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## Interview with the Author of“Nothing About Us Without Us”,Mr. David Werner

October 26th, 2009

at National Rehabilitation Center for Children with Disabilities

Interviewer :

Information Center

Japanese Society for Rehabilitation of Persons with Disabilities (JSRPD)

### About Mr. David Werner

Born in 1934

Biologist

Director, HealthWrights

<http://www.healthwrights.org/>

Working for community based health program in the mountains of western Mexico from 1965 as health worker. A strong advocate for inclusion and participation of people with disabilities in the community and a person with a disability himself, Mr. Werner has worked in more than 50 countries as a CBR consultant. His renowned books “Nothing About Us Without Us” and “Disabled Village Children” always gain one of the largest number of hits in our website.

DINF (Disability Information Resources)

[http://www.dinf.ne.jp/doc/english/index\\_e.html](http://www.dinf.ne.jp/doc/english/index_e.html)

David Werner's Collection

<http://www.dinf.ne.jp/doc/english/global/david/index.html>

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**Interviewer :** The title of the book “Nothing About Us Without Us” is being used by many people with disabilities for promoting International Convention on the Rights of Persons with Disabilities. What do you think about this?

Werner : The name of the book is taken from the slogan of the Independent Living Movement, which is “Nothing About Us Without Us”. It seemed to me that that was a very appropriate title for the book, in which is a collection of stories, really, about showing that when disabled people themselves and their families are involved in the problem searching process, the results tend to be better than when the professionals just prescribe down to them. It’s sort of the collaborative approach.

**Interviewer :** So you mean the “Nothing About Us Without Us”, the phrase comes from the concept of Independent Living? I think you made it up.

Werner : No, no, no. I didn’t make it up. I borrowed it. It seemed like a very good title. I was thinking of an appropriate title for the book, which is a collection of stories that show how important it is that disabled people take the leadership in the problem solving process and that rehabilitation workers work in partnership with them, rather than just prescribing for them. And so the slogan really fits that idea very much.

**Interviewer :** So I think this title is very good.

Werner : I think it’s an excellent title, but again, it’s not my invention. I borrowed it from the Independent Living Movement.

**Interviewer :** I see. In conjunction with the International Convention on the Rights of Persons with Disabilities, people now understand this concept much better than before.

Werner : Much better than they used to. I thought it was important to put the emphasis on that concept because when community based rehabilitation began, it was kind of a top-down process. Its objective was to move the focus of rehabilitation from the big institutions to the communities. But still it was with the idea that people in the community deliver services to the disabled people and teach them what they should do. The original manual written by World Health Organization was called “Training the Disabled People in the Community,” However “training” is something you do with a dog or a horse. Do you know what I mean? It tends to be a top-down process. We wanted to see it be a collaborative, sharing, working together process, rather than one person “training” somebody else. So the title “Nothing About Us Without Us” really fits into that idea of people working as equals.

**Interviewer :** And why did you start with the project held in Mexico?

Werner : In Mexico, well, the program focusing on disability grew out of a community based health program in the mountains of western Mexico. I worked for many years in the basic health

care before I got very much involved in disability activities. So I began working in community health or village health care back in 1965, which was a long time ago, 44 years ago, and the book "Where There's No Doctor", which has just been translated into Japanese. Have you seen the new book?

That was in, "Where There is No Doctor" was first published in Spanish in 1972. And that grew out of my work in primary health care. But then, in the village program in Mexico, the different villages, the people would choose the person they wanted to learn to become a village health worker or what we call village health promoter, and they tried to pick somebody that they thought would make a good health promoter in the sense that they really cared about other people and they cared about their well being and their health and this kind of thing, and also had some skills to offer and willingness to learn and to give of themselves. And it so happened that a number of the persons who were chosen by the villagers to become their health worker, one of themselves, they happened to be disabled. They happened to have disability. And that happened not so much because they thought the disabled person would make an especially good health worker, but simply because they were often the only people that had the time to do it because if they were physically disabled, they couldn't do the heavy farm work. Often they weren't married because of the taboos against getting married, so the women wouldn't have the children and the responsibilities. So they could train as a health worker and devote the time to it. And then with the passage of years, who turns out to be the best health workers? Very often these disabled persons because they had been sort of marginalized in their communities to begin with, their hearts would go out to other people who, for whatever reason were disadvantaged or vulnerable or poorer or be what it may. So in a way, by becoming a village health worker, the disabled person's weaknesses became their strengths in reaching out to other people in need.

