



HEALTHWRIGHTS

Workgroup for People's Health and Rights

Newsletter from the Sierra Madre #68
August, 2011



Rigo Delgado's story

A disabled activist's daring work in disability rights:

David Werner

Formative years at PROJIMO

When Rigoberto Delgado first arrived at PROJIMO in 2002 his hopes for the future were dismal. A few months before, at age 24, a car accident had left him quadriplegic (paralyzed from the neck down) for life. He had lost control of most of his body, including urine and bowel functions. He had limited use of his arms but couldn't grasp with his hands. He was completely dependent on family members for all his basic needs. It was as humiliating as it was depressing.

Rigo had heard about PROJIMO – a community rehabilitation program run by disabled villagers in the town of Coyotitan, Sinaloa, Mexico – and decided to go there as a last resort. The fact that the program's two leaders were spinal-cord-injured like himself gave him a bit of hope. If they could run a program helping disabled persons move ahead with their lives, perhaps he had a chance, too. But still he had misgivings. After all, the two women who directed PROJIMO were paraplegic (paralyzed from the waist down) and still had use of their hands – whereas his upper limbs were also involved. How could someone as incapacitated as he was ever dream of independent living? Yet he still held on to that dream. Depressed as he was, something inside him wouldn't give up.

Fortunately for Rigo, the person who took primary responsibility for his rehabilitation when he was first at PROJIMO was Julio Leyva, who like Rigo was quadriplegic. As a boy Julio had been shot by his younger sister when playing with their father's pistol. Julio had been with PROJIMO, off and on, for over 10 years – first as rehabilitatee, then as rehabilitator. Over the years he had learned a lot of skills and had become remarkably self-sufficient in terms of mobility, self care, and daily needs. Some skills he'd learned at

PROJIMO, some at Shriners Hospital's Spinal Cord Injury Unit in San Francisco, and some he'd figured out for himself through trial and error.

There was nothing Julio enjoyed more than teaching other spinal-cord-injured persons – especially “quads” like himself – to become more self-reliant. He believed in learning by doing, and taught in ways that were challenging and fun. And he was an example of what could be accomplished. For Rigo, Julio wasn't just a teacher: he was a mentor and a friend. With his guidance, Rigo learned how to propel a manual wheelchair, transfer to his bed, bathe and dress himself, and even put on his socks and shoes. He learned to use his teeth to hold and pull things, and to trigger his spasticity to push his legs into his pants. He found ways to use the contractures in his hands to feed himself, to write (if poorly) – and to use a computer, which turned out to be one of the most of the most liberating skills he mastered.

One of Julio's “income generating” jobs at PROJIMO was teaching Spanish-as-a-second-language to visitors from other countries. Julio invited Rigo to be an assistant teacher, and Rigo – whose diction is clear and who is a born pedagogue, jumped at the chance. The two made a good team. Julio – who had dropped out of school in the third grade – was best at conversational Spanish – using jokes, role plays, and

story-telling. Rigo had begun college. He had a very organized mind and enjoyed teaching grammar. He did so well he was soon given a modest salary. Students were delighted with Julio's and Rigo's teaching, and as news spread by word of mouth, many more Spanish students enrolled.

During the 9 years that Rigo worked at PROJIMO he became an increasingly important member of the team. One of his key roles was in the Community Awareness Raising Project. Twice a month several disabled team members would drive to a neighboring village and organize an event at the local school, or with village leaders. They would facilitate discussions and activities concerning inclusion, accessibility and the rights of persons with disabilities.



Rigo and Virginia (with her son Jose Carlos) teaching Spanish to visiting volunteers at PROJIMO. The Spanish course was set up to generate income both for the program and the disabled instructors.

What Rigo enjoyed most on these community visits, and where he proved most innovative, were the Child-to-Child activities. “Child-to-Child” is an approach whereby school-aged children learn to help protect the health and encourage the



Rigo leads a workshop in which people without disabilities learn something about what it might be like to be blind.

development of other children. I (David Werner) have been active in promoting the concept and practice of Child-to-Child, both locally and internationally, since this approach was launched in the late 1970s. Since the early 80s I have helped extend the Child-to-Child methods to include needs of disabled children. At PROJIMO the team introduced a number of Child-to-Child activities with groups of schoolchildren. But the person who made it a key part of his community visits was Rigo.

