



From Patient to Citizen: Implications of the UN International Convention on the Rights of Persons with Disabilities and the Role of Physical Therapists

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Thank you for the opportunity to speak with you today. When I first received the invitation to present at the World Congress I thought it is good that you were reaching out to get the perspective of disabled people in your efforts. I was aware of the work that you had been doing with the WHO regarding their work in the area of Community Based Rehabilitation.

I agreed to present to share with you my views of the progress that has been made across the world to improve the lives of disabled people, the role disabled people have played themselves in these efforts, the problems that millions of disabled people still face today and the possible role you as individuals can play to remove the barriers that exclude disabled people from becoming participatory members of their communities. I will ask you a number of questions intended to engage your thinking regarding the role you and your association can play in conjunction with disabled people's organizations to help advance the human and civil rights of disabled people.



I will speak for 30 to 40 minutes and then open the floor for discussion. During this period I would like to hear from you about the work that you are doing as well as to entertain questions.

I had polio in 1949 at the age of 18 months while living in Brooklyn New York. I was the first of three children born to an immigrant family. Like other families mine knew basically no other people who had a disability except for their knowledge of President Roosevelt. Like other families they were completely unprepared for my acquiring a disability and one that was quite significant.

The first few years after I had polio were focused on medical interventions. Therapy played a big part in my life and physical therapists were the primary people I remember being involved. I also worked with occupational therapists but the role of physical therapists was very important to my parents. They saw therapy as a way for me to be able to learn what I needed to so that I could become as mobile as possible. I remember the therapist who came to my home every week, the stretching that my father did almost everyday, and the number of hours that I stood in my braces' before and after I had surgery to release my tendons, etc. etc, . Standing and walking was the goal. There was very little discussion about what physical therapy could be expected to produce. As I was a quad was it realistic to assume that I would



ever be able to walk well using my crutches and braces or were there alternative approaches that should be considered?

It seemed to me at an early age that there was not a great deal of thought given to what the role of therapy should be in my life and the role that the therapist could play in helping my family to learn about the opportunities that I could benefit from.

Walking as the primary means of mobility was never going to be possible. The need to be able to walk more for health purposes and to also be able to use a wheelchair as my primary means of mobility was what needed to be discussed.

In the United States in the 1940's, 50's and 60's there were huge architectural barriers and little work being done to break down these barriers through research or legislation to address the best ways to build accessible buildings or accessible transportation systems. The disabled veterans who had returned from WW II and the Korean War were beginning to put pressure through their associations to pass legislation at the state and national level.

The barriers were both physical and attitudinal. Children with disabilities who were for example able to walk up steps to go to school and needed very little if any assistance in school were being denied the right to attend regular schools.



The medical model which was centered on making people physically whole was the prevailing paradigm.

I never recall the physical or occupational therapists participating in meetings that my parents went to when they were trying to get the schools to admit disabled students nor do I remember as I grew older having therapists participating in the meetings that we as disabled people were beginning to organize to combat the discrimination we were facing as children and adults. Quite frankly I guess I always saw the therapists as nice people who provided a valuable service but didn't see themselves as people who needed to be engaged in changing the societies they lived in to remove the barriers that their "patients" faced everyday of their lives.

The decades of work that disabled people and their families had been fighting have only recently seen the national associations of physical, occupational, psychological and speech therapists engaging more because they have a vested interest in the legislation that has been passed in areas like education and employment. These laws have included a range of therapists because they are seen as playing a valuable role in working towards the inclusion of disabled people in schools, and work and the society as a whole.



The involvement of the associations has proven very valuable. They have begun to learn about what the goals of families and disabled people are. They are seeing a larger role that they can play in working collaboratively with other professionals and with disabled people and their families.

I believe that most people enter the field of physical therapy to make a qualitative difference in the lives of the people they are working for. But too frequently there are not sufficient opportunities for students to actually learn from the people they are working for what their real hopes and dreams are and how they as therapists can become change agents in a social movement.

Helping people to learn about what efforts are underway in your countries and at the international level to produce change is very important. More and more universities are establishing disability studies programs. It would be valuable for students to take a few of these courses so that they can get a better understanding of the history of the disability movement, the types of barriers that have existed and are being removed and how and why it is relevant to integrate the views of disabled people into the fields they are studying.

How many of you are teaching at the university level? Are you encouraging your students to take some of these courses? Are you possibly putting together



reading lists of books your students could read to learn more about these issues? Do you invite disabled people to come and lecture in your classes? Are your students encouraged to work as volunteers with some of the disabled people's organizations to learn first hand about the needs that people with disabilities have and the approaches the organizations are taking to address these issues? Are your students being encouraged to help apply what they are learning in practical ways as they are students?