And so, along about 1980, a group of the disabled village health workers and myself, and I have of course a disability myself, decided that there just wasn't enough happening for disabled children, for other disabled people in the health program. Out of this concern grew the idea of starting a sister program to the health program focusing on disability and rehabilitation and needs of disabled people. But since the persons that had the primary concern were disabled themselves, from the very beginning, they felt it was important that disabled people have a leadership role in that process, take the lead in it. And so that's been sort of the way that the PROJIMO, the village health program has evolved with leadership by the disabled people themselves and their family members.

**Interviewer :** So the concept, it grew, then the title is very good fit for the project taking place in Mexico. But when it comes to the International Convention on the Rights of Persons with Disabilities, so many people use the phrase, "Nothing About Us Without Us" to represent the rights of person with disabilities. They concluded with the phrase, " Nothing About Us Without Us". What do you think about it?

Werner : Right, I didn't invent the phrase. I borrowed the phrase because it is appropriate. I think there's been a growing awareness on the part of disabled people - and slowly on the part of rehabilitation workers and professionals -- that they need to work more in partnership with disabled people and not just prescribing, telling them what to do and this kind of thing. And I think that's a very important concern. I would very much like to see more rehabilitation professionals be disabled persons themselves because if they have a disability themselves, they have an understanding of the needs and the feelings and the social attitudes from their own personal experience and they're more likely to reach out as equals to other disabled people than somebody who doesn't have the disability experience themselves.

**Do you think the number of people with disabilities working in the rehabilitation field has increased or just like the same when you wrote this book?**

Werner : I think that there are more people working in the rehabilitation field now than there were when we began the program and when I began writing in the area. And I think that's one important aspect of the changes that have been taking place. I think there's more focus on the importance of

inclusion of disabled people in the mainstream of society. This is not just because they have a right to be included, but because often disabled people can make a contribution as big or sometimes bigger than non-disabled people, especially in the area of disability, of marginalization, of vulnerability because they have the experience themselves in that area.

**Interviewer :** **And the world has changed a lot compared to the period when you wrote “Nothing About Us Without Us” and “Disabled village children”. What do you think about it, regarding the assistive devices or some other related things?**

Werner : When I began working in primary health care, in community based health care, the concept was fairly much that of taking care of people, of providing services. The village health worker was typically seen as a physician’s assistant, somebody who did what the doctor told them at the community level. It was a top-down process in which the doctors and the medical establishment were on top. In “Where There Is No Doctor” and the, it’s partner book, “Helping Health Workers Learn”, we began to look at it differently and say the village health worker is somebody that, in many ways, plays a more important role than the doctor. The doctor is a specialist in that narrow area of health called medicine, in curative care. The village health worker works with the whole community to improve the whole health situation to prevent problems, to get people working together to correct the social determinants of health, which are often related to unfairness, to the power of some people over others.

So the village health worker plays a very important role in the inclusion of all people and the equality of all people, working together to improve their situation together. And at first when “Where There Is No Doctor” came out, the World Health Organization didn’t really approve of it and UNICEF didn’t approve of it and the Christian Medical Commission didn’t approve of it. They said this is too much medical and health information. Ordinary people will misuse it or they won’t be able, they won’t have the patience to read through it. And basically, the idea was still that those people need to be taken care of by the medical establishment, which too often is part of the ruling class. But little by little, after “Where There Is No Doctor” was published, the World Health Organization and UNICEF began to say, see that ordinary people and village health workers and mothers in their homes were using the information and empowering one another with the information.