Conflict and departure from PROJIMO

In the “awareness raising” activities Rigo helped facilitate in neighboring villages, he and his peers put a lot of emphasis on equality, inclusiveness, participatory decision making, equal opportunities, and equal respect: in short, on democracy. This was the humanitarian vision on which PROJIMO was founded three decades ago. It was reflected in the fact that this program for disabled people was run by disabled people. In the early years, the program was led by elected and rotating “coordinators” (not directors) whose job was not to boss other people about but rather to see that the will of the collective was smoothly applied.

But as so often happens with programs that begin with ideals of democracy and equality, power gradually began to concentrate in the hands of a privileged minority. Two women leaders, who had in many ways done an outstanding job at keeping the program alive

over the years, and who were skilled in raising funds, became very powerful. Although the façade of democratic decision making was maintained, the program in fact came to be run in a very authoritarian manner by these two leaders. Eventually they were able to build stately homes for themselves and achieve a lifestyle that was far more expensive than that which was possible for the other team members, who lived in relative hardship. It was felt by some that this economic advantage was related to the manner in which the women ran the program.

Needless to say, this emerging class structure within the ranks of PROJIMO led to some discontent among those on the bottom of the stack – especially the old timers who recalled the early days of participatory democracy and relative economic equality. But those who tried to criticize the top-heavy power structure almost invariably have been forced out of the program. The stated grounds for the expulsion of dissenters has often been “breaking of the rules,” such as alcohol or drug use on the grounds. Julio was, among the first of the dissenters expelled. As the more outspoken members of the PROJIMO team were eliminated, the control by the chiefs became more deeply entrenched.

However, a bureaucratic obstacle to this “leadership for life” pattern emerged. Since PROJIMO became registered as a charitable organization, it is required by law to change its Board of Directors every two years. While this has been done on paper, the real leadership has remained in the same hands. The two program chiefs always try to make sure that the persons nominally “elected” as board members are subservient enough to pose no threat to the established power. A few years ago the chiefs selected Rigo as nominal President of the Board. Rigo is quiet, well mannered, and gets along well with all. When he first joined the program, he was very unsure of himself and non-complaining. But as his skills and self-confidence grew, so did his discomfort with how the program was managed. He was especially unhappy with the manner in which Julio was treated, and finally expelled. So when Rigo became the official President of the Board he began to look for ways to make decision-making more democratic – and to get other team members to speak up at meetings. At first his efforts were largely unsuccessful. Those who still remained on the PROJIMO staff had learned to keep silent and swallow their grievances.

But when the leaders unilaterally awarded a huge end-of-year bonus to themselves, this precipitated a crisis, and Rigo was able to organize a strike. One morning no one came to work. Instead, the workers presented their collective demands. The leaders were furious. They removed Rigo from his nominal role as President and from his membership in PROJIMO’s core group. They slashed his salary to a pittance. The rest of the staff were too cowed to do anything except go along with the leaders, in fear the ax might fall on them too.

Rigo remained in his demoted position at PROJIMO for several months. Already he had been dreaming of studying in the “Community Psychology” program at the Autonomous University of Sinaloa (UAS), in Culiacan, the state capital. When the head of the department, Mario Carranza (who takes groups of students on service projects to PROJIMO), offered him a scholarship, Rigo made the daring decision to accept. He resigned from PROJIMO, moved in with his sister in Culiacan, and enrolled in the UAS.



Professor Mario Carranza, Director of the Community Psychology at the Autonomous University of Sinaloa, has been incredibly supportive of Rigo’s studies and community work.

That was perhaps one of the best decisions of Rigo’s life. That is to say, best for Rigo, and best for a lot of people he has managed to help as result of that decision. Whether or not his decision was the best for PROJIMO is another question. His departure was a big loss to PROJIMO. But part of Rigo’s wanting to study Community Psychology was – and remains – his dream of eventually returning to PROJIMO and helping to restore the egalitarian spirit with which it began. In the meantime he is getting a good grounding for that role.

