2009

Health Care and the UN Disability Rights Convention

Michael Ashley Stein

Penelope J S Stein

Dorothy Weiss

Raymond Lang

Repository Citation
Stein, Michael Ashley; Stein, Penelope J S; Weiss, Dorothy; and Lang, Raymond, "Health Care and the UN Disability Rights Convention" (2009). Popular Media. Paper 34.
http://scholarship.law.wm.edu/popular_media/34

Copyright c 2009 by the authors. This article is brought to you by the William & Mary Law School Scholarship Repository.
http://scholarship.law.wm.edu/popular_media
Health care and the UN Disability Rights Convention

People with disabilities can be healthy. Yet too often they are excluded from general health care by numerous obstacles, including a lack of training of health professionals, physical inaccessibility, and communication barriers (such as a lack of sign-language interpretation). Moreover, individuals with disabilities lack coordinated care and are often excluded from health-outreach programmes. Disability-based exclusion is bolstered by a lack of awareness among policy makers about this minority group and their needs. In the absence of equal access to health care, people with disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation.

Prospects for change have arisen with the entry into force on May 3, 2008, of the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD obligates states to provide equal access to health care and related services for people with disabilities, and represents the first legally binding international instrument that specifically protects the rights of some 650 million such people worldwide. It is also the first treaty in which non-governmental organisations were present during negotiations and could make interventions. People with disabilities participated as members of organisations of persons with disabilities, state delegations, and UN organisations. Partly due to this inclusive process, the CRPD has received wide support, with some 143 states having signed and 71 states having ratified the instrument.

The core principles of the CRPD include respect for human dignity, non-discrimination, full participation, social inclusion, equality of opportunity, and accessibility. Rights relating to equal access to health care are laid out in separate articles on health, habilitation and rehabilitation, personal mobility, accessibility, women with disabilities, children with disabilities, and general obligations, among others. More specifically, Article 25 (Health) not only ensures the right of people with disabilities to equally access “the highest attainable
standard of health without discrimination on the basis of disability”, but also requires states to provide health services that arise due to the nature of an individual’s disability. Moreover Article 25 mandates that health-care professionals ensure “free and informed consent”. States must also work towards “raising awareness of the human rights”. Article 26 (Rehabilitation and habilitation) requires states to “organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes” while ensuring that programming supports community participation, is voluntary, and is located as close as possible to people with disabilities in their own communities, including rural areas. Article 4 (General obligations) mandates governments to take specific action, include promoting the availability of assistive devices, providing accessible information, promoting research on assistive technologies, advancing universal design (ie, accessible for all people), and training professionals working with people with disabilities.

Currently, fewer than 50 states have systemic disability laws. Consequently, state compliance with the CRPD has precipitated worldwide domestic law reform, as well as consideration of how these laws will be effectively implemented. Health-care providers in countries that have adopted the CRPD have legal, professional, and ethical obligations to facilitate the attainment of equal access to health care for individuals with disabilities. However, although training programmes commonly provide specific instruction in care for individuals belonging to racial, ethnic, and linguistic minorities, they do not do so as often for individuals with disabilities—the largest minority population that many providers serve. Yet education programming on care for and sensitivity to the needs of individuals with disabilities fits well into educational frameworks focused on cultural competence. Individuals with disabilities can be teachers in these programmes so that students will learn not to make assumptions about the lived experience of disability. Engaging individuals with disabilities in decision making about their own care is a key component of their health promotion and social empowerment.

In promoting equal access to health care, states additionally are required by Article 4 (General obligations) to consult actively with people with disabilities and their representative organisations. At the same time, organisations of people with disabilities should lobby their governments and monitor progress to ensure their equal access to health. Such organisations are central to achieving inclusive programming. Grassroots coalitions have access to valuable information on the location and culture of the local disability community, and connections with the larger disability social network. Inclusive programming might also be ensured by using an accessible venue (or meeting out of doors when buildings are not accessible), providing information in alternative formats (such as language accessible to those with intellectual disabilities), training staff on disability, and hiring people with disabilities. HIV/AIDS programmes, for instance, have begun to include people with disabilities. Inclusive health-care models will be key tools for governments creating poverty-reduction programmes due to the link between disability and poverty.

Greater research is required on how disability affects relative access to health care and medical outcomes. A rights-based approach to health care and delivery, with common language fostered by the CRPD, will allow the medical community along with researchers, policy makers, and people with disabilities to work towards the day when all people with disabilities have equal access to health care and related services. Vital to achieving a human rights framework of care is patients’ empowerment, self-determination, and community inclusion.

*Michael Ashley Stein, Penelope J S Stein, Dorothy Weiss, Raymond Lang
Harvard Law School Project on Disability, Harvard Law School, Cambridge, MA 02138, USA (MAS, PJSS); Department of Physical Medicine and Rehabilitation, Harvard Medical School, Cambridge, MA, USA (DW); and Leonard Cheshire Centre for Disability and Inclusive Development, University College London, London, UK (RL)
mastein@law.harvard.edu

Contributions by members of the Harvard Law School Project on Disability were supported in part by a grant from Foundation Open Society (Zug). We declare that we have no conflicts of interest.


3Groce N, Montero F. Habilitation, rehabilitation and general health care: facing challenges ahead to realize the goals of the CRPD. One in Ten 2008; 26: 16-18.
