This Newsletter looks at diverse disability-related issues in Mexico, Singapore, and the United States of America. It starts with an account of a hands-on training program in Community Based Rehabilitation, conducted at PROJIMO in rural Mexico.

The next article looks at the paradoxical situation in Singapore, where disabled people are well cared for, but where little effort is made to achieve their full integration into society. Up to now, organizations of disabled persons in Singapore—following the polite local custom of non-confrontation—have done little to actively protest the lack of equality and opportunities in their country. But a new generation of young disabled persons is beginning to take an organized stand for their rights.

The final lead article is taken from a paper presented by North American psychologist Ken Jue at a Symposium in Singapore. Ken describes the history of how, over the last 30 years in the United States, a shift has taken place away from institutionalization of mentally ill persons, toward re-integration into their families and communities. In his paper, Ken presents a strong case for building on the strengths and capabilities of mentally ill persons rather than focusing on their weaknesses. This approach conforms with that advocated by PROJIMO and in our newest book, Nothing About Us Without Us, which is already widely acclaimed (see the enclosed flyer).

A COMMUNITY-BASED REHABILITATION TRAINING WORKSHOP AT PROJIMO

A “Learning by Doing” Workshop for Liliane Mediators in Mexico

From March 3 to 5, 1998, disabled village rehabilitation workers at PROJIMO facilitated a training seminar for “mediators” representing Stichting Liliane Fonds (SLF), a Dutch foundation that helps disabled children in difficult circumstances.

"Mediators" are volunteers, backed by local organizations, who find disabled children with urgent needs and arrange for them and their families to get essential support from SLF. The mediators are often nuns, community leaders, social workers, nurses, or other persons who have a concern for the well-being of disadvantaged children. One purpose of the workshop was to have an interchange of experiences among mediators from different programs in Mexico, concerning the concepts and practice of community based rehabilitation (CBR)—with hopes that all of us might take a more enabling, integrative approach to meeting the needs and possibilities of disabled children.

The 3-day workshop was attended not only by mediators and prospective mediators from different parts of Mexico, but also by a large number of disabled children and their parents. The inclusion of many disabled children and parents in the workshop was important not only because the strong participation of such persons is key to success of CBR, but also because, with their presence and participation, the workshop could deal in a practical, hands-on way, with the real needs of individual children and their families—through a process of learning by doing.

Altogether, the workshop was attended by over 60 participants—half of whom were themselves disabled. (A special effort was made to have strong representation by disabled persons.) Most of the visitors stayed with village families, who cheerfully cooperated. To transport visitors from the city of Mazatlan to the village of Ajoya (nearly 100 miles away), the municipal president provided a government van. With these different forms of local assistance, overall costs for the workshop were kept quite low.
Strong input by disabled children and their parents in the Mexico workshop

For the seminar, we followed a program of events fairly similar to that of our 3-day workshops in the Philippines in January, 1998 (see Newsletter 37). However, the slide shows (on PROJIMO and Child-to-Child) were held after dinner in the evenings, and local villagers were invited to attend, as were all of the visiting mothers/fathers with their disabled children. Also, instead of using overhead projections, the PROJIMO team demonstrated actual examples of appropriate (and some inappropriate) aids and equipment they had made. The parents of Cruz Astorga participated for 2 days, and 3-year-old Cruz proudly showed everyone how he used his special cardboard seat and standing frame.

Making assistive devices for individual children

In conducting the assistive device workshop, the children's needs were assessed, plans for development/assistance were made, and equipment was designed and constructed for 11 children. By good luck rather than planning, the dynamics worked out especially well. At the suggestion of the participants, only 3 work groups were formed, each with 3 or 4 children and their parent(s) and 3 to 5 mediators/co-mediators/potential mediators. This placement of several parents and children in the same group allowed both for a lot of interaction and suggestions among the parents involved. It also led to greater confidence and participation by the parents—and to some extent, the children—in the problem-solving process. (In the Philippine workshops, each group of mediators had worked with only one child and his or her parents, so the interaction between the parents of different children did not take place.)

