2024 Law-Med Symposium



Case Western Reserve University School of Law Law-Medicine Center

March 1, 2024

# 2024 Law-Med Conference: Cognitive Decline and the Law Agenda

#### 8:15 - 8:45 - Breakfast

8:45 - 9:00 - Welcome & Introduction

Jessica Berg, Dean, Case Western Reserve University School of Law

Sharona Hoffman, Edgar A. Hahn Professor of Law, Professor of Bioethics, and Co-Director of Law-Medicine Center, Case Western Reserve University School of Law

9:00-9:30 – Brain Mechanisms Responsible for Cognitive Decline in Aging

Dr. Carol Barnes, Regents' Professor, Psychology, Neurology and Neuroscience, University of Arizona

9:30-10:45 - Decision-Making Support and Substituted Judgment

*Decision-Making Support in the Dementia Context: Beyond Agreements*, Rebekah Diller, Clinical Professor of Law, Cardozo Law

*Authentic Substituted Judgment*, James Toomey, Assistant Professor of Law, Pace University Elisabeth Haub School of Law

*Planning for Cognitive Decline: Combining Formal Supported Decision Making and Power of Attorney*, Megan Wright, Professor of Law, Medicine, Sociology, and Bioethics, Penn State Law

10:45 – 11:00 - Break

11:00 - 12:15 - Cognitive Decline in Prison, Politics, and Job Performance

Protecting Persons Living with Dementia Who Are Incarcerated: Does the 8<sup>th</sup> Amendment Work? Jalayne Arias, Associate Professor, Georgia State University School of Public Health

*Cognitive Decline in American Politics*, Mark Fisher, Professor of Neurology, University of California, Irvine

*Cognitive Decline and the Workplace*, Sharona Hoffman, Edgar A. Hahn Professor of Law and Professor of Bioethics, Case Western Reserve University

12:15 – 1:00 – Lunch

1:00 - 2:15 - Guardianship and Legal Capacity

*The Law and The Coming Dementia Tsunami*, Vaughn James, Judge Robert H. Bean Professor of Law, Texas Tech University School of Law

*Guardianship: From Law Reform to Court Reform*, Nina Kohn, David M. Levy Professor of Law, Syracuse University College of Law; Distinguished Scholar in Elder Law, Yale Law School

*Is It Appropriate for the Legal System to Rely on Lucid Moments in Evaluating Legal Capacity?* Katherine Pearson, Professor of Law, Penn State Dickinson Law

#### 2:15 – 2:30 – Break

2:30 – 3:45 – Research, Virtual Care, and Cognitive Resilience

*Data Access in Alzheimer Disease: Barriers and Solutions*, Jonathan Haines, Chair, Department of Population and Quantitative Health Sciences, School of Medicine

*Using Law to Create Cognitive Resilience*, Emily Murphy, Professor of Law and Harry & Lillian Hastings Research Chair, UC Law, San Francisco

*Advancing Virtual Care Practices Across the Cognitive Impairment Continuum*, Tara Sklar, Faculty Director, Health Law & Policy Program, University of Arizona College of Law

## **Jalayne Arias**

Associate Professor, Georgia State University School of Public Health

**Title**: Protecting Persons Living with Dementia who are Incarcerated: Does the 8th Amendment Work?

**Description**: This talk will evaluate the 8th amendment as a way to provide protections for persons living with dementia who are incarcerated.

**Bio**: Jalayne Arias, JD, MA is an Associate Professor in the Department of Health Policy & Behavioral Sciences, in the School of Public Health at Georgia State University. Her research harnesses training in law and ethics to evaluate critical challenges associated with aging, including neurodegenerative conditions.



