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International News and Views:

Interview with Lex Frieden, Newly Elected President of Rehabilitation International

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Introduction

I first met Lex Frieden in Jakarta, Indonesia in 1995 where we sat on a panel together, discussing international trends in independent living. I was immediately taken by his charming southern drawl and impressed by the amount of knowledge he seemed to possess in so many areas.

Since then, I've had the pleasure of working closely with him on a number of international projects. When I heard he was seeking the RI presidency, I felt in my heart it would be a good fit. Not only is he a well-respected long-established disability rights activist, but also the Senior Vice President of The Institute for Rehabilitation and Research in Houston, as well as a professor at the Baylor College of Medicine.

The beginning of the 21st century presents many interesting challenges for people with disabilities all over the world, including: our continuing struggle for access to adequate health care, education and self-sufficiency. As we gain experience in being in control of our own lives, we will need to learn how to blend the best of the "medical model" with the newer "social model" approach to disability issues. It seems to me that Lex's combination of activist and professional skills can provide a much needed bridge between the disability and rehabilitation communities. The following interview highlights his priorities and vision for the next four years as RI President.

Lex and his wife, Joyce, share their home with Grandson, Trey, Lex's attendant, Mac Brodie, and Great Dane, Governor.

(Photo appeared in the ***Houston Chronicle****, Sunday, October 25, 1998. Taken from http://home.houston.rr.com/frieden/)*

Interview

KM: In all the press releases I've seen, it says that you won on a disability rights platform in the election in Rio de Janeiro. What exactly does that mean?

LF: Well, I would say the electorate of Rehabilitation International, the members who have the right to vote in the election, had a choice between two candidates. In my opinion, one was an academic, a scholar, and an articulate orator who speaks authoritatively about certain issues pertaining to people with disabilities.

On the other hand, from my perspective of course, I hope I am regarded as a scholar, researcher and administrator who happens to have a disability and who is also an activist and a disability rights' proponent. I hope I am perceived as working to implement the concept of leadership by people with disabilities and as working for inclusion and equal opportunity for people with disabilities. Again, that's in contrast to the other candidate who has spoken and written from a mostly academic viewpoint about the value of special accommodations and the need for exceptional services for people with disabilities.

So, I think that those who voted for me saw me as a candidate who represents the contemporary paradigm of empowerment of people with disabilities, as opposed to an older paradigm. I would say that that is probably the explanation for why some of the press references have been made to a "disability rights platform."

KM: What do you think are the most important things for RI to accomplish in the next four years?

LF: Well, I think the most important goal unconditionally is for RI to work in harmony with other disability and human rights organizations to secure adoption of a United Nations Convention on the rights of people with disabilities. And I think that must be a strongly framed convention that includes a substantial enforcement mechanism. Furthermore, I think that the convention must incorporate other structural changes within the United Nations monitoring system of rights and their enforcement.

KM: To follow up, how do you see a new convention being more effective than just including disability in existing conventions?

LF: Well, I don't think they are mutually exclusive. As a matter of fact, I personally believe that we should not hesitate to advocate for the existing United Nations conventions and other instruments of the UN to be amended to include disability.

But I also think it's important to have in addition to that a free-standing convention that focuses strictly on the rights of people with disabilities. One reason is that I think it's very difficult to locate all the United Nations rules and to become familiar with all of them. I find it's challenging to get an overview or holistic picture of disability by going from one convention to the next, and trying to pull out of that what pertains to people with disabilities. I think there's a high likelihood that countries will be better informed by having disability issues addressed in a focused convention that relates specifically to the rights of people with disabilities.

So that's one point that I would say supports a free-standing convention.

Secondly, I think it's very difficult for disabled advocates and their partners around the world to get excited about adding disability to a lot of extant rules, some of which may not be very well enforced or very well-known. Also, I think it's much easier to develop a campaign, so to speak, if we have a single well- conceived instrument that establishes a United Nations commitment to disability rights at the level of a convention.

KM: How do you see that as increasing the feeling or the sense of the public that disability is a human rights issue?

LF: As an example, I can liken it to our experience in the U.S. with the Americans with Disabilities Act. In my view, on July 26, 1990, we probably educated and sensitized and made aware more people about disability rights' issues than at any other collective period of time in the history of the world. Because on that day at ten o'clock in the morning East Coast Time, CNN World News went live to the White House and broadcast all over the world extensive coverage of the President of the United States signing a disability rights law in front of a crowd of over 3000 advocates and allies. This made that law significant for every person, not just people with disabilities. Because every person uses the news media as a way to prioritize what's important in their lives and in society.

In addition to CNN, every major newspaper and television and radio outlet in America carried the passage of the ADA as the lead story.

So, on that single day, and in a fairly collapsed period of time, it's my contention that more of the general public was exposed to the concept of disability rights than could have been exposed over a longer period of time with us doing ordinary education and advocacy as we always have done and will do.

And I think the same would be true for the convention on rights of people with disabilities. Through this campaign process we will have the opportunity to educate, inform and sensitize literally billions of people around the world to issues pertaining to rights of people with disabilities.