Most of the children had cerebral palsy. Equipment made for the children included 2 standing frames and 4 special seats. One seat was specially designed for a child with dislocated hips who became uncomfortable after sitting upright for 15 minutes. The seat had an adjustable-angle back-rest to allow the child to shift easily between sitting upright and reclining. Two seats had variable-height back rests so that the children could sit with a low back-support to improve trunk control, then relax with a high back-support.

The wheelchair of Virginia, a girl with brittle-bone disease, was modified so her feet could reach the foot rests (which had been too low for her short legs.) A table was also built for Virginia’s wheelchair, which makes it easier for her to write to her "pen pals:" 3 sisters with brittle-bone disease in the Philippines. (See Newsletter #37).

Five children were evaluated for the need of orthopedic appliances. Participants took part in planning the braces and helped PROJIMO workers cast the children’s legs. Four children were fitted for wheelchairs, which were later custom-made by the PROJIMO work-program team. Also, the pregnant mother of three children with muscular dystrophy helped the PROJIMO team design a tricycle with a carrying seat for three children (plus a "crib" for the fourth baby to come.)

As in the Philippine workshops, most mediators had little experience in evaluating needs or making equipment for disabled children. As a result, some of the devices they made had problems. But the plenary session and discussion at the end of the workshop, with the children and parents using the equipment, was a good learning experience for all—in some ways, much better than if the equipment had been problem-free.

One of the most worthwhile events took place on the second day, when participants met with the disabled children and their families, to discuss the felt needs, hopes, and wishes of the children and parents, and the barriers and difficulties they faced in trying to meet those needs. The facilitators used the questions on a new, experimental report form (which had been tested in the Philippines) as guidelines for helping the mediators and families take a holistic view of their children's needs and to draw up a comprehensive plan of action. This approach was appreciated by the participants, who found it quite useful. One of the needs expressed by both children and parents was for the children to become as self-reliant as possible.
For the SLF workshop, in Mexico, Dolores Mesina—a disabled graduate of PROJIMO who is now a social worker with the government’s Integrated Family Development program (DIF)—arranged for the participation of several disabled children in need, whom the PROJIMO team had not seen before.

One of these children was 11-year-old Eli (Elizabeth), who lives with her father, Daniel, in a stick hut on the edge of the main North-South highway. Since Eli’s mother died 3 years ago, Daniel has stayed at home to care for his disabled daughter. He has lived by begging. Sometimes he takes his daughter to the nearest village on a 3-wheel bicycle, to the front of which he has attached an enclosed seat for her.

During the workshop, various ideas and designs were discussed to help Eli become more self-sufficient. At present she was completely dependent on her father, who fed her, bathed her, and did everything for her. However Eli had a lot of possibilities. She had good hand control, and although her legs were quite spastic she could stand by herself when holding onto a firm object.

The group discussed with Daniel things he could do to help Eli do more for herself. But although at one level he wanted her to become more independent, at another level, Daniel seemed to find a certain satisfaction in his daughter’s complete dependency on him. So the group decided to invite Eli and Daniel to spend a few weeks at PROJIMO.

After the SLF workshop, Daniel and Eli spent 2 months at PROJIMO. The team worked with father and daughter. They taught Daniel activities to help Eli begin to pull herself to standing, and to begin to walk between parallel bars. By learning these skills, she could take more responsibility for shifting herself onto a toilet, and from her new wheelchair (which they made for her) to a cot. A visiting physiotherapist from Holland, Gonneke Rota, who volunteers in a CBR program in Nicaragua, was helpful in figuring out appropriate, functional exercises for Eli.

Three-year-old Daniela and her parents came to the SLF Workshop. PROJIMO had already worked with Daniela. Marielos, a disabled young woodworker, designed a special seat to help Daniela sit better and improve her balance. The seat-back can be adjusted to 3 different positions:
When the National Council of Social Services in Singapore invited me to come talk on “Management of Long Term Disability,” I had misgivings. Too often, emphasis on “management” bespeaks a top-down hierarchy. As a person with a disability myself, I am less interested in management than in the never-ending struggle by disabled persons for acceptance, understanding, dignity, and opportunity. Most disabled folks I know do not ask anyone to “manage” their abnormalities. Rather, they seek liberation from prejudice, pity, over-protection, domination, and exclusion by society.