#### **Dr. Carol Barnes**

Regents' Professor, Psychology, Neurology and Neuroscience, University of Arizona

Title: Brain mechanisms responsible for cognitive decline in aging

**Description**: Cognitive changes are to be expected during normative aging, although normal cognitive and neural changes are mild compared to those that occur in neurodegenerative diseases such as Alzheimer's disease. This talk will review changes in a brain structure that is critical for memory, the hippocampus. It will cover changes that are to be expected during normative aging and the effects of age-related diseases that are superimposed upon older brains.

**Bio**: Dr. Barnes is the Regents' Professor, Psychology, Neurology and Neuroscience and Evelyn F. McKnight Chair for Learning and Memory in Aging. Dr. Barnes' work over the past four decades has focused on the aging brain and how cognition changes during the course of normal aging. She uses animal models of human aging that allow a detailed examination of the brain mechanisms of learning and memory and the circuits responsible for complex cognitive function. She also uses behavioral, anatomical, electrophysiological and molecular approaches to the problem of understanding brain aging – and believes that many levels of analysis are required to penetrate the mysteries of how the brain functions across the lifespan.

Dr. Barnes directs the Evelyn F. McKnight Brain Institute at the University of Arizona and the Division of Neural Systems, Memory and Aging. She is actively involved in collaborative projects with scientists within the state of Arizona, across the United States and the world. She has a track record of conducting difficult, systematic and thorough studies with interdisciplinary teams, as well as with her own students and postdoctoral fellows. These projects have led to over 275 publications, a number of which are now classic references on brain aging and behavior.



## **Rebekah Diller**

Clinical Professor of Law, Cardozo Law

#### Title: Decision-Making Support in the Dementia Context: Beyond Agreements

Description: Supported decision-making (SMD) is often understood to be synonymous with supported decision-making agreements—arrangements that permit a decision-maker to designate trusted supporters to assist in obtaining and processing information as well as in communicating decisions. SDM agreements have been largely developed for and used by persons with intellectual or developmental disabilities, who might otherwise be at risk of guardianship. Much less has been done to explore how to implement decision-making supports in the context of older adults with cognitive decline. This talk argues that we should be wary of just transporting the SDM agreement model into the dementia context. The different context requires a different and broader range of supports. The talk suggests three areas to explore. First, persons who do not have family or other caregivers in their lives often have more pronounced needs when implementing decisions than when making them. Practical services such as bill-paying and geriatric care management may be more essential to independent living than supported decisionmaking as it is widely understood. Second, requiring health care and other institutions to offer decision-making support as a reasonable accommodation can also play a role in preserving rights. Third, integrating supported decision-making concepts into advance planning can enhance autonomy and provide future surrogate decision-makers with guidance about the person's values.

**Bio:** is a Clinical Professor of Law at Benjamin N. Cardozo School of Law. Professor Diller codirects the Bet Tzedek Civil Litigation Clinic, which represents older adults and persons with disabilities in a range of civil matters, including restoration of rights for people under guardianship, consumer matters, public benefits claims, and disability discrimination cases. She previously launched and directed Cardozo's Guardianship Clinic, which represented clients in all aspects of adult guardianship, with a particular focus on developing alternatives to guardianship. Prior to joining Cardozo, Professor Diller was Deputy Director of the Justice Program at the Brennan Center for Justice at New York University School of Law, where she spearheaded research, advocacy and litigation to expand access to justice for low-income communities. Previously, she directed the Reproductive Rights Project at the New York Civil

Liberties Union and was a staff Legal Services for the Elderly testified before committees in her work has been featured in *Today, The Daily News* and a *magna cum laude* graduate of



attorney at Housing Works and in Queens. Professor Diller has both houses of Congress and the *New York Times*, *USA* many other outlets. Diller is NYU School of Law.

# **Mark Fisher**

Professor of Neurology, University of California, Irvine

#### Title: Cognitive Decline in American Politics

**Description**: Cognitive impairment among politicians is an issue of growing concern. In addition, cognitive decline in the electorate is a serious and underappreciated issue. The lecture will address the political and legal aspects of this topic. It will review the role of cognitive testing for political candidates along with the history of the Goldwater Rule. Dr. Fisher will present research findings on the relationship between cognitive decline/dementia and political behavior among the public and discuss the voting rights implications of these findings.