And so the concept of what primary health care was began to change. I think that my books and our work made a contribution to that, but there were many other different groups and people around the world working in the same area, towards these same kinds of changes. But, certainly, the fact that the books I wrote have been so widely used helped the process along to some extent. Then, in the area of community based rehabilitation, a similar dynamic happened in the early ‘80s when World Health Organization coined the term Community Based Rehabilitation or CBR. Certainly it had a humanitarian idealism, but the idea of CBR came from rehabilitation professionals who were not disabled themselves. Again, it had a kind of top-down approach of ‘we the experts will tell people in the community how to train disabled people so that they can be normalized into society’. There was a lot of protest amongst organized disabled people about this top-down process. They said, “We want to have the voice ourselves. We want to take the leadership ourselves.” And so we emphasized the importance of disabled leadership and empowerment, first with “Disabled Village Children” and much more so with “Nothing About Us Without Us”.

We built on this idea of self-determination, which comes from the disabled community itself. And it’s really, the idea of “Nothing About Us Without Us”. I think the books that grew out of our community work have contributed to a new and more empowering approach both to primary health care, initially through “Where There Is No Doctor” and “Helping Health Workers Learn”, the two early books, and then in the area of Community Based Rehabilitation. There’s a lot more emphasis on human rights. And in community based rehabilitation today, a lot more emphasis on self-determination and on leadership by disabled people and their families than there was when CBR began. And so I think we’ve played a role in that process.

**Interviewer : Was it very successful?**

Werner : Well, it still has a long way to go still. I don't know if historically, you know of how the Association of Disabled Persons International began?

**Interviewer : Yeah, But now, I think professionals of Rehabilitation International, they tried to approach people with disabilities. They want to work together. Because of this they want to even change the name of their organization. Have you ever heard of that?**

Werner : No, I haven't heard of the name change, but it could be a good idea. There's been a shift in consciousness within the rehabilitation establishment to the need to work as equals with disabled people and not just prescribe for them and do things for them and to them. And it's been an important process. It's been exciting to be involved in seeing these changes take place.

**So do you think DPI still wants to work separately from the Rehabilitation International? Can they work together?**

Werner : They can work together, although there was, historically, a period of some conflict. And I think that's necessarily the case. I mean this is one of the debates that I've had with some of the people like in Christoffel Blinden Mission (CBM) . The people of CBM were initially critical of PROJIMO, our program in Mexico, because they said, "Its leadership is completely disabled people and we want to see integration. We want to see disabled people and non-disabled people working together." And in principle that's a good idea. But when there's any group that is marginalized or not respected equally by society, in part of the process of the struggle for equality, those people need to form their own solidarity amongst themselves before then there can be a real sense of equality and working together. It happened in the United States with the Civil Rights Movement, where black people had to organize and take a stand on their rights. It certainly has happened in the Women's Liberation Movement, where women came together and formed their own organizations. And they were not about to have men as leaderships of their organization. They said "We women need to find our own voice so that we can be equal to the men." And so there's been historically a similar kind of process within the disability movement.

Ideally, everybody would be working together. Disability programs would have disabled and non-disabled people working together as equals. But still there tends to be a dominance of the non-disabled professionals and so disabled people are still pushing for their equal voice and their equal rights. And it's high time they began to push for their opportunities to become professionals in the rehabilitation field. We feel that it's very important that more disabled people become professionals in the areas where they work. For instance, in PROJIMO in Mexico, the people who make the prostheses are amputees. The people that make the orthopedic appliances are users of orthopedic appliances primarily. And the wheelchair builders are wheelchair riders. They have a personal experience with how important it is that the wheelchair or the leg or the orthopedic appliances really be adapted to meet the best needs of those people. I would like to see in the selection process in schools of rehabilitation, of physiotherapy, of occupational therapy, priority given to persons with disability, recognizing that having a disability is not a disadvantage, but a qualification, which gives more understanding of the other people's needs. And they are more likely to relate as equals with the people with whom they work.