In Singapore, however, management is as omnipresent and indisputable as a supreme being. Virtually everything and everyone is carefully managed. Singapore is a largely benevolent police state—benevolent, at least, to those who follow the rules. Big Brother reigns in the form of armed guards, security cameras, and a deeply entrenched value system that places good manners, obedience and conformity before individuality and or (forgive the thought!) independent living. The red tape for me to get a visa as a guest speaker was astounding. When I asked my hosts if it might be easier for me simply to enter as a tourist (for whom no visa is needed), my hosts were shocked by such a delinquent thought. The law, I was told, is inflexible and unforgiving. When I was about to cross an empty street mid-block, my guest restrained me, warning that jay walking brought a mandatory $60 fine. A printed notice handed to every visitor on arrival states bluntly, “WARNING: For possession of illegal drugs, the death penalty is mandatory.”

Months before giving my keynote address, I was told to send a script of it to the program planners. I later learned that the purpose of this was so that the appropriate officials could screen my speech and edit it for protocol. “Not as censorship,” I was told, but to be sure speakers say nothing that might cause discomfort for either them or their listeners.” My personal planners, who said nothing that might cause discomfort for me simply to enter as a tourist (for whom no visa is needed), were hosts who were least concerned about me. They were startled by such a delinquent thought. The law, I was told, is inflexible and unforgiving. When I was about to cross an empty street mid-block, my guest restrained me, warning that jay walking brought a mandatory $60 fine. A printed notice handed to every visitor on arrival states bluntly, “WARNING: For possession of illegal drugs, the death penalty is mandatory.”

The day after my talk, I met with government and NGO planners in the disability field. One participant was Ron Chandran Dudley, an exceptionally outspoken blind leader of the Singapore Association of Disabled Persons. In mock seriousness, Ron said, “I think we in Singapore should think seriously about what David Werner said in his address. Rather than put drug traffickers to death, why don’t we rehabilitate them into constructive citizens?”

To my amazement, the chief of the country’s biggest public service program (an ex-military man), took Ron seriously. “Even if it might work, I don’t think we should try it,” he replied. “The international community, especially the USA, would surely protest, claiming that shooting criminals in the spine as part of their rehabilitation is a violation of human rights. We don’t want to invite international reproach.” Most listeners nodded in agreement.

Full of titanic paradoxes, Singapore is a thriving success story of international capitalism. Wholly urbanized, this wealthy, cosmopolitan island’s commodity-driven culture has a global market lifestyle. Multinational corporations pilot people’s dominant hunger and values. Shopping malls, clothing and haircut styles, TV ads, and soap operas religiously mirror those in the US. Virtually all food and raw products are imported, as is most music and entertainment. Billboards for Marlboro and Coca Cola dominate the busy landscape.

I was astounded to hear a song taught in kindergarten, with these lyrics: “McDonalds! McDonalds! McDonalds! Burger King! Burger King! Burger King! Kentucky Fried! Kentucky Fried! Kentuck Fried!—with no additional rhyme or reason. In their free time, teenagers hang out in the shopping malls.

Average income, standard indicators of health, and life expectancy are quite high. Poverty is simply not permitted. Crowding is such that 84% of the population live in high-rise apartment buildings. A married couple often has to wait years for a place to live. Yet despite the extreme crowding, the government provides economic incentives for Singaporeans (or at least more educated ones) to have more children. More people mean more workers, more consumers, and faster economic growth. In Singapore crime rates are low and suicide rates high and rising, especially among young people.
Building Bridges with Mentally Ill Persons
by Kenneth Jue

Too often, in programs and seminars about rehabilitation, the disability known as mental illness is excluded. It was remarkable, therefore, that at the March, 1998, Symposium in Singapore on “Management of Long-Term Disability” (see page 4) two of the three main speakers were specialists on mental illness. The strong inclusion of this frequently “untouchable” disability reflects a growing concern in Singapore, where the rapid economic growth of this market-driven culture has been accompanied by a rising rate of stress-related disorders, suicide, and mental illness.