**Bio**: Dr. Fisher is Professor of Neurology at University of California, Irvine, where he holds appointments in the Departments of Anatomy & Neurobiology, Political Science, and Pathology & Laboratory Medicine, as well as in the Beckman Laser Institute, and he is a member of UCI MIND. After obtaining BA and MA degrees in political science from UCLA and University of South Dakota, he received his MD from University of Cincinnati in 1975. He completed Neurology training at UCLA-Wadsworth VA Medical Center and joined the faculty in the Department of Neurology at University of Southern California in 1980 where he established the first stroke program in Southern California. At UCI, he served as Chair of the Department of Neurology from 1998-2006. He has had continuous NIH stroke research funding for nearly 40 years, and he has received more than 50 citations of clinical excellence as a stroke neurologist from a variety of external organizations. In addition to caring for stroke patients, he is currently engaged in clinical and basic vascular neurobiology research. He is also active in interdisciplinary studies and is a member (inactive) of the California State Bar (JD Loyola Law School, 1997). In 2021, Dr. Fisher was named Director of the newly formed UCI Center for Neuropolitics.



## Jonathan Haines

Chair, Department of Population and Quantitative Health Sciences, School of Medicine

Title: Data Access in Alzheimer disease: Barriers and Solutions

**Description**: Alzheimer disease is the most common form of dementia and affects more than six million individuals in the U.S. Treatment options are limited and at best modestly slow progression. Since Alzheimer disease is strongly influenced by genetics, understanding its genetic architecture can lead to a better understanding of the underlying pathological processes and identify optimal targets for therapeutic drug development. To dissect Alzheimer disease genetics, numerous national and international efforts are underway, involving hundreds of thousands of human subjects. This talk will discuss the numerous barriers to the collection and sharing of genetic data and discuss current and potential solutions to these barriers.

**Bio**: Dr. Jonathan Haines is a genetic epidemiologist, Mary W. Sheldon M.D. Professor of Genomic Sciences, director of the Cleveland Institute for Computational Biology (CICB), and Chair of the Department of Population & Quantitative Health Sciences at Case Western Reserve University (CWRU). Dr. Haines has extensive experience in all aspects of human genetic epidemiology including both statistical and molecular analysis. His initial work helped identify the genes underlying over 20 different Mendelian disorders. He has been active in Illuminating the underlying genetic architecture of numerous common and complex genetic diseases for over 35 years, with a particular focus on neurological and ophthalmological diseases. His current research efforts are primarily focused on Alzheimer disease and age-related macular degeneration, with the goal of identifying and characterizing genetic variation that either increases or decreases the risk and/or progression of disease. He has published over 700 peerreviewed papers, has served on two different NIH advisory councils, and is the co-founder of numerous national and international research consortia.



## Sharona Hoffman

Edgar A. Hahn Professor of Law and Professor of Bioethics, Case Western Reserve University

Title: Cognitive Decline and the Workplace"

**Description**: The question of how to handle cognitive decline in the workforce has received very limited attention in legal circles. This talk examines a variety of strategies that employers might implement, including mandatory retirement ages, mandatory cognitive testing for older employees or all employees, testing for dementia biomarkers, or an approach of individualized assessment. It assesses these approaches in light of the relevant federal laws that prohibit age, disability, and disparate impact race discrimination and suggests necessary statutory revisions. The talk will provide recommendations as to how employers, employees, and professional associations can appropriately manage this very sensitive matter.

The talk will also focus on health care providers in particular. It will tackle the question of whether state medical boards have a role to play in identifying clinicians with cognitive decline. It argues that while employers are constrained in their ability to test health care providers for cognitive decline, state medical boards would be wise to adopt carefully designed late career screening programs. The talk offers recommendations for formulating such an approach.