KM: Considering both the impact of media coverage and the influence of the UN, can you comment about how the International Year of Disabled Persons may have contributed to increasing worldwide disability awareness as well?

LF: Actually, I think that the International Year of Disabled Persons, which was constituted by the United Nations, had a great impact around the world, certainly a greater impact outside the United States than inside.

And that is because many countries actually do pay more attention to United Nation edicts and press releases than do people in the U.S. From that standpoint I think a campaign for a UN convention really can address millions of people in developing and poor countries, and countries that depend on the United Nations for a lot of their information and for help in establishing policies and priorities. Further, I think whatever impact we saw with IYDP -and the subsequent Decades of Disabled Persons--will be magnified and amplified a thousand times, if we're talking about a convention which in my understanding is the highest level instrument of rights enforcement that the United Nations can grant.

KM: Besides the convention, what are your priorities as president of RI?

LF: I have several other priorities. One is to increase the representation of people from poor and developing countries in RI's membership. Right now RI, like many other membership organizations, depends upon the dues paying members to support the organization. In poor and developing countries organizations of, and those for people with disabilities for that matter, have relatively small budgets. It is very difficult for them to prioritize dues payment in any international organization given other responsibilities and objectives those organizations have in their own country.

Therefore, many organizations that should be represented in RI are not represented. It is my goal to change that, either by altering the dues structure of RI, or by finding some means of subsidizing the dues for these organizations, or by some other means.

I don't have the solution at this point but I'm committed to finding a solution to ensure that the organization benefits from the great intellect and wonderful ideas and strengths that lie in the people of poor and developing countries of the world. So that's kind of my second most important priority.

Now along with that, Kathy, goes my desire to empower people with disabilities more in the RI organization. As a result of its history, RI is made up of many organizations for people with disabilities. And that's not bad.

At the same time it's my personal belief that an organization like RI can be stronger and have a more credible voice around the world, if it has a better balance of the "of" organizations. That is, organizations that are made up primarily of people with disabilities and led by people with disabilities.

I think RI needs more of the "of" organizations in order to have better, overall credibility in its work. We need to have a better balance. We need to be a forum for conducting a dialogue between the "of" organizations and the "for" organizations.

On the horizon I can see signs of a new paradigm: the "of and for" organizations. I think that we talk too much in dichotomies as if there are only two types of disability organizations÷the "of" or the "for"÷but, I like a hybrid model.

KM: Actually, the World Blind Union utilizes that format.

LF: Great. I think that Rehabilitation International can be a forum to explore that concept and help develop it.

Let me be clear. I don't want to replace the provider organizations that are in RI or the government organizations that are in RI, with disability organizations exclusively. What I want to do is to complement those organizations by bringing in and empowering organizations of people with disabilities, so that RI becomes a more credible, valid forum for discussion of policy issues affecting people with disabilities.

I think until more disability organizations are included in the discussions that RI has, the validity of the outcomes may be questioned, regardless of whether they are the same outcomes that might have developed in a more balanced discussion.

KM: Well, you just led me to my next question. You have a wheel, so to speak, in both camps". you're a professor of physical medicine, and a disability advocate. How do you see being a member of both camps benefiting the direction that you want RI to take? Because to me that was a very significant factor in your being elected.

LF: Well, you know, in some respects I suppose the fact that I happen to have an academic appointment and that I happen to have certain professional training and experience, makes me less threatening to my non-disabled academic and scholarly peers. Perhaps less threatening than a disability advocate who is paid to advocate for disability rights.

Even so, I think people who know me, including my professional colleagues who may not have disabilities, realize that I am disabled 24 hours a day, seven days a week, and that at the root of all of my work, at the root of my being, is a person who has experienced disability, who understands the disability experience from a very personal perspective, and who breaths disability rights on a second by second basis.

So while some of my professional peers and colleagues may view me as moderate because I have certain training that they share, and certain experiences that they share, I doubt that any of them who know me, believe that my passion for inclusion and equal rights is moderated by those experiences.

I will say that perhaps I do have an appreciation for the possible advocacy that can be organized by certain non-disability groups. I have a kind of vision for how non-disabled people can contribute to the disability movement that some of my disabled advocate friends may not see. And if I do, I hope I can bring that to bear.

On that point, I would not understate it--at the root of my being is an advocate.

KM: I think that will be very clear. But you also have respect from professional colleagues that some of us may not have, given your training.

LF: Well, that's conceivable.

KM: How do you see the development of leadership in terms of RI? For a while I have been concerned that in the U.S. there are very few disability rights advocates, or young people just coming into the field, focusing on international development. How do you see RI developing as a training ground for people with disabilities?

LF: Quite honestly, I see any organization and every organization as a potential training opportunity and empowerment opportunity for people with disabilities.

Generally speaking, those of us with disabilities have not had an equal degree of opportunity to participate in organizations, to participate in social groups. I'll say that for myself, and I'll say that in a general kind of way for people with disabilities. I believe that's a result of historical exclusion to some degree. It's also partly a result of practical issues. For example, I don't have the stamina to go from early in the morning until late at night. I don't have the physical stamina to be involved in certain community groups in my town that other people might choose to attend.