Rigo's new life in Culiacan

With his move to Culiacan, Rigo confronted a spectrum of daunting challenges. First was wheelchair accessibility. The University, in theory, welcomed students with disabilities, and had made certain structural adaptations accordingly. But some of these accommodations were more cosmetic than functional. For example, several ramps had been constructed. But often they were far too steep, and in many places stairways remained a barrier. A long, very steep ramp zigzags up the side of the Social Science Building. But this ramp only reaches the second floor, whereas Rigo's Community Psychology classroom is on the third floor. Fortunately, a few husky classmates willingly pitched in to carry Rigo in his wheelchair up the stairs to the third floor.



At the University there were a number of students with different disabilities. Rigo soon realized, however, that as they tried to make the environment more inclusive, nobody had consulted the disabled persons about their needs. Decisions had been made for them but not with them. Nor had the disabled students joined together to have a collective voice. So one of Rigo's early projects in Community Psychology was to bring together the disabled students to explore their needs and take collective action to resolve them. In time this process led to the formation at the UAS of an Association for the Rights and Inclusion of the Disabled, made up of students with disabilities together with other concerned students and faculty.

Even though disability is so prevalent in these underprivileged settlements, and it takes such a large toll on families, this was not a concern that the Community Centers of the UAS was doing much of anything to address – or at least not until Rigo got involved.

Now Rigo, with the collaboration of the UAS and the Community Service Program, has launched a number of projects that focus on the rights, needs and inclusion of disabled people in these impoverished



University students try their skill at managing wheel chairs.

campos agrícolas. The Community Psychology Department has now formulated a plan known as “Community Based Rehabilitation.” This program draws on the leadership of local disabled persons and family members to identify and help those with special needs. The staff in the Community Centers plays a facilitating role in this process.

Mario Carranza, head of the Community Psychology program at the University, sees this as a big step forward for the Department. He hopes it will scale up into a new trend, whereby psychology departments of other universities make projects for and with disabled people a key part of their outreach program into rural areas and underserved communities.

Child-to-Child in Campo Schools



Non-disabled children participate in a wheelchair race over rough terrain.



In awareness raising through simulation of disability these girls lead their blindfolded teachers.

One of the most exciting endeavors that Rigo has undertaken in the marginalized farm communities around Culiacan is a “disability awareness raising project” in the local schools. This program uses the methodology of Child-to-Child that he learned at PROJIMO. One of the most important aspects of these activities is the utilization of local disabled persons, including children, as facilitators. Non-disabled school children have a chance to interact with the disabled children in situations where the abilities of the latter stand out. For example, the non-disabled children get a chance to ride wheelchairs. Then they run a race with a disabled wheelchair using child. The disabled child typically wins hands down. And the other children, rather than look at his debility marvel at his strength and agility.



A schoolboy, Jorge, tries out riding a wheelchair.



On experiencing the barriers to getting about in a wheelchair, after class Jorge took the initiative to fill the potholes in the school entrance.



Rigo and David Werner discuss possibilities with Minerva, who has club feet. A wheelchair will be designed and built for her in the Duranguito wheelchair shop.



At a meeting in PROJIMO Coyotitan, Rigo (on left), Professor Mario and his partner Susana (center), and Virginia (on right) discuss group dynamics.



Minerva's club foot

Child to Child activities help the schoolchildren understand the motto of disabled persons:
LOOK AT MY STRENGTHS, NOT MY WEAKNESSES.

In order to gain a deeper understanding of people with disabilities, non-disabled children participate in simulation exercises. For example they are blindfolded to simulate blindness, and they play games trying to find their way around, or identify things by touch. Then they are introduced to a blind child, who can guide the blindfolded child and perhaps even read with her fingertips using Braille. Again, the non-disabled children marvel at the ability, rather than disability, of the “differently-abled” child. When he facilitates Child-to-Child in a school, Rigo also involves the teachers in the simulation games and other activities. This serves two purposes: it gets them on more equal terms with the children and it raises their awareness as well. In this way Child-to-Child promotes greater equality at all levels of society.

