

The Convention on the Rights of Persons With Disabilities: What Is at Stake for Psychiatrists and the Patients We Serve

Feature Editor Introduction: Kristi L. Kirschner, MD

Where, after all, do universal human rights begin? In small places, close to home, so close and so small that they cannot be seen on any maps of the world. Yet they *are* the world of the individual persons; the neighborhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere.

Eleanor Roosevelt, *The Great Question*. United Nations, 1958 [1]

In 1945, in the aftermath of World War II, former First Lady Eleanor Roosevelt (and wife of our first president with a disability when elected) was appointed by President Harry Truman to chair the United Nation's (UN) Human Rights Commission. By all accounts, she relished the experience and recognized the moral force that a Universal Declaration of Human Rights could have in establishing international norms. In 1948, the UN Assembly adopted the Declaration. What followed over the subsequent decades were a series of UN human rights treaties and conventions that called out and underscored that various vulnerable populations (such as children, women, racial minority groups) deserved human rights protections too. Whereas, a UN declaration was intended to be aspirational and not legally binding, such was not the case with a human rights convention or treaty [2]. In addition to being a commitment to the international community, a convention also would require appropriate oversight and monitoring and reporting of the signatory countries. Unfortunately, concerns about national sovereignty have often impeded U.S. Senate ratification of UN human rights conventions, including the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and, more recently, the Convention on the Rights of Persons with Disabilities (CRPD) [3].

Attention to the rights of people with disabilities has gained traction since the 1970s, both in the United States and internationally. In 1971, the UN General Assembly adopted The Declaration on the Rights of Mentally Retarded Persons, followed 4 years later by The Declaration on the Rights of Disabled Persons [4]. A push for civil rights laws for people with disabilities in the United States began in the 1960s, which culminated in such landmark legislation as Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) in 1990.

Not surprisingly, those who helped to draft the ADA in the United States also became leaders in the international movement for disability civil rights and helped to craft the language for the UN CRPD. The document, whose stated purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" [5] was adopted by the UN in 2006 and has been ratified by 141 countries to date [4]. Despite being signed by President Obama in 2009, efforts to obtain the supermajority (two-thirds or 66 votes) needed for U.S. Senate ratification have thus far fallen short. The reasons for opposition include concerns that the CRPD will infringe on parental rights, endorse abortion rights, and compromise U.S. sovereignty. To learn more about these issues, please see the fact sheet prepared by the U.S. International Council on Disabilities that addresses these concerns (<http://www.usicd.org/doc/CRPD%20MythsFacts%200719%202013.pdf>).

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I would like to extend a special thanks to Cheri A. Blauwet, MD, Rehabilitation Institute of Chicago Sports Medicine fellow, and an elite Paralympic wheelchair racer, who suggested that the *PM&R* ethics legal column shine a light on the CRPD. I heartily agreed. Although the support of a human rights doctrine for people with disabilities is not particularly controversial for our field, it also does not seem to prompt the same sort of passion and advocacy action as Medicare payment fee schedules for physical medicine and rehabilitation services. This column is a chance for us to hit the pause button, to think about the CRPD, and to reflect on the questions posed below:

1. Why is passage of the CRPD of importance to the United States?
2. Should physicians (and, specifically, professional physician organizations, eg, the American Academy of Physical Medicine and Rehabilitation [AAPM&R]) be engaged in advocating for the passage of the CRPD? Why or why not?
3. What role can and should AAPM&R play?

To tackle these questions, I invited the following commentators: Marca Bristo, Cheri A. Blauwet, MD, Walter

Frontera, MD, PhD, Dorothy Weiss Tolchin, MD, EdM, Michael Ashley Stein, JD, PhD, Kurtis M. Hoppe MD, Sam S. H. Wu, MD, MA, MPH, MBA. As always, I welcome your comments, critiques, and suggestions for future columns.

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Commentary from Marca Bristo

On a trip to Berkeley, California, in 1978, my life changed forever. I was young and newly disabled with a spinal cord injury. I was a nurse practicing at Northwestern Hospital. What I saw in Berkeley was an entirely new paradigm for what people with disabilities should expect and demand from their lives. What I witnessed was the nascent global movement of independence, accommodation, and inclusion for people with disabilities. When I returned home, I joined Henry Betts, MD, and a group of clinicians at the Rehabilitation Institute of Chicago. When facing the reality that social barriers blocked the possibility of rehabilitating people with disabilities to full participation and potential, rehabilitation professionals began to listen to disabled consumers in a different way. The field of physical medicine and rehabilitation paved the way for the disabilities rights movement and that partnership remains an essential part of the fight for the rights and quality of life for one billion people with disabilities across the planet.

Dr Betts and his team helped found Access Living, a center for independent living in Chicago, Illinois, where I have been president and chief executive officer since its inception. I cofounded the National Council on Independent Living and served as chairperson of the National Council on Disability. Today I am president of the U.S. International Council on Disabilities. I am proud to be part of the movement of people with disabilities that passed the ADA, the Individuals with Disabilities Education Act, the Air Access Act, and amendments to the Fair Housing Act. Around the world, people with disabilities, advocates, medical professionals, and governments now look to the United States for guidance on how

to move from discrimination and prejudice to full participation of disabled persons in society.

The CRPD is awaiting ratification by the U.S. Senate. To date, 141 countries have ratified the convention, which calls for the inherent dignity, autonomy, and independence of all persons, full social participation, equal opportunities and access for one billion people with disabilities around the world [1]. Leadership by the United States is critical to meet those goals. “U.S. ratification of the UN Convention on the Rights of Persons with Disabilities will stand as a reminder to our government of the importance and relevance of the UN Convention to the entire world,” said Obadiah T. Moyo, president, Zimbabwe Disability Rights Organization, which echoes the sentiments of disability advocates everywhere [2].

In countries with life expectancies of more than 70 years, individuals spend an average of approximately 8 years, or 11.5%, of their life span living with disabilities. Eighty percent of persons with disabilities live in developing countries. Mortality for children with disabilities may be as high as 80% in countries where under-five mortality as a whole has decreased below 20% reports the United Kingdom’s Department for International Development, adding that, in some cases, it seems as if children are being “weeded out.” UNESCO reports that 90% of children with disabilities in developing countries do not attend school. Thirty-five percent of working-age persons with disabilities are in fact working, compared with 78% of those without disabilities. Only 45 countries have antidiscrimination and other disability-specific laws [1].

The numbers are overwhelming; the human stories are even more compelling. As former U.S. senator Bill Frist, a

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