

Human rights: transforming services?

social care
institute for excellence



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I would like to thank the organizers for asking me to speak today and for creating an opportunity that is enabling us - those with and without disabilities, those responsible for the provision of social services, lawyers and human rights advocates - to address the issue of access to services for disabled people from a human rights perspective.

I will share with you some of my experiences living and working in the United States as the Disability Rights and Independent Living Movement was born and matured. I will also try to engage you in some of the work I am doing today as the Advisor for the World Bank on Disability and Development: bringing the voices of disabled people and parents into the agenda of poverty reduction and trying to get the Bank and developing countries to look at doing their work differently.

My work focuses on assisting staff at the World Bank and the governments of middle income and poor countries to learn about who the population of disabled people are, learn more about the causes of poverty and to propose ways of integrating disability into the overall poverty reduction strategies of the Bank. The mission of the Bank is: “a world free of poverty.” With more than 400 million disabled people living in developing countries – most of them poor - this goal cannot be achieved unless we develop reforms that will have a positive impact on their lives.

Why is this relevant to today’s discussion? The United States, England, the other countries in the EU and other governments who provide financial support to developing countries all have experience in the development of policies and practices aimed at removing barriers of exclusion and creating opportunities for disabled people to take their rightful place in their own countries.

If we can take what we have learned through our work in the Independent Living Movement and apply this knowledge to the service delivery systems of today we would be able to create a different set of services and a different way of delivering those services here and abroad. This new model might well produce better outcomes for people with all types of disabilities and from all walks of life.

It is difficult for large bureaucracies to change-but they can. Reforming the way we deliver social services may be one of the most difficult changes to make. These changes challenge what some of us have been taught in school. They challenge what many people consciously or unconsciously believe and that is that disabled people need to be protected and cared for and that we are unable to make the same types of contributions to society as the average non disabled person can make.

The Disability Rights Movements in the wealthier countries have been working for many years to get their governments to reform the way they develop and implement policies.

People with all types of disabilities have been learning how to express their views about the adverse effect negative policies and practices have had on their lives and have worked to create proposals of what governments need to do to reform themselves. As disabled people and their families have begun to be proactive they have taken feelings of anger and redirected them into advancing constructive reforms.

We have demanded that our societies move from a medical model to a social model. The medical model saw us as objects of charity in need of protection with few opportunities to be self directing or to be in charge of what types of services we needed or how we wanted them provided.

We are moving towards the social model which is based on empowerment, equality, and respect. The effective implementation of the social model will result in disabled people being given the opportunity to assume responsibility for their own lives and to be able to participate in their communities like never before in the history of civilization.

These reforms have not been easy nor, as we know, are they complete. But nevertheless we are seeing tangible changes. Everyday in our communities we see barriers falling that have prevented people with all types of disabilities from participating in society with dignity.

Let's look at some examples. In the past 20 years we have seen inaccessible street corners transformed as accessible curb cuts or ramps have been built in their place, we have seen manufacturers who said they couldn't produce cost effective accessible buses begin to do so, we have seen new buildings and major renovations to older ones made accessible including housing and public accommodations.

Today I presume that many citizens of the EU don't remember what it was like not to be able to take a baby carriage easily across the street, or not to be able to go to a restaurant or a theater and use the bathroom because it was not accessible, or what it meant not to have captioning on our televisions or not to

have accessible computers and software that can help older people who are losing their eyesight or blind people have access previously denied them, or what it meant for a deaf person and millions of others to do text messaging cheaply and easily.

The previously inaccessible built environment is being transformed like never before because of hard fought battles. The struggles began with governments, many professionals and society at large seriously questioning why these changes should be made. What we heard, again and again, was: It would cost a lot of money. Disabled people would not use public transportation, because they were afraid to come out of their homes, they preferred door to door transport systems, and they could be hurt during rush hours, and on and on and on. Today, most responsible government officials recognize that these reforms have not only been of value to the society overall but everyday see hundreds of thousands of people with and without disabilities benefiting from these hard fought reforms.