**Bio**: Sharona Hoffman is the Edgar A. Hahn Professor of Law, Professor of Bioethics, and Co-Director of the Law-Medicine Center at Case Western Reserve University (CWRU). Professor Hoffman received her B.A. from Wellesley College, her J.D. from Harvard Law School, an LL.M. in health law from the University of Houston, and an S.J.D. in health law from Case Western Reserve University School of Law. She has written over seventy journal articles on health law and civil rights topics, Professor. Hoffman is also the author of two books: *Aging with a Plan: How a Little Thought Today Can Vastly Improve Your Tomorrow*, Second Edition (First Hill Books 2022) and *Electronic Health Records and Medical Big Data: Law and Policy* (Cambridge University Press 2016). Dr. Hoffman has lectured throughout the United States and internationally and has been widely quoted in the press. She is an elected member of the American Law Institute. For more information see her website http://sharonahoffman.com/.



## Vaughn E. James, JD, DD, PhD

Judge Robert H. Bean Professor, Texas Tech University School of Law

Title: The Law and the Coming Dementia Tsumani

**Description**: This talk will discuss two ways to address society's approaching dementia tsunami. First, it will advocate for the enactment of preneed guardianship statutes throughout the United States. The talk will discuss the Texas Declaration of Guardian provisions and the Florida Preneed Guardianship statute. It will compare them to the quite different standby guardianship statutes found in states like Nevada and New York. The talk will go on to highlight the positive attributes of the preneed guardianship statutes but will also discuss their weaknesses. Overall, the talk will strongly advocate for the adoption of preneed guardianship statutes throughout the United States.

Second, the talk will advocate for easier and more palatable ways for guardians to transfer guardianships across state lines. Very often, elderly people have children and other informal caregivers who relocate to other states after having been appointed guardians. What happens to the guardianship then? What happens to the ward? Can the guardian simply transfer the guardianship from the current state to his or her new state of residence? After analyzing these questions, the talk

will propose ways to make the guardianship system more palatable and workable.

**Bio**: Professor Vaughn E. James is the Judge Robert H. Bean Professor at Texas Tech University School of Law in Lubbock, Texas, where, among other courses, he teaches Elder Law and Wills & Trusts. A graduate of Syracuse University College of Law, Prof. James is licensed to practice in New York, Texas, the Federal Northern District of Texas and before the United States Tax Court and the Internal Revenue Service (IRS). He is also a Registered Tax Return Preparer. As regards the practice of law, Prof. James provides over 100 hours of *pro bono* legal services each year, with an emphasis on Elder Law, Federal Income Taxation, Trusts & Estates and Probate. He is a member of the National Academy of Elder Law Attorneys (NAELA) and of the Elder Law & Special Needs Section of the New York State Bar Association.

Professor James is the author of *The Alzheimer's Advisor: A Caregiver's Guide to Dealing with the Tough Legal and Practical Issues* (New York, NY: AMACOM Books, 2009); *Texas Elder Law* (Washington, D.C.: Full Court Press,) and *Elder Law—Cases and Materials* (New Orleans, LA: Esquire Books, 2019). He is the recipient of a 2009 *Texas Lawyer Magazine* Extraordinary

Minority in Texas Law Award University President's

Prof. James is blind and has capacity. He "reads," "writes" world through the help of



and the 2010 Texas Tech Academic Achievement Award.

only 50 percent of his hearing and communicates with the computer software programs.

#### Nina A. Kohn

David M. Levy Professor of Law Syracuse University College of Law; Distinguished Scholar in Elder Law, Yale Law School

#### Title: Guardianship: From law reform to court reform

**Description**: In recent years, the use of guardianship to respond to cognitive limitations has come under intense criticism—in the popular media, among disability rights advocates, and even in academic circles. This talk will identify key ways in which the current guardianship system fails to protect and respect individuals with cognitive disabilities and suspected cognitive disabilities. It will then show how the law enables these failures, and highlight the key reforms needed to ensure that the guardianship system can be a system for protecting against, not effectuating, abuse of vulnerable persons. In doing so, the talk will explain why the focus of reform efforts must shift from rooting out "bad guardians" to reforming the courts themselves.

