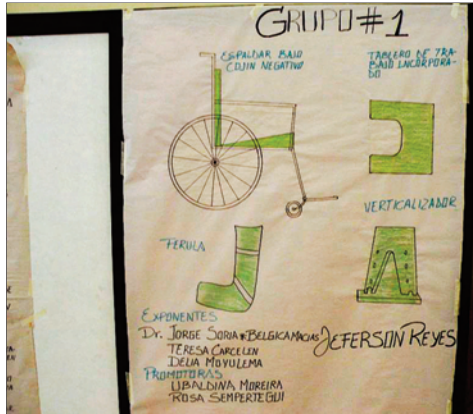


Jeferson tries drawing and writing with his mouth.

But what Jeferson most longed for was a computer. Every day his brother pushed him in his wheelchair to school, and he was learning a lot. But his efforts to write were very frustrating. He had trouble holding a pencil, and before he could complete a letter his hand would jerk this way or that. But with effort he could punch the keys of a computer, and perhaps with practice he could learn to express himself with the written word. That could be the window to a whole new way of communication. Jeferson was so excited with his dream of a computer that we all agreed that an effort should be made to get him one.

The workshop in Guayaquil was an empowering experience for Jeferson and his family, which opened up many new possibilities. But it was just a start. Where it would lead remained to be seen.

**News from Jeferson a year later.** In the year that passed after the Guayaquil workshop I had received bits of news but no detailed feedback. Then—at the CBR Congress Oaxaca this March—I was cheerfully greeted by Elizabeth Terranova, the CBR Coordinator in Guayaquil, who handed me a small package “from a friend!” It contained a typed letter and a CD video.



The group also made a variety of modifications of his wheelchair, so he could sit more stably and begin to do more things for himself.

The letter begins, “Hola Dr. Bewner. Soy Jeferson. tengo mucho que contarle,” and he tells me all the things that he has learned to do thanks to the ideas and devices that had come out of the workshop. “My mother fixed up a room and now I can go to the toilet myself, brush my teeth, bathe myself, and eat without help.” In the video (filmed by the local CBR worker) Jeferson—who now speaks more clearly—eagerly demonstrates some of his new skills. He shows how he can now climb off his bed onto the floor and (using homemade kneepads) tumble and roll himself to wherever he wants to go. He proudly shows how he can take off his shirt, which—given his constantly writhing body—is an impressive gymnastic feat.

Also in the video he jubilantly shows off his new computer, which he is passionately learning to use. The computer was donated through a local radio campaign organized by the CBR team and friends.

At the end of his letter, Jeferson says:



“I have now finished grade school and am entering *el bachillerato* (high school). I want to study *informática* and be able to connect with you by computer so I urge you send me your email address. Affection and hugs. *Chao.*”



Ubaldina, a CBR promoter, helps Jeferson learn to move about more effectively.

*It is this kind of personal, heartfelt feedback from those I have connected with that makes this kind of hands-on workshop worthwhile.*



In the video Jeferson sent me, he shows how, since the workshop, he has worked very hard to learn to take off his shirt.



Although it took a big effort, he is proud of mastering his new skill.



# Outcome of the Congress on Community Based Rehabilitation in Oaxaca

One of the key outcomes of the Continental CBR Congress in Oaxaca was *an emerging sense of solidarity at three levels:*

**First**, solidarity at the level of Community Based Rehabilitation programs within countries and internationally. A commitment was made to form a *Continent-wide network* for all of Latin America and the Caribbean. This network would in turn be part of *worldwide net-*

*work* being spearheaded by Dr. Chapal Khasnabis of the World Health Organization.

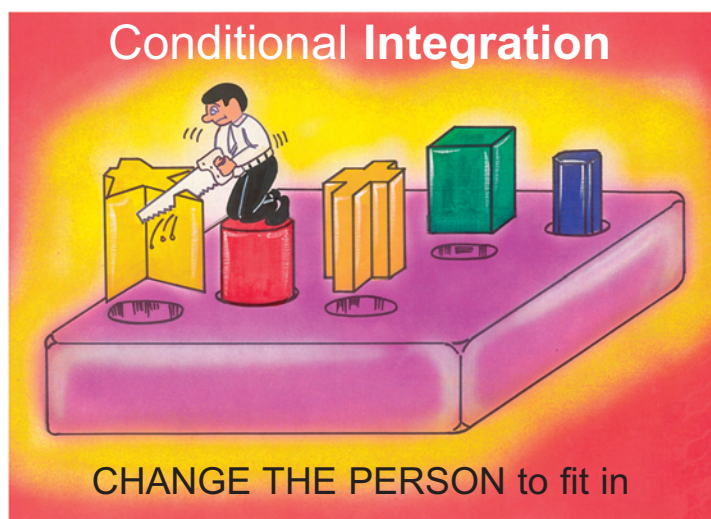
**Second**, an empowering sense of solidarity at the level of people with disability, their organizations, and their families, *embracing all disabilities and strata of society.*

**Third**, a growing spirit of solidarity with *all oppressed and marginalized groups*, locally, continent-wide and globally. This

broader vision of CBR—or better said, *“Inclusive Development”*—as part of a grassroots struggle to build *a fairer, more inclusive, more sustainable world for all*, was to many of us the most promising and empowering hallmark of the Congress.

The evolution of CBR toward a developmentally revolutionary, politically inclusive movement was reflected by speakers at the Congress, in the following cartoons:

Katharina Pfortner of Christofel-Blindenmission (CBM) illustrated the difference between the earlier goal of “Conditional Integration” or “Normalization” of the disabled person into society and the current CBR goal of “Inclusion” and “Empowerment.”



Formerly the goal was to change or normalize the person-who-is-different to fit in to society as it exists.



Today the goal is social change: to welcome diversity and build a fairer, kinder, and more sustainable society for all.

EDUCATION FOR ALL

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**cbm**  
juntos logramos más

**Tensión entre las respuestas de los proyectos RBC y las necesidades sentidas de las personas con discapacidad**

In his presentation, Olmedo Zambrano stressed that the evolution of CBR has in large part resulted from the *“Tension between the response of CBR programs and the felt needs of people with disabilities.”*

In closing, I’d like to echo the sentiment of disabled activists in many corners of the world:

*“We do not want to be normalized into an unjust world that excludes those who are different or disadvantaged. Rather we wish to join with all underprivileged groups to build a kinder, more socially just world: a world that celebrates diversity and upholds Equal Rights and Full Inclusion for All.”*

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**April 2010**

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In a workshop David Werner facilitated in Guayaquil, Ecuador in 2009, participants and a young friend fit a footrest onto Jeferson's wheelchair.

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This issue of *Newsletter from the Sierra Madre* was created by:

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*“It’s society that needs to be rehabilitated!”*

—Joshua Malinga, South African disabled activist

