



life beyond wheels

Accessible Dream Homes



Disability Jokes

Homemade Gear

Independent
Living in Peru

Independent Living:

from Kansas to Peru



Front row, left to right: Billy Altom, Toshiyuki Chiba, Glen White, Jose Isola, Marcelino Landeo.
Back row: Shelby Kamenstein, Gary Maddox, Kathleen Kleinemann, Mike Oxford, Ron Garcia, and Chiaki Gonda.

BY GLEN W. WHITE with VALERIE RENAULT

Peru is a country with incredibly rich culture, history and beauty. But there has been no Ed Roberts, Judy Heumann or Justin Dart in Peru to lead and develop an independent living movement — not yet, that is. There are many passionate and dedicated Peruvians, though, who are eager to build an IL movement that fits their country's unique culture and needs.

I first visited Peru in 1998, and since then I've made another dozen visits. I fell in love with the people and the culture, and my personal experience inevitably merged with my professional interests. As a wheelchair user, I am a beneficiary of and, I hope, a contributor to the IL movement in the United States. In my working life, I direct the Research and Training Center on Independent Living at the University

of Kansas, where I also teach in the department of applied behavioral science.

With each visit to Peru, my vision grew stronger: to bring an "IL Dream Team" to help Peruvians establish an Independent Living movement and a center for independent living.

My time in Peru has thus been a mix of tourism and advocacy. I experienced the stunning vistas of Machu Picchu and led students to study Peruvian culture and disability, collaborating with Dr. Liliana Mayo, who directs the Centro Ann Sullivan del Perú. She founded CASP in 1979 in her father's garage with just eight students with severe disabilities; it now serves over 450 students with disabilities and their families through community-based programs.

I also collaborated with disability leaders and advocates to help build the leadership

capacity in Peru. We conducted workshops on community problem solving and, with Bob Michaels, taught the basics of advocacy. We invited Peruvians to attend NCIL and APRIL conferences. Now, the growth in leadership among these Peruvians convinces me that the time is ripe for an IL movement in Peru.

Being There

In January 2009 my vision of the IL Dream Team became reality. Nine of us came to Peru for six days to learn, observe and share what we know. We arrived in Lima near midnight. After passing through customs and collecting our bags, we entered the pandemonium outside the airport, and finally found our hosts amid the crowd of Peruvians. Our next task: to figure out how to get people using three manual wheel-

chairs, one power chair and one scooter into three vehicles, along with four other people, our drivers and everyone's luggage.

We were then introduced to traffic in Lima: no rules and no fear! Americans are taught defensive driving, but it seems that drivers lessons in Peru are taught in a parallel universe that encourages "offensive driving." Wills are tested and machismo is declared in seeing who will get to the intersection first, then who actually gets through alive.

It was near 3 a.m. when we checked into our Miraflores hotel. Two hours later, Mike Oxford, the director of Topeka's IL Resource Center, called my room to say his battery charger had exploded from using the 220-volt power outlet instead of the usual 110 volts for the charge.

Welcome to Peru! Our Dream Team had arrived to spread the message of Independent Living to Peruvians with disabilities and their advocates through a U.S.-Peru IL Working Summit.

Purposeful Tourism

Of course we had our own lessons to learn, and Oxford's interaction with voltage was just the beginning. Fortunately, the main electronics of his scooter were spared, and with the help of our driver, Marcelino Landeo, Oxford eventually found trickle chargers to boost his batteries at "the store with [almost] everything" — ACE Hardware.

While our journey would culminate in two formal meetings, the informal gatherings were just as important in spreading the IL philosophy. Our interactions began with food and music — the best way to build any team. At a barbeque hosted by Jaime Huerta, Billy Altom sang ballads and songs familiar to the U.S. team, and Luis Miguel's son, Lucho, sang Peruvian songs and ballads.