**Bio**: Nina A. Kohn is the David M. Levy Professor of Law at Syracuse University College of Law, a Distinguished Scholar in Elder Law with Yale Law School's Solomon Center for Health Law and Policy, and a member of the American Law Institute. She has served as a Visiting Professor at Yale Law School and Cornell Law School.

Kohn is a leading expert in elder law, advance planning and medical consent, and the civil rights of older adults and those with diminished cognitive capacity. A prolific writer, her recent work has appeared in such diverse fora as the *Harvard Civil Rights-Civil Liberties Law Review*, the *Boston University Law Review*, the *Georgetown University Law Review Online*, and the *Washington Post*. She also authored the textbook *Elder Law: Practice, Policy & Problems* (Wolters Kluwer, 2d ed. 2020). Kohn has served in numerous public interest roles, including as Reporter for both the Uniform Health Care Decisions Act and the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act.

Professor Kohn earned an A.B. summa cum laude from Princeton University and a J.D. magna

cum laude from Harvard Honorable Fred I. Parker of Appeals for the Second academia, she served as a direct representation to elders. She is a recipient of Law's Res Ipsa Loquitur and Syracuse University's Distinguished Faculty



University. She clerked for the the United States Court of Circuit. Prior to entering Skadden Fellow, providing nursing home residents and frail Syracuse University College of award for teaching excellence, Judith Greenberg Seinfeld Fellowship.

# **Emily Murphy**

Professor of Law and Harry & Lillian Hastings Research Chair, UC Law San Francisco

#### Title: Using law to create cognitive resilience

**Description**: Law is one of the many social determinants of brain health. As scientific understanding of factors that affect cognitive decline increases, law can and should prioritize the preservation of the collective cognitive capital of the population via both legislation and by administrative decision-making that fully accounts for the cognitive burdens and benefits of various regulations. This talk will outline the theory of collective cognitive capital as a focus of legal decision-making and apply the theory to the challenges posed by myriad social, environmental, and economic factors impacting brain health and cognitive decline.

**Bio**: Professor Murphy's research focuses on the intersection of neuroscience, behavioral science, and law. She writes about the use of neuroscience as evidence and how neuroscience and behavioral science shape public policy and legal systems. Her work has been published or is forthcoming in Stanford Law Review, The Journal of Law & the Biosciences, Connecticut Law Review, William & Mary Law Review, Law & Psychology Review, Psychology Public Policy & Law, and Science.

Professor Murphy earned her A.B. magna cum laude in Psychology from Harvard University, her Ph.D. in Behavioral Neuroscience and Psychopharmacology from University of Cambridge, Trinity College, as a Gates Cambridge Scholar, and her J.D. from Stanford Law School. Prior to law school she was a postdoc with the Program in Neuroethics at the Stanford Center for Biomecial Ethics, Stanford Law School's Center for Law and the Biosciences as well as the MacArthur Foundation's Law and Neuroscience Project. Following law school, she clerked for the Honorable Richard A. Paez of the U.S. Court of Appeals for the Ninth Circuit. Prior to joining UC Law SF, Professor Murphy spent a year as a fellow in the Program in Understanding Law, Science, and Evidence at UCLA Law School. Before that, she practiced law at Munger, Tolles & Olson LLP, handling all aspects of complex commercial litigation, with an emphasis on professional liability and internal investigations. Her pro bono practice focused on housing issues and civil rights work addressing homelessness and incarcerated persons with disabilities.