People who acquire a disability today and their families will have a very different experience from someone like me. I was born at a time when there were no requirements for the built environment to be accessible and it was completely legal to deny me and millions of other disabled children the right to attend school.

So again I ask why is this relevant to my presentation today? First, it is important for us to see that while change is hard it can make a tremendous difference if we are not afraid of it. It is relevant because governments of the EU, Canada, the US, Australia, New Zealand and Japan can be examples for these emerging governments. They can show the benefit to their own countries and thus encourage their counterparts to listen to the voices of disabled people. The EU and other governments can provide technical assistance so that emerging governments can do it right - the first time. The technology which didn't exist 100 years ago as buses were coming into our communities, for example, does exist today. Today, we know that curb cuts are essential and that making new buildings accessible benefits everyone and results in positive change.

It is ultimately easier to transform the built environment than it is to change the way we provide services to people.

If the government of a developing country came to an EU government or to a local ministry of education or health or social welfare and asked, "What is the best way for us to use our limited money to provide services for disabled people in our countries today," what would we say?

Before you respond to the request from this government I suggest that you read a number of documents. You should read these to be able to think about the type of world we are aspiring to create and you should read them because you are giving advice to a government that has little in place, has little money, wants

to do it right the first time and has come to you for guidance. While I know this may be a difficult exercise I would like to challenge you to think outside the box and provide the best advice you can even if it isn't what is currently being applied in your own community.

Please read the "Universal Declaration of Human Rights" which was passed by the General Assembly of the United Nations in 1948.

The Declaration recognizes the "inherent dignity and the equal and inalienable rights of all members of the human family" and sees this as the "foundation of freedom, justice and peace in the world..." Article 2 states that, "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." And Article 3 states that, "Everyone has the right to life, liberty and security of person."

While the Declaration doesn't mention disabled people because it was written in 1948, we can assume that the phrase "such as" certainly in today's context would include us.

Then I would read a few important documents that have been passed by the United Nations and which are resulting in changes that have elevated the status of disabled people. The 1981 "**International Year of the Disabled**", the 1982 "**World Programme of Action concerning Disabled Persons**", 1992 resolution, "**Standard Rules on the Equalization of Opportunities for People with Disabilities**", and now the tremendous work being done to create a **UN Convention for People with Disabilities**.

These documents make it clear that as disabled people we share the same dreams and desires as everybody else.

We want to be citizens of our communities at the local, national and international levels. Whether we have an intellectual, physical, sensory or psycho-social disability, and regardless of our age, we want to be included - not marginalized or disenfranchised.

We don't want pity or charity nor do we want to be forced into begging to secure financing to live. We want to be able to marry free of stigma, and we want the media to include us not as objects of pity or charity but as members of our community. We want equal opportunities to live and to contribute. We do not want to live in poverty.

We want to live with dignity and respect, to have equal opportunities for education and employment and health care, to be free from fear of violence. We do not want to be institutionalized but to live in the community - with supports if needed that facilitate our empowerment and ability to participate, and to have

access to technology that will facilitate our participation. We don't want custodial services.

In all countries of the world some disabled people and some families need services in order to participate in society. Services like personal assistance, modifications to our homes, and appropriate technology that is durable and reliable.

Services can be restrictive, intending to provide mainly custodial care. But think about whether this is really what is best. Restrictive services will not only result in the disabled individual's life being restricted but it also may restrict the life of one or more family members.

This could reduce the overall wages of the family and keep them living in poverty. So when talking to the government who has sought your advice, you should encourage them to look at their overall budget. You may keep costs down under one budget but another part of the budget may then have pressure put on it. You may, by restricting one service have to consider providing a monthly stipend that otherwise could be avoided.

Maybe you can begin to see how good advice to this government might be good advice for your own work.

We have been learning from the Disability Rights Movement and from parents of children with disabilities that the old way is not necessarily the right way. So you can also tell this government; "We haven't created a system of services that are delivered as we believe they should. We recommend that you invite in the disability community and family members and listen to them: don't be afraid. They will probably come up with solutions that will be more cost effective and produce better outcomes. Taking human rights principles into serious consideration could produce many positive outcomes."