I simply don't have the energy. I have to be selective about what I participate in, and there are other practical issues. Many meetings are held in places that are not accessible to people with disabilities or they don't provide interpreters for deaf people or appropriate accommodations for visually impaired people and so on.

So, for a variety of reasons people with disabilities have not in my opinion had the opportunity to develop leadership skills in organizations that most non-disabled people have had.

Therefore I see every organization as an opportunity for people with disabilities to have training and to be empowered. And I intend through the role of RI president to appoint people with disabilities to lead committees, to lead task forces, to serve on important commissions and in other ways to gain the opportunity be mentored by others who have certain experiences. I think a great deal of learning can occur through the act of participating. People can "learn by doing" and to the extent that I can identify people with disabilities who are willing to take part in the organizational processes of RI, I intend to find opportunities for them to do so. Because I think we are bound to promote ourselves by assuming and practicing leadership.

KM: So what does the president of RI do when he's not working either as a professor or director or a president.

LF: Well, as you know, I do so many things, it's hard for me to figure out sometimes whether I'm working or . . .

KM: Or having fun . . .

LF: I must say that I probably err by trying to do too much. But if I err, I would prefer to err in that direction than that of trying to do too little. And I think it's probably difficult for anybody to have the perfect balance in life.

So I will try as hard as I can to do those things that I choose to do as well as I can, and sometimes I fail in doing so. Very often I have to prioritize, but ultimately I will always try to concentrate on those things that I think will be the most likely to move the disability movement forward. There are very few things I do, Kathy, besides my work in advocacy and my work in my job, with the exception of my grandchild, Trey, who's nine years old. I like to reserve time to play with Trey and his dog, Luke, I like to go to Trey's soccer games. Spending time with Trey and my wife, Joyce, is the one exception I make to a rigorous schedule.

But that sounds almost depressing and I don't mean it to. Quite honestly, I would not work and I would not advocate if I didn't enjoy doing those things. The worst thing I can possibly imagine would be to have a job that I didn't like. In fact, I'm not even sure I would have a job if I couldn't find one I liked.

KM: Tell me more about your relationship with Trey. For example, how does he handle the disability factor, how does he explain it to his friends? Does he ride around in your lap? Give me some personal insights.

LF: Trey likes to show off my wheelchair. I'm almost a carnival act for some of Trey's friends.

I use a wheelchair that will raise me up and down, and I can go from the floor level up to a level equal to a tall, standing person. And Trey loves for me to do that in front of his friends. I mean he can almost charge admission for them to watch me manipulate the wheelchair.

And my wife, Joyce, who also uses a wheelchair, spends a lot of time volunteering at Trey's school. And the kids at the school, little kids in the kindergarten classes she reads to, refer to her as the granny on wheels.

So, we feel like we're fairly well acclimated and integrated into our community. People seem to regard us as an ordinary part of the community. I think we live in a good kind of accepting community and that includes the kids. Part of that is because we've made a commitment to be involved in Trey's school and with his friends. We go to his scout meetings and to his club meetings and his karate tournaments and practices and so on.

KM: Lex, I know that you're a fan of the Internet. What are some of your favorite websites?

LF: Well, in reality, I'm kind of fickle"I find some websites that I like and I'll go to them for awhile, and then find some others that I like and I'll disregard the old ones and start going to the new ones.

I like to tinker around websites that are productivity oriented. One I like is called http://www.hotoffice.com/ Another one is http://www.intranets.com/ A third is http://www.ecircles.com/

I think there's a really powerful future in web meetings that can involve people with common interests. So, I enjoy exploring these websites that are trying to set up vehicles for group communications. I am constantly sending them emails about whether or not I believe they are accessible to people with disabilities--particularly visually impaired people who I think have the greatest difficulty at the present time, really benefiting from the promise of the Internet. I make a point of not participating in those sites until I am convinced they are fully accessible. But I do think that these sites that are capable of bringing people together in a kind of synergistic communications network are the future of society, in terms of communications.

KM: Back to RI for one last question. Given your obvious commitment to the empowerment of people with disabilities, should non-disabled people feel threatened or as if they'll be more or less pushed aside?

LF: Absolutely not. I hope the world that we live in is big enough to accommodate people with disabilities and non-disabled people. I'm committed to that belief. As far as RI is concerned, I think the role of people with disabilities must be complemented by the role of non-disabled people.

There are lot of professionals working in the disability field who know a whole lot more about certain issues pertaining to disability than I do, because they've studied it, whether they're disabled or not. They've done research. They have information that I need in order to be independent and successful. Believe me, I don't want non-disabled people to feel left out. In fact I want more of them to come to RI. But, I want there to be a partnership, and I want people who don't have disabilities to adopt the same commitment that I have to empowering people with disabilities.

I can't imagine why anybody working as a special educator, a teacher of disabled children, a rehabilitation doctor, or a rehabilitation counselor, wouldn't want ultimately to empower people with disabilities. I mean isn't that their job? Isn't that their commitment? And given that belief, it's hard for me to imagine how real professionals would be threatened by having people with disabilities in leadership. To me that is the ultimate example or illustration of their achievements as professionals.