

## Leading Change Session: Disability Rights, Ethics and Genetics

Generating Conversation for Policy and Practice on Tuesday at 8:30 AM - 10:15 AM

### Session Description

This session is designed to create a foundation for AUCD network-wide dialogue about the impact of scientific advances in the arena of genetics and genomics on the policies, public education, and clinical interventions impacting people with disabilities and their families, with a particular focus on social justice issues and historically stigmatized populations.

Hot topics in Genetics	Description, Link to Background, Details
Gene editing <sup>1</sup> , Gene therapy <sup>2</sup>	CRISPR stands for Clustered Regularly Interspaced Short Palindromic Repeats which can be used modify genes in living cells and organisms and, in the future, may make it possible to correct mutations at precise locations in DNA to treat genetic causes of disease or disability. <sup>3</sup>
Patient-centered research <sup>4</sup>	PCORI stands for Patient-Centered Outcomes Research Institute which helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.
Pre-natal genetic testing <sup>5</sup>	Measuring a level of risk for genetic diseases in the fetus
Disability Identity	A social process of mirroring, modeling, and recognition of forming one's self-identity of/with disability
Disclosure of genetic information	Health Insurance Portability and Accountability Act of 1996 (HIPAA) went into effect in 2003. The rule created new requirements to protect the privacy and security of health information, including genetic information, that could identify a person. <sup>6</sup>
Ableism	The ideology of ability is at its simplest the preference for able-bodiedness. <sup>7</sup>
Funding mechanisms	Health insurance and coercive practices that serve for profit interests rather than patient interest
Customized/personalized medications	A form of medicine that uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease. <sup>8</sup>

### Laws, Regulations, and Funding Mechanism on Disability Rights and Genetics:

- [Genetic Information Nondiscrimination Act](#) (2008) protects all Americans by prohibiting insurers in both the group and individual health insurance market from

<sup>1</sup> <https://bioethics.com/archives/48410>

<sup>2</sup> <https://jme.bmj.com/content/26/2/89>

<sup>3</sup> <https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting>

<sup>4</sup> <https://www.pcori.org/>

<sup>5</sup> [https://jme.bmj.com/content/27/suppl\\_2/ii21](https://jme.bmj.com/content/27/suppl_2/ii21)

<sup>6</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2677756/>

<sup>7</sup> [http://thedigitalcommons.org/docs/siebers\\_complex-embodiment.pdf](http://thedigitalcommons.org/docs/siebers_complex-embodiment.pdf)

<sup>8</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3128266/>

- "requesting or requiring" genetic testing of an individual or his family, or
- using genetic information to determine eligibility or establish premiums;
- [Kennedy-Brownback Prenatally and Postnatally Diagnosed Awareness Act](#) (2008) provides better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a disability.
- [Newborn Screening Saves Lives Reauthorization Act](#) (2014) established the Advisory Committee on Heritable Disorders in Newborns and Children.
- [The 21st Century Cures Act](#) (2016) is to help accelerate medical product development and bring new innovations and advances to patients who need them faster and more efficiently.
- [Patient-Centered Outcomes Research Extension Act](#) (2019) funds the Patient-Centered Outcomes Research Institute (PCORI), an independent, non-profit, non-governmental organization authorized by the ACA to study how different medications and treatments compare, so that patients and their caregivers have the information they need to choose the health care and treatment options that are best for them.
- [State Medicaid coverage policies](#) vary by state regarding genetic testing.
- [CRISPR regulations from FDA](#) considers gene editing in humans to be gene therapy and are regulated by the FDA's Center for Biologics Evaluation and Research.
- Federal agencies with oversight and funding over genetics: [ACL](#), [FDA](#), [NIH](#), [HRSA](#)

#### Opportunities for Engagement:

- Educating researchers and professionals, and pre-service training
- Educating people with disabilities of their rights – informed consent, supported decision-making, etc.
- Utilizing patient-centered research
- Member of advisory council
- Evaluation research of ethical practices
- National Core Indicator surveys
- Collaborating with Insurance and Healthcare Systems
- [Genetic Alliance](#)
- the [National Coordinating Center for the Regional Genetics Networks \(NCC\)](#)
- Engagement with bioethicists

#### Questions to Ask:

This discussion touches on notions of normality, discrimination and fundamental values of human dignity, and prompts a number of questions:

- How is information shared to the public about things that will affect their life?
- How is funding being allocated and for what purposes?
- Will society's attitudes towards and treatment of persons with disabilities become determinant purely on their genetic makeup?
- Will such people be further ostracized as a result of potentially not having 'desirable' genetic trait(s)? Who decides what is an impaired gene?
- Will there be active eugenic practices to 'eradicate' genetic disability? And, will there be a way to stop that from happening?
- To what degree should society dictate who we are and what we will become?