You can tell this government that there are some other things they must avoid. Denying children the right to go to school with their peers is not only harmful to the child and family but to the society over all. Segregation hurts everybody. Children and adults must learn to live together. Government can provide some simple supports to enable this to happen effectively. First, encourage parents to organize in order to help you identify disabled children and to learn the best way to assist them in school. Second, make sure that teachers are given appropriate training in the beginning on how to teach diverse learners. Make sure that all principals and teachers understand that it is their responsibility to educate all children - with appropriate supports from government and donors. Disabled children cannot be kept out of the system. You understand why this is important because today in your country you still have children needlessly segregated and not being prepared to work in the world when they graduate.

You can tell the government official that putting a human rights and disability lens on all reforms could prove quite beneficial for the society over all.

Encourage dialogue between staff, policy makers and disabled people and parents that would enable a more formal discussion about the different types of services and methods to provide those services.

Why must we make reforms to the current service systems. We must institute reforms because the old way is limited and has not been producing the results it could. Because there is an unemployment rate for disabled people that should be unacceptable to all. The reason government is not alarmed is because it doesn't believe that disabled people can in fact participate in the world of work that same as non disabled people.

Disabled people and their families want to be taxpayers and contributors. They will tell you the types of services they need to work. We are not happy living on the margins unable to make contributions to our society. We are not trying to break the financial back of governments – just the opposite.

In 1973 I moved from Brooklyn, New York, where I had been an elementary school teacher after I sued the Board of Education for denying me a job because I couldn't walk. I left behind a wonderful disability rights organization called Disabled in Action which worked on organizing disabled people to work with government to reform policies and practices and moved to Berkeley California to become an early part of the Independent Living / Disability Rights Movement.

In Berkeley at the CIL we were developing services that disabled people needed and providing them as we believed most beneficial. We believed that disabled people could make contributions and that while policy reforms were high on our list, services that could help disabled people become empowered and begin to contribute to our community was essential.

I learned this personally and everyday as I saw the development of good services transform the lives of thousands of disabled people and their families. I saw naysayers and disbelievers begin to realize that there was another way to conduct business. Slowly old beliefs were being shattered.

For me, it was the first time that I could select my own personal assistants and pay them directly. It was the first time that I could get my wheelchair fixed quickly when it broke. It was the first time when, working together with other disabled people and family members, we were transforming our dreams into reality. A reality which said that society was wrong. Services which were developed with the view towards equality could produce dramatic changes for people with disabilities of all ages and with all types of disabilities.

More than 50 percent of our staff had a disability themselves. When we worked with another disabled person we were a role model. When we worked with the government or an employer we understood the problem and the solution. The services we provided were based on what the community said it needed.

Look at the Independent Living Centers in England, for example, and see the number of disabled people working in responsible positions, handling budgets, delivering services and being positive forces for change for their communities overall. Ask yourself, “Why don’t I see these same people working in my office everyday?”

Phil Draper was a dear friend of mine. He broke his neck in Vallejo California because he was drinking and driving. He came from a working class family and had a high school degree. After he broke his neck he wound up in a nursing home because there weren’t services to support him in the community.

His life could have ended at that point. Instead he was able to get personal assistance support through one of the State agencies. The funding was in reality not sufficient for him to live outside of the nursing home but he met a woman who he later married who helped him with his personal assistance needs. They moved to Berkeley where he became very involved with the creation of the Center for Independent Living and eventually became its director.

Phil believed that, **“You can’t provide independent living services without advocating for social change.”** He also knew that the services had to be responsive to the needs of disabled people and that the system had to reform itself frequently against its wishes.

Phil was right. Jane Campbell is right. All of the presenters here today are correct. We must continue to change the way we provide services. We must listen to and include the voices of disabled people and their families as we commit ourselves to reforming the social service systems here and across the world. Disabled people are today amongst the poorest of the poor in every country. This is shameful and unnecessary and each and every one of us can and must put an end to these statistics. We know what to do we must now have the will to see it through.

Thank you.