**Interviewer : The International Convention of Persons with Disabilities stipulates support for developing countries. What do you expect in the field of CBR with the Convention?**

Werner : I think things are slowly moving in the right direction. There's been a big shift toward the focus on inclusion of disabled people, not just integration, but toward fuller inclusion into the processes of society, with more emphasis on a leadership role of disabled people in matters that involve disability.

I think that another important trend in CBR has been towards diversification of approaches. When CBR was initially defined by the World Health Organization, it was very much of a package. That is

to say a prescription based kind of process. You did it like this, like this, like this. You organized like this. You had a hierarchical structure, the national supervisor supervising the state supervisor supervising the community supervisor supervising the family supervisor supervising the disabled person. So it was a whole totem pole, a pyramid, if you like, with the disabled people on the bottom. For this reason, we've often talked about turning the pyramid on its side so that disabled people are not on the bottom, but rather they come first on a pyramid that's been turned on its side. This way disabled persons have the first voice and then the family members and then the community rehab workers and the members of the community and finally come the professionals and the rehab experts, who are at the service of the others rather than dominating them. So there's more sense of equality and of people working together for solutions.

**Interviewer :** **The situation is very much improved, I think, even though it is very slow.**

Werner : It is very much improved. On the other hand, for every disabled person that benefit from community based rehab and this process of awareness raising and inclusion, the violence and aggression in the world today creates too more disabled people who receive no services and are excluded. The injustices and the inequality, not just between disabled and non-disabled, but between rich and poor, the gap is growing. And the WHO has determined that one of the biggest causes of disability, for instance, is malnutrition, not just of the child but of the mother who is inadequately nourished. She is more likely to give birth to a premature child with the combination of disabilities and this sort of thing. So poverty and malnutrition are really some of the most basic causes of disability.

In the world today, the World Health Organization has just come out with the announcement that more than a billion people are chronically hungry, or one in six people in the world today are hungry. And that's the first time that it's gone over a billion. So when you get an increase world hunger, and then with global warming and economic crisis and running out of petroleum products and other world crises all coming together, I'm not very optimistic. I think given the overall global trend, our inequitable and unsustainable free-market economy is going to create many more disabled people rather than less . And the growing competition for food, for jobs, for different things like that is going to make it more difficult rather than less disability for people who are different or disabled or more vulnerable for any reason. So I think that the struggle for the rights of disabled people has to be tied to the struggle for the rights of all human beings to earn a living, to have a voice, to participate in genuine democracy. We need to build a world where everybody has a voice and where a ruling class isn't creating a situation which widens the gap between rich and poor. That is what is happening today, and what, in turn, is causing more violence and more aggression, more wars which produce more disability. So it's a complex situation. I don't think that disability rights can be separated from the other human rights, especially the rights to enough food, to adequate living conditions, to education that really helps people think, as distinct from most of our schooling, and to helping prepare ordinary people to analyze the situation in which we live today, with the converging crises we face so that everybody can begin to participate in looking for solutions. The current leadership of the world is not doing its jobs in terms of calling for the changes that are necessary to create a healthy society that minimizes disability.

**Interviewer :** **We are particularly working and focusing on access to knowledge and information by disabled people. In order to help people with disabilities get more access to knowledge and information, we are promoting Information and Communication Technology and universal design concept. So we are trying to approach mainstream events, like World Summit on Information Society (WSIS) led by United Nations and ITU (International Telecommunication Union) to participate in the program to represent voices of people with disabilities, but still their issues are not well recognized in the mainstream activities. We are also developing information technology for people with disabilities.**

Werner : That's good! I know it's a slow process. It takes a lot of time, a lot of education, and a lot of technological sophistication in some ways.

**Interviewer :** Yes, do you have any advice on our activities for helping people easily get the information like primary health care?