Note: For more information on the Child-to-Child methodology see David Werner's books, *Helping Health Workers Learn*, *Disabled Village Children*, and *Nothing About Us Without Us*, all accessible online at www.healthwrights.org.

On this same site you can find newsletters that tell of Child-to-Child workshops in various countries.

Helping individual disabled children

As part of his Community Based Rehabilitation work, Rigo helps disabled children and their families to access supportive services, and be included in school and community. When poor families have trouble covering the child's disability-related costs, Rigo has a way to help with some of the expenses. He can do this thanks to an agreement with Stichting Liliane Fonds (SLF), a charitable foundation in Holland, for whom he functions as a local “auxiliary mediator.”

Rigo has helped access services for children with a wide variety of needs – both physical and social. Such things as medical evaluation, medication for epilepsy and other disabling conditions, orthopedic appliances and other assistive devices, urinary catheters and bags, and even surgical correction of foot deformities. If a child has difficulties in the neighborhood or school, often he uses Child-to-Child activities to help gain greater understanding and good will. His work with a boy named Jaime is a good example.

The story of Jaime

Jaime was 6 years old when Rigo met him in the town of Navolato. The boy's pelvis had been crushed in a car accident when he was four. The fractures eventually healed and Jaime was able to walk with a waddling gait.



Not surprisingly, Jaime's urine collection bag and drainage hose led to a lot of teasing by his classmates.



Raymundo Hernandez – who is himself paraplegic and leads the Duranguito wheelchair shop – evaluates a child for a wheelchair. Rigo cooperates closely with the shop in identifying children who need custom-made wheelchairs.

But damage to the urinary tract was so severe that after partially reconstructing the bladder a urostomy was placed in the boy's abdomen, through which the urine drained through a catheter. The doctors connected the catheter to a large stiff plastic hose, which passed outside the boy's clothing and into a big collection bag strapped to his waist.

At home this cumbersome urine collection system was inconvenient but manageable and Jaime – who is bright and energetic – learned to cope. But once he began school it



Alfredo, head of the Association of Differently-abled People in Navolato, with Jaime. The boy has grown fond of Alfredo, who is disabled too, because the man accepts him as he is.

was another matter. Classmates began to make fun of him. They called him derogatory nicknames, like Chibote (Pisspot). Jaime had a quick temper and would try to fight his tormentors, which only added fuel to the fire. Then one day the class bully yanked on the hose so hard it pulled the catheter out of Jaime's abdomen, complete with the balloon of water at the bladder end. This forced removal caused great pain and bleeding – and required urgent medical intervention.

With all this teasing and bullying, Jaime soon dreaded going to school. He became rebellious and uncooperative. When Rigo first began to work with Jaime and his

family, he found it hard to get the boy to speak about his worries. But the fact that Rigo was also disabled, and also used a catheter, gradually led the boy to let down his guard. Rigo was patient and related to him as a peer. In the end Jaime opened up and poured out his heart. The two became trusted friends.

Since Jaime's biggest felt need was to put an end to the teasing at school, Rigo helped with two important measures:

The first was so simple he wondered why no one had thought of it. Instead of the thick hose and big urine collection bag which hung outside Jaime's pants, Rigo obtained a thin, flexible tube and a "leg bag" with elastic bands, like he used himself, which Jaime could keep inside his pants, hidden from view.

The second was to facilitate a series of Child-to-Child awareness raising activities in Jaime's school. These included simple role plays in which, in the first scene, children would reject or be mean to a child who was "different." In the next scene, by contrast, the group of children would look for ways to include and befriend the "different" child, and to play games where the child's difference was not a disadvantage. They also played simulation games,

pretending to have different disabilities, and then discuss what it was like – and how much it matters that the group of children accepted and include the child who is different.



Children in one of Rigo's programs show their posters on accident prevention.

In these Child-to-Child events Rigo also let several disabled persons talk with the disabled children about what it was like. Everyone asked questions and exchanged perspectives. This way they all discovered that a person with a disability has the same feelings, dreams and needs – including the need for friendship and understanding – as anyone else.

