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## **The Human Right to Science and Disability**

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## **Introduction**

Advances in science and technology are occurring at an unprecedented rate, particularly in health care and medicine. Innovations abound in the development of diagnostic tools, medications and biologics, surveillance tools for monitoring chronic conditions, preventive health, and wellness promotion. Within this landscape, the human right to science is more salient than ever, and critical for people living with chronic disabilities. The human right to science, as articulated in Article 15 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) asserts the right to benefit from science and its applications (UN General Assembly 1966). Despite its incorporation in ICESCR in 1966, the human right to science has not been legally defined nor received sufficient attention by human rights scholars as compared to other human rights (Chapman 2009; Wyndham and Vitullo 2018).

The year 2020 marked the long-needed publication of General Comment 25 on the human right to science (UN Committee on Economic, Social, and Cultural Rights 2020). While articulating the rights to science, the Comment seeks to explore the broader relationship between science, technology, and economic, social and cultural rights (UN Committee on Economic, Social, and Cultural Rights 2020). People with disabilities often rely on assistive devices and modifications that are critical to their participation in society, however, they experience barriers resulting in unequal opportunities attaining necessary technology. Can the human right to science be used to overcome barriers to technology and advocate for social and cultural rights for people with disabilities?

## **Barriers to People with Disabilities**

In the United States, and other nations whose health care systems operate under capitalist structures, access to science and technologies by people with disabilities is tenuous. Complex rehabilitation technologies are expensive, and often not covered by private or public insurance plans. As a result, people with disabilities are reliant on personal financial resources, philanthropy through non-governmental organizations, or government-sponsored social programs that feature narrow eligibility requirements and high restrictions for qualification.

For many with disabilities, inability to access resources through one of these channels manifests in lack of technological supports and restricted societal participation. For example, spinal cord injury (SCI), is an experience that dramatically alters the lives of people who sustain the injury. Resulting paralysis has far reaching implications on all aspects of life including access to environments and community-based services that foster independent living, transportation, and employment. People with SCI rely not only on environmental modifications, but personal complex rehabilitation technologies such as power wheelchairs, voice activated control systems, and prosthetics or neuroprosthetics necessary for everyday life. Barriers to procuring these important technologies causes a significant percentage of people with this injury to be sidelined from successful participation in society. Successful participation, regardless of ability status, starts with access to places and spaces within society, but must go further to include personal control and even spontaneity that fosters active citizenship through engagement in the roles and activities that make life meaningful. Technology is a critical component of

societal engagement by people with disabilities. The human right to science, therefore, offers promise as a tool for enhancing realization of successful societal participation.

While access to existing complex rehabilitation technologies is challenging enough, some assistive technologies designed for people with disabilities never reach commercial availability due to poor sustainability within market-based health care systems. Many applications of science in the form of medicines, biologics, equipment, and devices fail to translate from scientific discovery to commercial availability, even after proven safety and efficacy, especially if they are specific to the small population of people with SCI. The proverbial “valley of death” refers to obstacles encountered while translating scientific discovery and knowledge into clinical applications (Barrable et al. 2014; Coller and Califf 2009; Meslin, Blasimme, and Cambon-Thomsen 2013). Significant challenges to technology access for SCI and other smaller disability groups in market-based health care systems include poor profit potential due to low prevalence of this condition as well as inadequate reimbursement from third party payers. Today’s funding structures in the U.S. are a byproduct of post-World War II politics, when advancements in basic science were deemed more valuable than the application, or translation, of such knowledge (Chapman 2009; England 1976). Thus, discoveries and products from government-sponsored research, largely funded by citizen taxpayers, became the responsibility of private industry to commercialize and disseminate at a profit. Unfortunately, reluctance on the part of private industry to invest in expensive technologies with low profit potential, prevents innovations from reaching the citizens who contributed to their development. While there is not a cure for SCI, there have been great advances in discovery research, promising clinical interventions, and significant technology development over the past decade (Morse et al. 2020), however, the threat of such discoveries falling into the translational valley of death has never been more real. The human right to science can be a useful framework for understanding how support persons, scientists, health professionals and others may facilitate provision of life enhancing interventions and technology for people with SCI.

### **Human Rights Awareness and Advocacy**

Successfully invoking the human right to science as a tool for enhancing access and availability of technologies for people with disabilities relies on advocacy and increased awareness by the disability community and health professions. Increasing human rights literacy among stakeholders can inspire creative and effective policies to improve access to science and technology. Worldwide liberation movements for groups disadvantaged and marginalized by race, sex, and disability have historically and successfully invoked global human rights language and norms, thus building a culture of human rights (Vellino 2004). However, such broad and global conceptualizations of human rights, most often understood in terms of civil and political rights, are left at the accessible waiting room doors of general medical and rehabilitative care institutions. More often than not, health professionals and people with disabilities are unaware of the human right to science, necessitating education to address the long-term social needs of people with disabilities. Encouraging health professionals to adopt a human rights perspective of disability challenges dominant medical model perspectives and practices, and has the capacity to

reduce internalized feelings of burden held by people with disabilities. A potentially successful approach toward implementing a human rights model of disability involves engagement of health professionals and people with disabilities as partners. A key step toward increasing human rights discourse involves education of both parties about human rights doctrine and its potential value in advancing the rights of people with disabilities to benefit from life enhancing technology. The same is true of other stakeholders, including support persons of the people with disabilities.

Promoting the value and meaning of the human right to science to people with disabilities and health professionals can be accomplished through a number of different methods. Educational information can be disseminated via various consumer groups and organizations. Human rights ombudspersons can hold seminars and forums with stakeholders, including government, non-profit, and for-profit organizations. Information can be disseminated to professional societies across the health professions. Educational opportunities can be developed through certification and licensure renewal activities required of health professionals, as well as through annual ethics training programs that many health care institutions mandate. Information to developers of technology can be provided through engineering and related professional organizations. Perhaps most importantly, all stakeholders can communicate the importance of the human right to science to policymakers.

### **Conclusion**

The current state of access to science by persons with disabilities, especially in the wake of sudden injury and severe disablement calls for creative and novel solutions that can be informed by the human right to science. The processes of science dissemination and technology distribution are as complex as the science itself, and persistent inequities in access are particularly concerning for people with disabilities. Educating the SCI community, and the broader disability community, about human rights doctrine and engaging them in defining the human right to science, is a critical first step to improving access to innovations that fail commercial translation in current market-based health systems. Awareness leads to action. The General Comment on the human right to science offers optimism and guidance for making the world a more inclusive space for people with disabilities.

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