Werner : I think that a lot has been done on alternative methods of communication of helping people that don't have hand control or has difficulties in communication, for example, Braille, voice recognition. All of these things are very important. I think that it's also important in our schooling process with children that we look for ways to make it easier for all children to learn certain things. And for children to learn process to enjoy helping each other learn. In another word, sharing in classroom situation. Children who are quicker or learn faster feel responsibility of reaching out to the child who learns more slowly or has difficulties in communication. A number of tricks can be used to simplify the learning. For example, many children have difficulty learning mathematics. If ways can be developed to make the learning easier for the child with a learning disability, it will make it easier for non-disabled children as well.

**Interviewer :** Finally, it helps everyone.

Werner : Yes, it is help for everyone, exactly. My books are an example of how information can be simplified so that it is more accessible to everyone.

**Interviewer :** Thank you very much.

Werner : It's my pleasure.



## David Werner

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**David Werner** (Born 1934) is author of the book *Donde No Hay Doctor* *Where There is No Doctor*, co-founder and co-director of HealthWrights (based in [Palo Alto, California](#)) and a Visiting Professor at [Boston University](#) International School of Public Health.

A [biologist](#) and educator by training, he has worked for the past 44 years in village health care, community-based rehabilitation, and [Child-to-Child](#) health initiatives in the Third World, especially Mexico.

For several decades Werner served as facilitator and adviser to Project Piaxtla, a pioneering villager-run program which contributed to the early conceptualization and evolution of Primary Health Care. It was located in Ajoya, San Ignacio, Sinaloa but moved to nearby Coyotitan in 2000.

Out of Piaxtla grew PROJIMO, an innovative Community Based Rehabilitation Program Organized and run Disabled Youth of Western Mexico, still located in Coyotitan. In 1975 Werner co-founded the [Hesperian Foundation](#), which publishes *Where There Is No Doctor* and many other books on community-based healthcare. He left that organization in 1993, and with a group of friends, created a new organization, [HealthWrights](#).

Werner has authored and illustrated several handbooks on topics including basic healthcare, innovative solutions with limited resources, and assistive technology. In 1998, he co-authored the book, *Questioning the Solution: the Politics of Primary Health Care and Child Survival*, which explores the root causes of poor health and possibilities for a healthier, more equitable way forward.

Werner has worked in more than 50 countries, mostly developing countries, helping to facilitate workshops, training programs, and approaches to "health education for change." He has been a consultant for UNICEF, WHO, the Peace Corps, UNDP, and UN-ESCAP and various state and federal governments ranging from Mexico to India and Iran. He has received awards and/or fellowships from the [World Health Organization](#), the American Pediatric Association, the American Medical Writers Association, Guggenheim[1], and the MacArthur Foundation[2], among others. Werner is a founding member of the International People's Health Council. Werner has also been active in the Planning and Analytic Group for the People's Health Movement, which was launched at the People's Health Assembly, Bangladesh, 2000.

Werner is the author or co-author of the books *[Where There is No Doctor, Helping Health Workers Learn](#)*, *[Disabled Village Children](#)*, *[Nothing About Us Without Us](#)*, *[Developing Innovative Technologies For, By and With Disabled Persons](#)* and *[Questioning the Solution: The Politics of Primary Health Care and Child Survival](#)*.

In the last several years he has facilitated Community Based Rehabilitation workshops that focus on simple but functional assistive equipment made by participants, family members and disabled children themselves. Many of these workshops are described in HealthWrights' *[Newsletters from the Sierra Madre](#)*. Some are available on DVD through HealthWrights.

## **[edit]** External links

- ["HealthWrights site"](#)
- ["Politics of Health site"](#)

## **[edit]** References

1. <sup>^</sup> ["David B. Werner \(1977\) - US & Canada Competition Natural Sciences - Medicine & Health"](#). <http://www.gf.org/fellows/15589-David-B-Werner>. Retrieved 2009-01-29.
2. <sup>^</sup> ["David B. Werner, Health Care Leader, July 1991"](#). [http://www.macfound.org/site/c.lkLXJ8MQKrH/b.1142813/k.9401/Fellows\\_List\\_\\_W.htm](http://www.macfound.org/site/c.lkLXJ8MQKrH/b.1142813/k.9401/Fellows_List__W.htm). Retrieved 2009-01-29.

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