Additionally, how many of you are currently serving on boards of directors for DPOs or are working in a paid capacity in such an organization learning to work with disabled people and being a part of a team fighting for social justice.

Let me share a few examples of effective approaches being used to integrate the knowledge that therapists have at the same time they are helping to strengthen the disability rights movements.

One of the first examples of therapists being involved in disability advocacy work that I remember was in 1973 when I became involved with the world's first Center for Independent Living in Berkeley California. CIL was and is a self help organization which works to empower disabled people. This is done by listening to what disabled people need and creating support services to address those needs as well as working



on the implementation of existing legislation and when necessary the development and passage of new legislation. This was the first organization of its kind in the US at that time. Today there are more than 400 similar programs in the US. The model of self help and empowerment of disabled people is one that is being developed across the world. There are similar programs across Canada, Europe, Latin America and programs are emerging in countries across Asia.

The Berkeley CIL had a number of therapists and a nurse involved from the beginning. They however were not providing therapy, rather they were working with disabled people to go into their homes and help them evaluate the kinds of accommodations that needed to be made for them. They were involved in helping to get local governments to provide funding for home modifications. They played an important role both with the disabled population and helped to educate elect representatives and government workers to learn that the removal of barriers can make disabled people's ability to contribute to their community through work and social participation possible. They the therapists felt a part of the community that was fighting for change. They saw themselves as change agents working with and frequently being led by disabled people.

The Philippines Organization of Disabled Persons has been working to get children with significant disabilities into the public schools. Venus Ilagan the



Director of the program and also the President of DPI, began many years ago with support from the Danish government to develop a project which is using physical therapy students coming to their more than 65 sites around the country to provide therapy for the young people and to work with their families. Today their efforts are not only resulting in more schools taking these students but in the creating of a parent organization representing thousands of parents of disabled children who are learning how to fight for the rights of their children. Additionally, many of these parents are learning about what their children can do. They are beginning to be able to fight against the discrimination that they and their children have faced.

In Pakistan, there is an organization named Milestone. It is an independent living center very similar to the CIL in Berkeley California. They received technical assistance from the Independent Living Movement in Japan which studied in the US and Sweden where there is also an IL Movement. In Pakistan one of the primary roles the disabled staff were playing before the earthquake was to help disabled people learn how to take care of themselves physically – how to transfer – bowel and bladder care – how to push their wheelchairs, etc, etc. After the earthquake they were out in their trucks the second or third day after the quake trying to find where the disabled people were. They were particularly trying to find where the newly disabled people were. As you may know there were more than 800 people who



became spinal cord injured after the quake and many of these people were woman because they were home when the quake struck. The disabled people were trying to get into the hospitals to be able to provide similar services to those they have provided previously. In the beginning they were having difficulty because they were not seen as being professional. After a brief time they were able to become a part of the work that was going on the hospital. Additionally, Handicapped International became involved bringing in physical therapists to help work with amputees and people with other injuries. Today these two programs are working together in many different ways. The government of Pakistan with support from Japan is putting money into creating another 40 independent living centers.

In Mexico there is a project called Proyecto Proximo which is located in one of the poorest communities in Mexico. Here disabled people come to live in a community led by disabled people. They help people get the types of low cost equipment they need to enable them to become more physically mobile and productive. Physical therapists go down to volunteer their time. What has been seen is that some of these therapists stay because they find the work they are doing is producing results that they find quite tangible.

These are four examples of different ways that therapists can use their professional skills while also



learning to become an important part of the reform efforts underway in different countries.

We have seen over the past 20 -30 years important changes happening in countries around the world. Disabled people have created their own organizations which are focused on the social model rather than the medical model. This has meant that we see ourselves as being a part of society – contributing members of society. We have been organizing at the local levels. We have come together as disabled people to fight for the removal of barriers which had relegated us to positions of poverty by denying us opportunities to attend school, to work receiving real wages for real work, to receive health care, to live in accessible housing, to have access to accessible technology, accessible transportation, to marry and have children.

We awoke one day and realized that our goal of equality could only be achieved if we were able to create a movement which would come from the grassroots up and would be able to effectively argue that our poverty was not because we are unable to contribute to society but rather that discrimination had placed barriers before us similar to those that women and children and indigenous populations had faced. We had to persuade our governments and eventually the United Nations that the problems were so egregious they had to be addressed through legal



reforms, that focused on the inclusion of disabled people in human and civil rights.

Organizations such as Disabled People's International, the World Blind Union, the World Federation of the Deaf, and the new consortium the International Disability Alliance, the Global Partnership for Disability and Development and hundreds of local DPOs have been gaining in knowledge and capacity and are having a positive impact at the local, national and international levels. They have been working on empowering disabled people who are now playing leadership roles to advance an agenda to produce meaningful change. Helping people to learn how policy is made so they can become meaningfully involved with reform efforts in their countries.