How much the good results were due to putting the urine bag inside Jaime's pants, and how much they were due to Child-to-Child in his classroom, is hard to say. But after these interventions Jaime began to notice a difference in how other kids treated him. They were friendlier and teased less. And when someone would make an unkind remark about Jaime, instead of everyone laughing, some of the kids would come to his defense.

As his situation improved, Jaime gained self-confidence and became less defensive. He didn't hate going to school nearly as much as he used to. At home his mother says he is still (two years later) somewhat scatter-brained and temperamental, but he is gradually gaining more composure and consideration for others. After what he's been through, the process of debriusing can take time. But Jaime is on his way.

Awards and prizes.

Although Rigo is still a student at the University, he has already received recognition for his groundbreaking initiatives. He won a prize from the mayor's office in the City of Culiacan, as the disabled person who has made the largest contribution to the common good. At the national level he was presented an award for his innovative work in promoting disability rights, by the wife of the President of Mexico.

Rigo's Cooperation with Other Programs and Faculties

One of the most promising aspects of Rigo's work is his ability to bring different programs and groups together to work for the common good. For example:

•**Duranguito children's wheelchair-making program.** Rigo has been cooperating closely with the PROJIMO Duranguito program (which is completely independent of PROJIMO Coyotitan where Rigo spent years). Rigo has helped arrange that scores of needy children get custom-made wheelchairs and other assistive equipment designed and built individually to their needs. Because the wheelchair builders are themselves wheelchair riders, they take extra care to make sure each chair is optimally suited for its user. Most of the cost of these chairs is covered by Stichting Liliane Fonds in Holland.

•**Service programs in the area.** There are many different educational and service programs in the area, run by government or non-government organizations at the town, municipal, state, and federal level. Most of these have had no special focus on disability. Even those that did often had limited or no communication with each other. Rigo, with the help of Mario Carranza and the Community Psychology program at the UAS, is now reaching out to these programs, seeking their cooperation and support. Thanks to Rigo's efforts, not only are some of these service programs beginning to give more attention to needs of disabled persons, but are cooperating more with each other in the process.

•**Workshops with different faculties at the universities.** Ideally, many different fields of study at the university should play a role in providing assistance to persons with disabilities, yet teach students little or nothing in this area. For this reason Rigo has been holding workshops with various faculties – notably social work, architecture, and dentistry. Rigo has also facilitated workshops with students from other universities and institutions.

•**Rehabilitation programs that have grown out of PROJIMO.** Rigo has also been reaching out to a rehabilitation program in Culiacan called MasVálidos, which was started more than 20 years ago by two disabled “graduates” of PROJIMO. MasVálidos is no longer run by disabled persons (as are the PROJIMO programs). But it does have a network of cooperating doctors, surgeons, therapists, and medical facilities that provide their services either free or at low cost. So when Rigo has a child from los campos who needs surgery or other specialized attention, he sometimes turns to MasVálidos.

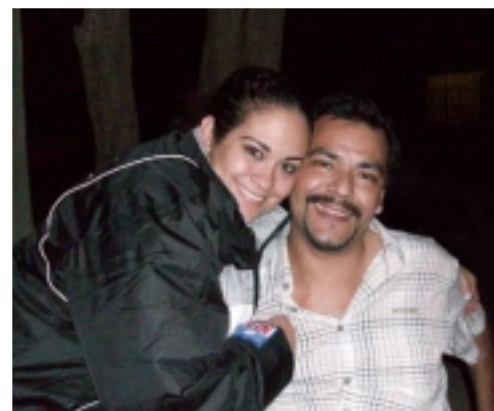
•**Scaling up – the multiplying effect.** When Rigo began his awareness raising activities, he was the primary facilitator. But now he is training other groups of young persons. Throughout Mexico students of the secundaria (middle school) and preparatoria (high school/college prep) are required to do a public service project. Recently Rigo has been counseling groups of students to become Child-to-Child facilitators. Rigo explained to me, “Kids are likely to pay more attention to other kids closer to their own age, with whom they can identify.” And of course for the older students, there is no better way to learn something than to teach it.

