



Science and Human Rights Coalition Focuses on Disability Rights

February 10, 2014

On January 27 and 28, the American Association for the Advancement of Science (AAAS) [Science and Human Rights Coalition](#) held its biannual meeting, the theme of which was “Disability Rights and Accessing the Benefits of Scientific Progress and Its Applications.” The Coalition, made up of over 50 member and affiliated organizations, including COSSA, focuses on integrating human rights into the practice of science and vice versa.

The program began with a panel that introduced the disability rights framework. Moderator Maya Sabatello, Columbia University, explained that between 15 and 17 percent of the world’s population has a disability, which equates to between 800 million and one billion people, 150 to 200 million of whom are children. Eighty percent of people with disabilities live in the developing world. Persons with disabilities face pervasive societal stigma and prejudice, segregation and discrimination, and a mentality that views their disability as an individualized medical issue to be “fixed.” It is in this context that the [Convention on the Rights of Persons with Disabilities](#) (CRPD) was drafted in 2006. The CRPD currently has been ratified by 141 parties (the U.S. is not among them). Some of the principles enshrined in the CRPD include: respect for human dignity, non-discrimination and equal opportunity, respect for difference as part of human diversity, and inclusion as a human right. It represents a paradigm shift from viewing disability as disease to a social-relational approach and asserts that states have a positive obligation to promote the rights of their disabled citizens. Science has a role to play in disability rights, Sabatello explained, because it can improve accessibility, communication, and assistive technologies.

Charlotte McClain-Nhlapo, U.S. Agency for International Development (USAID), shared how the principles of disability rights shape policy and practice at USAID, which is working to integrate disability rights into its everyday activities. David Morrissey, U.S. International Council on Disabilities, discussed disability rights in America, beginning with the Americans with Disabilities Act, passed in 1990. Although the U.S. signed the CRPD in 2009, it failed a ratification vote in the Senate in 2012. Morrissey emphasized that U.S. ratification is important because it will bring America to the table and position it to share the benefit of its experience with other countries.

Accessing the Benefits of Science and Technology

Vint Cerf, Google, delivered the keynote address on improving accessible technology. Cultural norms and biases are one of the major barriers impact availability of these technologies. Cerf noted that every Google engineer is trained in accessibility methods and introduced the principle of “universal design.” He explained accessibility needs must be considered from the initial design phase onward; it is much more difficult-- and less effective-- to reverse engineer existing technologies to make them accessible. It is also important to recruit the expertise of the people who will be using the assistive technology and ask for their feedback as design progresses.

A panel discussion, moderated by Edward Walsh, Acoustical Society of America, delved further into these issues. Eric Mathews, Disability Rights International, talked about the advocacy work his organization is doing to promote the full integration and inclusion of disabled people (particularly the most vulnerable, such as those with intellectual, developmental, and psychological disabilities) into society across the world. He argued that the involuntary institutionalization of the disabled (especially the placement of children into orphanages) violates the CRPD. Mathews explained that of the 10 million children in orphanages worldwide, 95 percent have a living parent. He asserted that most families would keep their children at home if they had the resources to care for them. Mathews concluded by recommending that those in government, the private sector, and civil society focus on how science and technology can help move people out of segregated environments, rather than trying to improve segregated institutions with science and technology.

James Thurston, Microsoft, discussed technology, human rights, and digital inclusion. He explained that Microsoft is committed to human rights and is exploring ways to use its technology to improve access (for example, researchers are working to adapt the Microsoft Kinect motion-tracking gaming console to translate sign language into spoken or written text). Thurston identified six forces driving global digital inclusions: 1) changing demographics (and companies' recognition of the market for assistive technology), 2) social responsibility, 3) market demands (such as the U.S. government's commitment to only purchase accessible technology), 4) advances in technology, 5) growing awareness, and 6) effective policy, much of which was instigated by the CRPD.

The Status of CRPD Ratification

Paul Skedsvold, Federation of Associations in Behavioral and Brain Science, led a conversation with Michael Gamel-McCormick, Senate Committee on Health, Education, Labor and Pensions (HELP), focused on efforts to ratify the CRPD. The treaty failed ratification in 2012 by six votes. The Senate began to hold hearings on the treaty in late 2013 and the Foreign Relations Committee is expected to schedule another ratification vote sometime this year. The administration is confident that adoption of the treaty would not require any changes be made to existing the U.S. law. Gamel-McCormick discussed some of the objections that have been raised. First, some have suggested that the treaty could be used to overrule parents' decisions, though this reading of the CRPD has been discredited by a number of experts. Second, some are concerned that language in the CRPD guarantees a right to abortion, though this is mainly a non-discrimination clause that affirms that disabled people should have access to the same reproductive health care as non-disabled people. Finally, some in the Senate are suspicious of signing any international treaty because they believe it erodes U.S. sovereignty. Gamel-McCormick emphasized that though the U.S. is already in compliance with the CRPD, ratification is important because it allows us to participate in the evolving discussion on how to implement disability rights.

Participating in Science and Technology

Laureen Summers, AAAS, introduced a session on expanding participation in science and technology and highlighted AAAS's EntryPoint program, which offers internships to people with disabilities majoring in science, technology, engineering, and mathematics (STEM) fields. A video message was played from Temple Grandin, professor of agricultural science at Colorado State University and autistic activist, who asserted that "science needs all kinds of minds."

Anju Khubchandani, American Psychological Association, moderated the panel. Celia Fisher, Fordham



University, discussed the importance of allowing persons with disabilities to participate in scientific studies and how to tailor the informed consent process so their agency is respected. Fisher argued that the principle of justice asserts that everyone should have equal access to both the benefits and burdens of research. Persons with disabilities (especially intellectual disabilities) are often excluded from clinical trials based on the perception that they are an inherently vulnerable population, a mindset Fisher called paternalistic. Researchers must try to balance respect for the dignity and autonomy of the individual while taking care to avoid exploitation. Fisher suggested that instead of thinking in terms of whether an individual is too vulnerable to consent, researchers instead should try to fit the consent process to the characteristics of the prospective participant. This may entail rethinking what qualifies as a “rational” reason to participate or not in a study, simplifying the language, or utilizing verbal consent instead of written.

Marco Midon, NASA’s Goddard Space Flight Center, discussed his experience as a blind person working in science and technology. He explained that while he had assumed that new technology would make accessibility continually easier, the advent of the touch-screen smartphone in 2008 shifted his perspective. He observed that if he had tried to design a technology that would make life harder for blind people, he could not have come up with anything better than a touch-screen interface, which has no textural indicator of what is on the display. Midon said that there are tasks he was able to do eight years ago that he cannot do now. This is an example of the unintended consequences of new technologies and why it is important to consider accessibility from the outset.

Robert Dinerstein, American University Washington College of Law, talked about the importance of involving people with cognitive disabilities in decision-making that affects them. He suggested reframing our thinking of disability from something that is a problem within an individual to a product of the interaction of an individual with their environment (this can also include attitudinal barriers and stigma). He echoed the sentiment of other speakers that it is much easier to consider accessibility from the initial design phase than retrofit the technology. Dinerstein argued that persons with disabilities should be considered equal partners in research, training, and dissemination, and that the scientific community should value their life experiences as much as formal education.