Additionally, these organizations have learned that it is important for them to partner with a broad variety of groups. This is frequently not easy as many of the groups they need to partner with have little knowledge or experience in what and how disabled people can contribute. Their national and local governments and organizations such as the ILO, WHO, the World Bank, national development organizations such as FADIDA, Canadian CIDA, and Swedish SIDA have begun respond to local and international disability organizations who are applying for support to develop projects to help end poverty. Governments, the UN family, and national development agencies have



begun to realize that the ability to effectively reduce poverty in the local, national and international levels will not occur unless the needs of disabled people are addressed. This is a challenge as so much of the work in the past focused at looking at disabled people as helpless people who needed to be taken care of and could not make meaningful contributions. Little research has been conducted which enables us to look at effective practices to address issues discussed earlier. But this lack of information cannot thwart efforts to move forward.

We must learn as we go and document the results we have to share with others. Quality research is critical as we work in countries with limited experience and limited resources. We can learn from the work that has been done in Northern countries but we must use approaches that can be achieved in countries with fewer resources.

Liz Carrington representing the WCPT has played an important role with the work the World Health Organization has been doing in reviewing Community Based Rehabilitation. You will find it informative to read Liz's papers. CBR projects are aimed at reaching some of the poorest and most remote areas in poor countries. The work can bring together physical therapists, disabled people, families and community leaders to provide low cost rehabilitation services. The collaborative approach is also a good model which cannot only provide meaningful



assistance to the disabled person and family but also provides positive examples which can allow local village people fearful of disability to learn about the valuable role disabled people can play in their communities. Removing the stigma of disability is one of the biggest challenges we face.

In 2002 the UN began an effort to develop and adopt a UN Convention on the Rights of Persons with Disabilities. This Convention was deemed necessary by the disability community and had gained the support of many in the UN as a result of the work of the Rapporteur on Disability who had documented the extent of the discrimination that disabled people were facing in countries around the world and recommended that a Convention was necessary. From 2002 and until Dec 13 of 2006 work was conducted twice a year at the UN in Ad Hoc sessions. Hundreds of disabled people from around the world worked with member states at the UN to craft this document. Many in the beginning questioned whether this would actually occur and if so believed that it would take 7 to 10 years for passage.

What was so critical over this 4 year period of time was that for the first time in UN history representatives from civil society, in this case disabled people's organizations were given the opportunity to speak at the Ad Hoc sessions. Twice a year people came together for 2 weeks at a time. This long period of time enabled delegations from



governments and disabled people to really have time to learn about what the types of discrimination disabled people were facing as well as what remedies would have a positive impact on change.

The result was the adoption of the Convention on Dec 13 and the opening for signature from the member states on March 30 of 2007.

Collaboration and cooperation from many different sectors have brought us to this time with the Convention. Now the hardest work must begin. Not only do countries need to sign the convention and then ratify it at the country level but it must be implemented. Everyone knows that implementation will take many years. Even wealthier countries that have passed legislation providing rights for disabled people have not seen the rapid progress. But progress is occurring.

There are a number of articles that are quite relevant to your work in the area of children, education, health, habilitation and rehabilitation and employment.

I have had the privilege of working in many different jobs over the course of my career. I have worked with disabled people in local organizations, served on local, state, national and international bodies fighting for the rights of disabled people, I have worked for State, national and now local government and I worked for five years at the World Bank.



In the richest and poorest countries of the world we have seen progress being made to advance the rights of disabled people. These efforts have been led by disabled people, families and concerned professionals and allies.

The UN Convention provides great opportunities and hope that progress can be hastened. This progress would be greatly enhanced if you as physical therapists could play a leadership role by getting your members to learn more about the convention and to proactively seek out opportunities at the local level to work with DPOs and governments to pass the convention at the national level and then to work proactively for it's implementation.

Pass a resolution this week committing the WCPT to educating it's members about the convention – what it is and how they can work for it's passage and implementation at the country level – commit yourselves to playing a leadership to engage other organizations of health care workers in this effort; focus your attention on those articles in the convention most related to work such as health or rehabilitation or education; work with the media to help end the stigma that disabled people face in their communities; reach out to bring more disabled people into your profession; and bring disabled people into your classrooms to teach students.



December 3 is the International Day of Disabled Persons. This year the focus is on Decent Work for Persons with Disabilities. Begin to work now with disabled organizations to develop a program that can show the value of the work you do to bring people back into the work force or to prevent injuries before they occur. Work with employers, clients who have benefited from your services, legislators who could learn from these efforts. Link it to article 27 of the Convention.

Martha Piper's presentation last night was very empowering. She has challenged you to be bold and daring and to push beyond where you are today.

Heed her words and commit yourselves to becoming **agents for social change** to help advance the rights of disabled people around the world.

Thank you.