In Singapore—where conformity and good behavior are paramount—the standard management of persons with mental illness is to lock them away in mental hospitals. While in many other countries the current trend is to deinstitutionalize such persons and look for ways to reintegrating them into their families and communities, Singapore still takes a very segregating, approach.

Ken Jue, one of the main speakers at the Symposium, is a psychologist from Vermont, USA, who for 30 years has been a pioneer in the productive re-integration of persons with mental illness into the community. In his talk in Singapore, Ken told of his experiences in this domain, and challenged the rehabilitation establishment in Singapore to respond more humanly and creatively to the needs and potentials of persons with mental illness. With Ken’s permission, we include here the part of Ken’s talk where he describes his own discovery of how important it is to build on his clients’ strengths, not their weaknesses.

In 1996 and 1997 I worked at a large state mental hospital in the US. I was assigned as a caseworker to a ward with 50 female patients. The ward was always locked. The average length of stay for these women was 15 years. Some had been there for 30 years without any leaves of absence or weekends home. Usually they had no homes, or no one wanted them anymore. Almost all had been diagnosed as schizophrenic or with some other psychotic condition. They were all heavily medicated and shuffled around the ward in their formless hospital shifts and slippers. Many were unwashed and smelled badly of urine or stale body odor. If they acted out, they were given stronger medication, placed in strait jackets, isolated in their rooms to rage, denied “privileges” and activities, or moved to another ward. Some were removed for a time and were returned having undergone a lobotomy, which was a poorly researched and imprecise form of brain surgery at that time. These people came back docile, unresponsive to conversation, and appeared never to be the same person... These were horrid circumstances.

A group of hospital staff, including a new ward psychologist and myself, eventually succeeded in convincing the hospital administration to allow us to unlock the ward for several blocks of time each week. We accompanied patients on walks around the grounds. This lead to “picnic” outings in a large unused field. Our staff cleaned off the field for games and other activities. The hospital administration was pleased at our success with the patients and became more supportive of our activities as there were no adverse incidents.

As time passed, we convinced the hospital administration to allow us to construct a day camp across a small stream bordering the edge of the field, where there was a small grove of shade trees on the other bank. We proposed to build a small bridge across the stream. However, none of our staff had ever done that kind of thing before.

Our patient outings had grown to include the women on our ward and also men from another ward in an adjacent building. One afternoon during a picnic, several of our staff were discussing what to do about the bridge. An unfamiliar voice behind us quietly said that he knew how to build bridges since he used to be an engineer. We turned and were surprised to see one of the male patients. He was in his early 50s. We had not held any kind of conversation with this man before. We had assumed he wanted to be left alone to enjoy the few precious moments outside his ward. He went on to draw a picture of a simple but charming bridge. He told us how it could be done and the tools we needed. We were astonished at the discovery of this talented individual.

We asked the man if he would help us build the bridge. After some hesitancy, he agreed to work with us, but said he could not do it alone. He called to one of the other men, who turned out to be a former carpenter, and spoke aside with him. Both agreed to help. Before we could say anything, both took off their shoes, rolled up their pants, and crossed the narrow stream. We did the same and followed them to the grove of trees. That afternoon we designed the day camp. The two men helped us explain the project to the other patients out with us that day. We had a lively discussion with many questions and answers.

It took several weeks of bureaucratic negotiations and pleading, but we finally got all the necessary tools to build the bridge and camp. We made sure that patients would be involved in this project and would be using the tools, which included axes, hammers, and saws. You can just imagine the alarms this would have set off with the hospital administration.
In the meantime, the two men organized co-ed work teams to carry out certain tasks, including chopping down small trees to use for the bridge, for seats and tables and lean-to shelters to use for rainy days, and to clear out eating and cooking areas in the shady grove.

The organizational skills of the two men were very impressive. They ended up as the project managers by default. They instructed us on our tasks and roles, and showed us how to do certain things.