In the first days of our visit, we saw the sights and soaked up the Peruvian atmosphere. The Museo del Oro (Museum of Gold) was stunning. In San Isidro, an area of Lima, we saw a beautiful olive grove that is over 400 years old.

One lovely day we wheeled from our hotel to the old Indian Market, where you can find souvenirs from alpaca sweaters to silver spoons and jewelry. The six-block trip had many ramps along the way, but some were way too steep for most wheelchair users.

We met a truly steep incline at the ancient Peruvian Templo de Huallamarca, a pre-Incan pyramid where VIPs were buried. Several of our U.S. team members

felt frisky and wanted to tackle the huge slopes of the pyramid. Altom, Landeo and Toshi made it up the ramp with a little push-power from our teammates Chiaki Gonda, Shelby Kamenstein, Ronald Garcia and Gary Maddox. When Oxford tackled the slope with his three-wheeled scooter, he made it about an eighth of the way up before his scooter shut down. He did repairs right there on the ramp — and probably felt at home, just like being in an ADAPT march.

Of course how you get from point A to B is part of any travel story. Our U.S. team members went in groups based on the vehicle that best met their needs. Oxford, Garcia and Kamenstein rode with Landeo in his Chrysler minivan. Oxford's scooter fit behind the front seats while the rest of the crew rode in the back seat.

Kathleen Kleinmann, who uses a power chair, rode in the only accessible ramped van in Lima that we knew of, which has about a 40 percent ramp incline. Once inside, Kleinmann sat over the back axle, with little suspension beneath the van to soften the bumpy roads of Peru.

Altom, Toshi and I, all paraplegics, rode in a sedan or small compact wagon. It was a tight ride. Our wheelchairs were often placed in the other vans, and we hoped and prayed that when we got where we were going, our wheelchairs would also wind up at the same destination!

One day we visited an artist's collective in a barrio outside the Lima metro area. About 24 people with disabilities who live in a

12-block area take part in the sewing group, making brightly colored canvas messenger bags. Together, they bring in about \$2,000 per month, or \$20 a week per person.

The leader of the collective invited us into her home, where we saw electrical wires hanging everywhere. We also saw an old racing wheelchair hanging on the wall and a collection of ribbons and medals. The medals were dusty and the shine had long since tarnished on some, yet the pride and spirit they captured was alive in this home.

Obstacles to Overcome

During our visit we also met with government and non-governmental officials, like Wilfredo Guzman Jara, chairperson of Disabled Peoples' International. This organization has 142 members around the world and has championed the United Nations Convention for Human Rights.

We told him we were in Lima to discuss the possibilities of starting a CIL there. He told us that Peru's economic growth in 2008 was 8 percent, yet little of this increase trickled down to Peruvians with disabilities. He acknowledged the many transportation obstacles: There are over 44,000 buses in Peru, yet not one is accessible! There are no accessible taxis.

We lunched with Guillermo Vega, director general of CANADES, which is equivalent to our country's National Council on Disability. Three months ago they achieved a major goal: They released a plan of equal opportunity for Peruvians with disabilities.

The American "IL Dream Team":

Billy Altom, executive director, Association of Programs for Rural Independent Living, Little Rock, Ark., www.april-rural.org; 501/753-3400

Toshi Chiba, visiting international fellow from Tokyo, Japan, Research and Training Center on Independent Living, University of Kansas, Lawrence, www.rtcil.org; 785/864-4095

Ronald Garcia, executive director, New Vistas Center for Independent Living, Santa Fe, N.M., www.newvistas.org; 505/471-1001

Chiaki Gonda, graduate research assistant, Research and Training Center on Independent Living, University of Kansas, Lawrence, www.rtcil.org; 785/864-4095.

Shelby Kamenstein, occupational therapy doctoral student, Washington University, St. Louis.

