



Center for
Bioethics & Health Law

Ethics, Disabilities, and Healthcare

Friday, April 12, 2024 | 8:00 am – 3:30 pm | Breakfast @ 7:30
Passavant Hospital Foundation Conference Center
700 Cumberland Woods Drive, Allison Park, PA 15101

***Ethical, Legal, and Social Challenges for Neurodivergent Adults in our Communities:
Shifting to a Supported Engagement Model***

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Justice for All? Bioethics in Medical Prognostication, Ableism, and the Disability Paradox

Amanda K. Booher, PhD
Bioethicist, Summa Health

Barriers to Effective Healthcare for Disabled People: Signs of Progress in Medicine and Law

Mary Crossley, JD
Interim Dean, Professor of Law, John A. Murray Faculty Scholar
University of Pittsburgh

CONFERENCE ABSTRACT AND OBJECTIVES

Effective communication is key to providing and receiving high quality healthcare. Yet healthcare providers frequently feel less well-prepared to communicate effectively with their disabled patients, and those patients frequently struggle to be heard and understood in their own terms. Patients with disabilities face myriad problems with the healthcare system. They frequently face disrespect, assumptions of incapability unrelated to their disability or illness, lack of recognition of the disabling aspects of common illnesses, and assumptions about their quality of life (the disability paradox).

Two groups that both seek to support the rights and interests of people living with disabilities—bioethicists and disability activists—have often found themselves talking past each other. “Unspeakable Conversations,” a 2003 *New York Times Magazine* cover story by a disability rights activist with disabilities about meeting her with a bioethicist, begins: “He insists he doesn't want to kill me. He simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I once was.” Such writing is emblematic of tension between bioethics and disability studies/activists. Bioethicists, who traditionally attempt to bridge the communication gap between clinicians and patients, sometimes seem to widen the communication gulf for patients with disabilities.

This conference seeks to bring into productive dialogue fields that have traditionally been in tension—Bioethics and Disability Studies. It will present approaches to communication and caregiving which are respectful of the needs of people with disabilities. Speakers will emphasize communication skills and anti-ableist language. Conference content will provide humanistic understanding of disability-associated stigma, self-stigmatization, and discrimination, as well as present legal requirements and remedies. It will consider how traditional bioethical approaches may be applied in ableist ways that threaten the well-being of those with disabilities. It will prompt participants to reconsider assumptions, while develop new skills and perspectives to more effectively involve people with disabilities in medical decision making.

THE 31ST ANNUAL HEALTHCARE ETHICS CONFERENCE

Providing attendees with an opportunity to learn from national and local experts about pressing medical ethics issues, the Center’s annual Medical Ethics Conference features morning lectures and afternoon concurrent sessions. It is designed for clinicians and researchers, health policy analysts, lawyers, clergy, clinical ethicists, bioethicists, disability studies scholars, patient and disability rights advocates, community members, and students of the health and social sciences and the humanities.

CONFERENCE SCHEDULE

7:30 – 8:00 am **Registration and Continental Breakfast**

8:00 – 8:15 am ***Improving Healthcare for People with Disabilities: Bringing Bioethics and Disability Studies into Dialogue***

Lisa S. Parker, PhD

Dickie, McCamey & Chilcote Professor of Bioethics

Director, Center for Bioethics & Health Law

University of Pittsburgh

Abstract: People with disabilities face particular challenges in obtaining healthcare. Moreover, healthcare providers often feel less well-equipped to meet the needs of their patients with disabilities. At the same time, bioethicists and disability rights advocates—and the fields of bioethics and disability studies—have sometimes had an uneasy intellectual and political relationship. This brief introduction to the conference will mark those tensions and challenges while outlining the path forward the conference intends to forge.

Following this presentation, participants should be able to:

- Articulate key topics in bioethics on which disability rights advocates and bioethicists have differed.
- Suggest approaches to resolving tensions between the two fields.
- Identify practices in clinical care that reflect these suggested approaches.

8:15 – 9:15 am ***Justice for All? Bioethics in Medical Prognostication, Ableism, and the Disability Paradox***

Amanda K. Booher, PhD
Bioethicist, Summa Health

Abstract: This talk will primarily consider the bioethical principle of justice in relation to disability and medical prognostication. It will explore the concepts of "disability paradox" and the bias of ableism, as well as how these affect both medical personnel and patients and families. Additionally, the talk will address steps we as members of the medical community might take to confront these biases in ourselves to help best support patients and families.

Following this presentation, participants should be able to:

- Explain the terms "disability paradox" and "ableism" and their relevance to the bioethical principle of justice.
- Articulate how the disability paradox and bias towards ableism can negatively impact patient autonomy.
- Consider what steps could be taken to diminish disability biases and misinformation, and how that might inform healthcare professionals' relationships with and advice for patients.

9:15 – 9:30 am **Break**

9:30 – 10:45 am ***Ethical, Legal, and Social Challenges for Neurodivergent Adults in our Communities: Shifting to a Supported Engagement Model***

Nanette Elster, JD, MPH
Associate Professor, Neiswanger Institute for Bioethics
Loyola University Chicago Stritch School of Medicine

Kayhan Parsi, JD, PhD
Professor, Neiswanger Institute for Bioethics
Loyola University Chicago Stritch School of Medicine

Abstract: In our 2022 co-edited book, [*Transitioning to Adulthood with Autism: Ethical, Legal and Social Issues*](#) (Springer), we examined a number of salient issues related to autistic adolescents transitioning to adulthood. In our next co-edited volume, we plan to examine a number of new issues facing autistic adults, such as housing, self-care, advocacy, spirituality, oral health, and masking. This talk will preview a new model called "supported engagement" through which we will examine these topics.