When the camp was done, it was a sight to behold. The bridge was sturdy and had a wonderful rustic look. It took a few weeks to do all this. We took photos of the project and showed them to the hospital administration. The whole hospital used the camp.

We did not lose a single tool or nail. No one got hurt. No one ran away. No one fell apart during this entire experience. Some of the patients who worked with us on this project soon left the hospital for the first time in years, to live in an outside community.

The two men left. We never saw them again. Both had been long-timers in the hospital, and neither appeared to be leaving any time soon when we first met them. The two men had regained something. We didn’t do “talk therapy” with them. We allowed them to take charge and be responsible. They were not the lifeless men we saw when we were first introduced to them. They became animated and alive. In a few short weeks their whole demeanor and bearing had changed. They possessed a capability and competence that had not been detected earlier, but that had been submerged.

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This experience remains with me today. I can see the field, the bridge, hear the voices and see everyone working.

I learned many lessons from this experience, but one stands out for me. People have strengths, skills, capability and potential. I decided that summer to stay in a human service profession and that I would work to help bring out the positive aspects of each person’s being, and try to support clients to capitalize on their own capabilities in helping themselves do what they wanted to do to improve their own lives.

How These Ideas Evolved: The Situation Today (30 Years Later)

Today [as Director of Monadnock Family Services in Keene New Hampshire] I (Ken Jue) see people on a daily basis who are doing things that many believe severely mentally ill people could never or should never do. Some of the users of my agency’s services have become employed as skilled electricians, carpenters, restaurant workers, bakers, clerks, bank tellers, supervisors in area businesses, or have completed technical training programs or college degrees. A large group of [our clients] operate and manage a work cooperative that we helped them establish 10 years ago. They have a variety of small enterprises, including the design and manufacture of lawn furniture, a landscaping service, and a home renovation business.

Their newest venture is a vocational training institute, which is now under sub-contract to my agency, to prepare severely mentally ill people for real job experiences and eventual employment. The CO-OP has had its share of skeptics, detractors, and “non-believers.” Some state officials even tried to close it down.

First and foremost, at my organization we believe that the optimal place for most people with severe and persistent mental illness is in their own home community. This allows people to be close to their family, friends, and natural support networks. We have designed a system of community-based support services that make it possible for this to happen.

Another belief we have is that people with mental illness have the right to employment in whatever circumstances they decide they want to achieve. In our society one’s work status significantly defines one’s value and worth as a member of society. A person’s sense of personal value and dignity is directly related to our perception of whether we are needed by our family and our society. Being loved and being needed are essential to our humanity and to our individual sense of self worth.

“Supportive employment” is defined as a way to help people with psychiatric disabilities to choose, get, and keep paid jobs in integrated work settings by providing job development, training and support to reap the benefits of work. Its goal is to find paid employment for all who want it.

Mr. J’s re-entry into society, with work and dignity

In closing, I would like to relate the following:

Three years ago a 45 year old man named Mr. J had already spent 22 years in a state psychiatric hospital. He had a history of acting out at the hospital and had assaulted some hospital employees over the years. No one wanted him out in the community. He was deemed to be assaultive and a safety risk. Our staff decided to bring him home. They devised a plan that included a daily companion and a place in our transitional group home. We asked him prior to discharge what he most wanted if he were to live in the community. He stated that he wanted a job and wanted to go eat in a restaurant. We got him a job through the CO-OP. With that we finally worked out Mr. J’s discharge.

Mr. J has been a near perfect citizen. There have been no assaultive incidents. The daily companion has long been unnecessary.

One evening I was sitting in a local restaurant with a friend. I looked up and saw Mr J enter the restaurant and wait for the host. Mr. J had on a suit jacket and was neat and clean. The host seated him, and Mr. J perused the menu and gave his order to the waiter. Mr. J has a loud voice, so I could hear him speaking to the restaurant staff. He was polite and appropriate. Although he was alone, he enjoyed his dinner and left after paying his bill.

I still often think of my early experiences in the state hospital and compare them with this image of Mr. J. There was little dignity evident among the state hospital patients I once knew 30 years ago. In that restaurant I thought that I could have reached out and touched the reality of Mr. J’s dignity.