Kathleen Kleinmann, executive director, Tri-County Patriots for Independent Living, Washington, Pa., www.tripil.com; 724/223-5115

Gary Maddox, executive director, Southwest Center for Independent Living, Springfield, Mo., www.swcil.org; 417/886-1188

Mike Oxford, executive director, Topeka Independent Living Resource Center, www.tilrc.org; 785/233-4572

Glen White, executive director, Research and Training Center on Independent Living, University of Kansas, Lawrence.

In Peru, disability is still perceived through a charity model, and although Peruvian law specifies “inclusive education,” it is not working. There is no access and there are no special education teachers. The special education budget has diminished.

We met with former multi-term Peruvian Congressman Javier Diez Canseco and Liliana Peñaherrera Sánchez, a South American representative to the International Society of the Red Cross, to discuss disability issues in Peru and South America

at large. We learned that although the Organization of American States voted to have the Decade of People with Disabilities in The Americas (2007-2016), the commission has never met.

How can we as Americans help? Peruvians are currently trying to build links between the UN Convention on Rights and Disability and their country’s legislation and policies. The U.S. team offered to provide documents — as possible models to adapt — that would help shape Peruvian laws.



The IL Dream Team meets with members of an artist’s collective for people with disabilities.

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The Summit

The formal IL summit consisted of two meetings. About 45 Peruvians were in the audience for the first session at the San Isidro Municipality building. The U.S. team talked about the concept of Independent Living and all the topics we would discuss in more detail the following day. What is a Center for Independent Living — its philosophy, structure and core services? Our audience was greatly excited about the topics of job placement, support for sports and transportation. We received many thoughtful questions.

The next day we met with an audience of about 150 for the full session of the U.S.-Peru Independent Living Working Summit, held in the Senate Chamber of the Peruvian Congress Building. We entered this beautiful building under the watchful eye of elite armed Peruvian Guards as part of a VIP recognition for our delegation. We used new electronic lifts at each of two flights of steps.

It was a bit overwhelming for those of us who were presenters to sit on the dais in the ornate Senate Chamber. I was a presenter, along with Oxford, Kleinmann, Garcia, Maddox, Kamenstein, Altom, José Isola and Huerta.

I opened by telling the audience that on the outside I might look like a gringo, but on the inside beats the heart of a Peruvian. I explained the origins of the summit: During my first visit in 1998, I conducted a survey



about problems Peruvians with disabilities experience, such as inaccessible communities, lack of employment, discrimination and lack of accessible transportation. I asked if a survey were again taken today, some 10 years later, would much have changed? The crowd responded with a resounding "NO!"

Our panel then discussed in more detail the various aspects of IL, ranging from the philosophy of IL to the core services provided by a CIL.

Next Steps

As Huerta said, "We should start as a movement first, not necessarily as a building. We can open a small office later and eventually obtain some accessible vans to help get Peruvians with disabilities to the center and other sites."

The Peruvian IL Summit Team:

Cecilia Velásquez Alli Guillen
 María Luisa Huerta
 José Antonio Isola de Lavalle
 Rosario Galarza Meza
 Monica Ochoa
 Celia Orpella de Paredes
 Jaime Huerta Peralta
 Lillian Chavez Reyes
 Darío Portillo Romero
 Flor de María Diaz Salcedo
 Javier Santayana
 Luis Miguel del Aguila Umeres

It is humbling to be part of this movement at the true grassroots, the ground level, where small steps are essential to create a larger wave of action. The American and Peruvian teams are now taking some of these steps.

The Peru group is working on a mission statement for Peru's first CIL. We can provide technical assistance and moral support for creating a CIL.

The U.S. team hopes to set up Web casts for disability leaders that focus on specific

interests and needs: transportation, employment, public attitudes and sensitivity.

We are reviewing what we learned on this trip, to make recommendations and follow up with a teleconference.

And we can return, hopefully with new ideas, inspiration and maybe even a donated accessible van. Americans are generous, even in a time of economic downturn. Most importantly, we are committed to sharing the personal wealth that comes from our dearest value: independence. ■

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