Following this presentation, participants should be able to:

- Understand the various models used to explain neurodiversity.
- Identify various ethical and legal challenges facing neurodiverse adults.
- Learn about a model of supported engagement for neurodiverse adults.

10:45 am – noon Panel: ***Medical Decision Making on the Spectrum***

David Kappel, MD
Deputy State Medical Director for Trauma
WV Office of Emergency Medical Services

Joann Migyanka, DEd
Professor Emeritus of Communication Disorders, Special Education, and Disability Services
Indiana University of Pennsylvania

Andrew Nelson, EdD
Senior Director Autism Response Team at Autism Speaks
Autism Community Consultants

Valerie Violi Satkoske, PhD, MSW
VP of Mission Effectiveness, Spiritual Care, & Ethics / UPMC Mercy
VP of Ethics UPMC

Abstract: Adults on the autism spectrum are often assumed to lack the capacity to make medical decisions for themselves and others. In some cases, these assumptions are based upon the autism diagnosis/label alone. In others, it is based upon how the disorder manifests, especially when it affects communication and emotional response. During this presentation, we will share recommendations to improve communication between medical professionals and autistic adults when engaging in advance care planning and surrogate decision making conversations.

Following this panel, participants should be able to:

- Describe common health care barriers encountered by autistic adults.
- Identify core approaches individuals with autism value in healthcare interactions.
- Articulate the nuances of the advanced care planning process and strategies to better support adults with autism when discussing advance directives for themselves and/or medical decision making for others.

Noon – 12:30 pm Lunch

12:30 - 1:30 pm ***A Crosswalk of Common Ethical Challenges in Substance Use Disorder Treatment & Disability Ethics***

Todd Harvey, MSN, RN, CARN
Programmatic Nurse Specialist, Addiction Medicine
UPMC Mercy

Abstract: In the treatment of patients living with substance use disorders (SUDs), clinicians often confront a variety of unique ethical issues for which they must account, within themselves and within the broader healthcare system. One significant factor, stigma, both for SUDs and disabilities, limits the overall beneficence of receiving treatment due to unaddressed clinician biases or gaps in knowledge. This presentation will discuss how stigma manifests in treatment settings while highlighting action individuals can take to improve the treatment of both SUD and patients with disabilities.

Following this presentation, participants should be able to:

- Identify common ethical issues in the treatment of patients with Substance Use Disorder (SUD).
- Identify the role stigma plays in treatment of SUD and disabilities.

- Adapt 3 clinical behaviors or approaches to improve ethical treatment of patients with SUD.

1:30 – 1:45 pm **Break**

1:45 – 2:45 pm ***Barriers to Effective Healthcare for Disabled People: Signs of Progress in Medicine and Law***

Mary Crossley, JD

Interim Dean, Professor of Law, John A. Murray Faculty Scholar

University of Pittsburgh

Abstract: More than three decades after passage of the *Americans with Disabilities Act (ADA)*, persons with disabilities continue to face substantial physical, attitudinal, and knowledge barriers to the receipt of effective healthcare. These barriers contribute to inequitable health disparities for disabled people. Currently, however, promising efforts to address these barriers are emerging in medical, public health, and legal fields.

Following this presentation, participants should be able to:

- Describe physical, attitudinal, and knowledge barriers to effective health care for disabled people.
- Identify an example of progress toward barrier removal in the medical/public health realm.
- Identify an example of progress toward barrier removal in the legal realm.

2:45 – 3:30 pm ***Disability Related Accommodations in Healthcare***

Chatón T. Turner, Esq.

Senior Associate Counsel and Vice President Risk Management/Disabilities Services

UPMC

Abstract: This presentation will discuss the requirements that healthcare facilities must satisfy in order to comply with applicable civil rights laws intended to ensure that people with disabilities enjoy equal access to their services. There will be practical examples from one of the leading integrated delivery and financing systems in the country.

Following this presentation, participants should be able to:

- Discuss the barriers faced by people with disabilities (including ineffective communication) in accessing effective health care that may or may not be associated with their disabilities.
- Learn how healthcare facilities can provide people with disabilities with equitable access to appropriate, accessible, and high-quality health care.
- Explain why training should be provided to all health care providers so that they are able to provide high-quality care to patients with disabilities.
- Identify ways that healthcare providers can maximize the quality of life of their patients with disabilities by preventing and treating health conditions.
- Discuss why providing persons with equal access to healthcare and complying with disability related laws is a prudent risk management measure.

3:30 pm **Conference Adjournment**

COURSE DIRECTORS

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CONTINUING EDUCATION CREDIT

In support of improving patient care, the University of Pittsburgh is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

Physician (CME)

The University of Pittsburgh designates this live activity for a maximum of 6.25 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nursing (CNE)

The maximum number of hours awarded for this Continuing Nursing Education activity is 6.25 contact hours.

Pharmacy (CPE)

This knowledge-based activity provides 6.25 contact hours of continuing pharmacy education credit.

Physician Assistant (AAPA)

The University of Pittsburgh has been authorized by the American Academy of PAs (AAPA) to award AAPA Category 1 CME credit for activities planned in accordance with AAPA CME Criteria. This activity is designated for 6.25 AAPA Category 1 CME credits. PAs should only claim credit commensurate with the extent of their participation.

Social Work

As a Jointly Accredited Organization, University of Pittsburgh is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. State and provincial regulatory boards have the final authority to determine whether an individual course may be accepted for continuing education credit. University of Pittsburgh maintains responsibility for this course. Social workers completing this course receive 6.25 continuing education credits.

Other health care professionals will receive a certificate of attendance confirming the number of contact hours commensurate with the extent of participation in this activity.

This program has been approved by the **Pennsylvania Continuing Legal Education Board** for 6 hours of substantive credit.