For a copy of Kenneth Jue’s complete paper, titled “Normalized Employment: Path to Personal and Societal Dignity,” from which the above article has been extracted, write to:

Kenneth Jue, Chief Operating Officer
Monadnock Family Services
64 Main Street, Suite 301
Keene, New Hampshire 03431
The International People’s Health Council is undergoing some structural reforms in order to increase communication between interested individuals and groups in the different countries around the world. While there will still be regional coordinators, there will also be an effort to relate directly to country representatives and to representatives of groups and/or networks interested in developing links with IPHC.

In June several members of IPHC participated in an expert meeting with the Government of Holland, the principle Dutch donors, consultants, and “Health Counts”, a European Consortium founded in 1998 that calls for the adjustment of economic policies to respect equity and the right to Health. Its members include WEMOS (the Netherlands), MEDACT (UK), and Physicians for Social Responsibility (Finland). The discussions with the Dutch government and the donor agencies stressed the need to develop the 20:20 Initiative, proposed at the Social Summit in Copenhagen in 1995, for more investment by all countries in basic social services. There was general agreement that this initiative and other lobbying tools are extremely important at this time, considering the severe consequences of macroeconomic policies on the health of our people.

Following the expert meeting, IPHC coordinators Mira Shiva, Pam Zinkin and Maria Zuniga, met with the Health Counts representatives to look for ways to integrate our efforts and to work toward future collaboration between the two groups. A joint proposal is being developed to establish an international lobby and policy advocacy network with the overall goal to call upon national and international agencies involved in economic and health policy to respect equity and the right to health. Another meeting will be held in mid-September to further define this relationship.

**The IPHC forms closer links with “Health Counts” and other Networks**

*Update by Maria Zuniga, worldwide coordinator of the IPHC*

**IPHC to be included in 2nd Alma Ata Conference**

1998 is the 20th anniversary of the Alma Ata Conference, at which the world’s governments subscribed to the goal of “Health for All” and proposed a strategy of Primary Health Care to move toward that goal. In November of this year the World Health Organization is organizing another global conference at Alma Ata, Kazakhstan, to evaluate why we are still so far from reaching the goal, and to look for a more effective and sustainable way forward. David Sanders and David Werner, co-authors of *Questioning the Solution: the Politics of Primary Health Care and Child Survival*, who are both regional coordinators of the IPHC, have been invited to speak at this conference.

**Other network news:**

The Regional Committee for the Promotion of Community Health, a network of community based health workers and programs in Central America and Mexico, recently prepared a 3-year strategic plan leading into the 21st Century. Members of the Regional Committee are working on issues related to the health sector reforms being carried out in each country, including plans for lobbying efforts at the national and regional levels. They are also taking a close look at alternative therapies and are sharing experiences in this area. Other programs include AIDS education and popular health education methods.

Several members of the Regional Committee are celebrating important anniversaries this year: ASECSA, the Guatemalan Association of Community Health Programs is 20 years old. CISAS, Center for Information and Advisory Services in Health in Nicaragua, COSALUP, the Committee for Popular Health in the Dominican Republic, and PRODUSSEP, the Mexican Community Health Association, are all celebrating 15 years of service. Congratulations to all of you and to the communities that have benefited from your work over these long years.

**Announcing a groundbreaking publication:**

*The New World Order: A Challenge to Health for All by the Year 2000*

*Published by Health Systems Trust, 504 General Building, Durban, South Africa*

*Available from NPPHCN/SAHSSO, PO Box 192, Gatesville 7700, South Africa, and from HealthWrights for US$7.00*


The South African conference was organized by the IPHC together with the National Progressive Primary Health Care Network (NPPHCN), and the South African Health and Social Service Organization (SAHSSO). The book includes papers by D. Werner, M Chossudevsky, J. Seaman, D. Sanders, A. Sambo, V. Shiva, R. Davies, P. Bond, B. Ashley, F. Baum, D. Beltran, B. Ekbal, Z. Choudhury, V. Biruta, and I. Friedman.

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September 1998

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

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