•**National events.** Rigo has taken groups of students to Mexico City and elsewhere, to participate in competitions and demonstrations. News reporters have written on his work, which has been widely lauded. In the summer of 2011 he went to Mexico City with a group of school kids to participate in a contest of children doing socially constructive activities. His group focused on accident prevention in a campaign to prevent disability.

The challenge of financing Rigo's change-making work.

That Rigo has managed to accomplish so much groundbreaking work while studying at the university is remarkable. To have done so as someone paralyzed from the neck down, for whom simply getting around in a wheelchair is a big challenge, is more remarkable still. One of the most formidable obstacles relates to his transport needs to reach the outlying communities where he carries out his groundbreaking activities.

Fortunately Rigo has had lot of enthusiastic help. His sister has provided a home, which doubles as an office. (It's handy that his sister runs a small cybercafé at her home.) Rigo's wife, Citlalli – whom he met on the Internet – has become a devoted colleague in his community work, helping him capably in countless ways including with a lot of his paperwork and reports.



Mario Carranza, professor of Community Psychology at the University, has been a huge help in many ways. He arranged a full scholarship, and has been totally supportive of everything from Rigo's disability awareness work, to the wheelchair project. Professor Carranza and his colleagues helped set up small non-government organization, called SEMUC (Servicios Multidisciplinarios de Calidad,) to help Rigo get tax-deductible donations and assistance from groups like Stichting Liliane Fonds.

David Kebler is a former Spanish student of Rigo's at PROJIMO. In addition to assisting HealthWrights, Kebler has been a huge help to Rigo. Among other things, he helped pay for a van (which at long last has a wheelchair lift) for Rigo to travel to and from the towns and villages where he works. Citlalli, Mario, and fellow students, help as volunteer drivers.

Being quadriplegic, Rigo has many disability-related expenses on top of his daily living needs, and he has very little income. After he left PROJIMO, Rigo began to teach Spanish-as-a-second-language via

Skype (voice communication by computer). David Kebler – a computer whiz – helped him set this up. On top of his studies and community work, Rigo also worked part time operating a copy machine in a hospital. But the pay barely covered his transport.



As Rigo's remarkable work becomes better known, he has been able to get some small grants from different programs and persons. A man in Wyoming linked to a congregation there has made occasional modest donations. The Francisco Vargas Memorial Fund in Mexico City has helped cover the cost of Child-to-Child workshops for several months. Friends like David Kebler have pitched in when the going gets rough. Liliane Fonds has helped with costs of medical and developmental assistance to individual disabled children. And HealthWrights helps a little now and then; however in recent times we too have had a hard time making ends meet. The help he has received has been encouraging, but it has not been enough.

A call for assistance to Rigo's life-changing work

Rigo is doing important, groundbreaking work that brings direct assistance to disabled children in need and at the same time helps to educate society – especially children – to be more welcoming and inclusive of persons with disability. The fact that he is himself extensively disabled, shows people that disabled persons can and do make a valuable contribution to society.

Help Requested:

We encourage anyone who would like to contribute to Rigo's outstanding work to do so. Donations are tax-deductible when made to HealthWrights (see flyer). Be sure to earmark them for Rigoberto Delgado's Disability Project.

Opportunity For Language Study

If you would like to study Spanish with Rigo by Skype, he now has openings. Write him at "Rigoberto Delgado Zavala" <teacherigo30@gmail.com>. You can learn a lot in an enjoyable way, and at the same time help him support himself.

HealthWrights also needs your help.

**For more information see
www.healthwrights.org**

Announcing a new publication in Spanish: "CEREBRAL PALSY"

by David Werner with Bruce Hobson

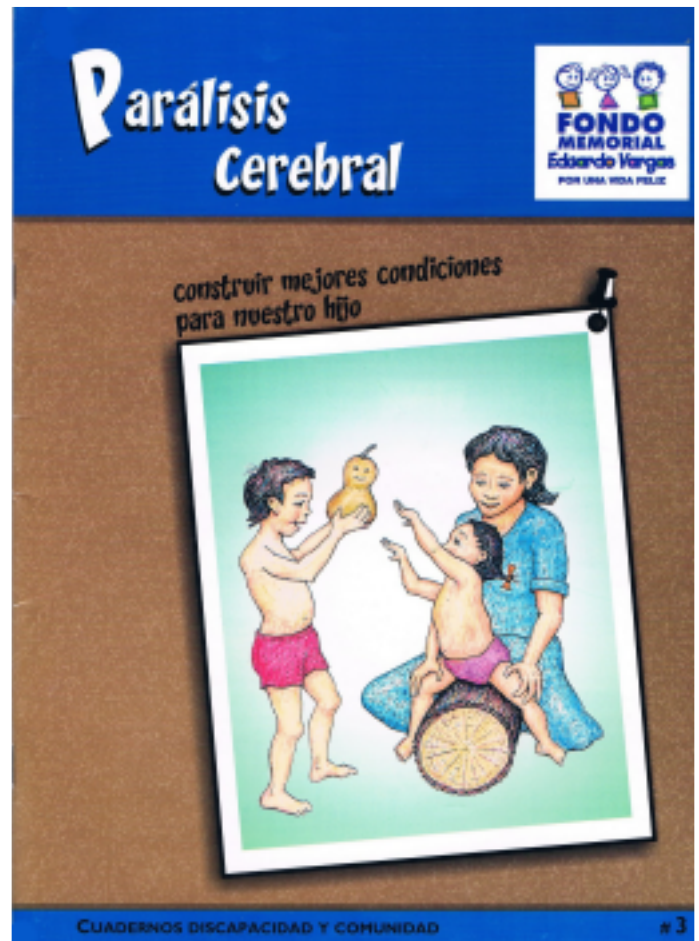
Edited by Alicia Molina, and illustrated by David Werner

This booklet is produced by Fondo Memorial Eduardo Vargas in collaboration with the Sistema Nacional para el Desarrollo de la Familia (DIF), México, 2011. This 36 page booklet in Spanish is the third in a series titled Cuadernos Discapacidad y Comunidad, prepared for families with disabled children. Copies will be given free to parents at DIF centers throughout Mexico. DIF is often the first contact with services for families with disabled children, so the booklet will reach families unlikely to see David Werner's books. The clear, basic information will also be useful for service providers.

This booklet is based on material in David Werner's books, *Disabled Village Children* and *Nothing About Us Without Us*, but language and content are further simplified. For non-readers, the drawings alone provide ideas for beneficial activities, assistive equipment, social inclusion, and learning of basic skills.

To date the booklet is only in Spanish. However HealthWrights plans to bring out a somewhat expanded edition both in English and Spanish. Meanwhile the Spanish draft is freely available online at www.healthwrights.org.

Request for help: We are looking for volunteer assistance in formatting and layout of the expanded edition of this booklet on Cerebral Palsy: now the most common childhood disability.



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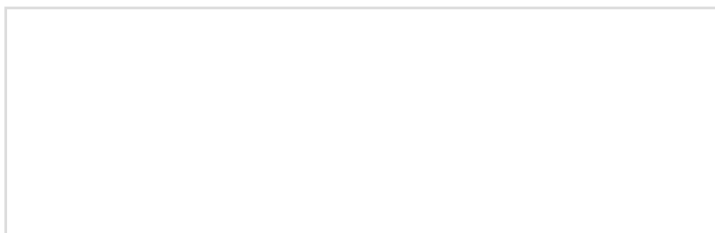
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August 2011

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Rigo (center in wheelchair) cooperates with the Duranguito wheelchair shop in attending children who need wheelchairs – like this one being measured by Teo in Villa Juarez.

In this issue...
read about how Rigo Delgado, a disabled person, rehabilitated and educated in the Projimo program many years ago, is now creating exciting and innovative programs in Mexico. He focuses especially on people who not only face the physical and social problems associated with having a disability, but who are marginalized economically as well. Child-To-Child programs are central to his work. Having been through it himself, he is respected as someone who knows what he is talking about.

"We don't stop playing because we grow old; we grow old because we stop playing."

-- George Bernard Shaw