# **Prof. Katherine Pearson**

Professor of Law, Penn State Dickinson Law

**Title:** Is it Appropriate for the Legal System to Rely on Lucid Moments in Evaluating Legal Capacity?

**Description**: In a well-known and often-cited case decided by the Pennsylvania Supreme Court in 1989, an older widower's weekend transfer of title on valuable property to a former son-in-law was justified in part because a medical expert testified that a person with advanced Alzheimer's Disease could still have "lucid moments." The evidence of such lucidity came from the attorney who completed the deed transfers. Now, more than 30 years later, and with a better understanding of neurodegenerative disorders, it is appropriate to rethink the concept of short-term lucidity when considering a legal standard for transactional competence.

**Bio:** Katherine C. Pearson is a Professor of Law at Penn State Dickinson Law in Pennsylvania. Her scholarship focuses on laws and policies connected to aging. She is the author of articles and chapters on long-term care contracts, financing for retirement, capacity concerns, and filial obligations, and is the co-author of a treatise, The Law of Financial Abuse and Exploitation (Bisel 2011). A U.S. Fulbright Research Scholar (U.K. in 2009-10), her work includes international, comparative analysis of laws affecting families, and she has worked as an international consultant to promote better systems for safeguarding and adult social care.



## Tara Sklar

Faculty Director, Health Law & Policy Program, University of Arizona College of Law

Title: Advancing Virtual Care Practices Across the Cognitive Impairment Continuum

Description: Thoughtful modernization of laws and regulations has the potential to promote the advancement of high-quality virtual care for people living with cognitive decline. Facing a growing aging population, hospitals and healthcare systems across the country are treating increasing numbers of patients on the cognitive decline continuum with progressive, diverse and debilitating needs. This talk proposes regulatory innovations to advance virtual care practices across the cognitive decline continuum. Ultimately, these health policy recommendations aim to ensure years lived with cognitive impairment are dignified and human years, supported by a system designed to maximize patients' values and needs.

**Bio:** Professor Tara Sklar is the Faculty Director of the Health Law & Policy Program and a Distinguished Public Service Scholar at Arizona Law. She also holds appointments as Associate Director of Telehealth Law & Policy at the Arizona Telemedicine Program, College of Medicine-Tucson, and as a Senior Advisor with Innovations in Healthy Aging at the University of Arizona Health Sciences. She currently serves as a subject matter expert on telehealth policy for home health and other topics with the National Consortium of Telehealth Resource Centers and with HHS Health Resources & Services Administration (HRSA) in the Office for the Advancement of Telehealth.

Sklar's teaching and research examine legal, regulatory, and ethical issues that arise in adapting health policy to a diverse aging population, with a particular focus on digital health equity. She teaches courses on Telehealth Law & Policy and Aging Law & Policy at the University of Arizona.



## **James Toomey**

Assistant Professor of Law, Pace University Elisabeth Haub School of Law

#### Title: Authentic Substituted Judgment

**Description**: The doctrine of substituted judgment in surrogate decision-making has long struggled with the possibility that people might, under radically new circumstances, genuinely change their mind, and often takes writings composed prior to cognitive decline to be dispositive of what the person would have done. But of course, people change their minds all the time, and indeed a growing body of empirical evidence shows that ordinary people acknowledge this and would want future surrogate decisionmakers to take into account the possibility that they might have authentically changed their mind under future conditions. This talk will explore the implications of the possibility that people would want surrogate decisionmakers to make the decision they would actually, authentically have made, recognizing that they may or may not have authentically changed their minds.

**Bio**: James Toomey is an Assistant Professor of Law at the Elisabeth Haub School of Law at Pace University, where he writes in bioethics and private law theory. His scholarship has been published or is forthcoming in the *Virginia Law Review*, the *Washington University Law Review*, the *Indiana Law Journal*, and the *North Carolina Law Review*, among others, as well as in peer-reviewed publications such as *AJOB Empirical Bioethics*. Prior to joining the faculty at Pace, Toomey was a Climenko Fellow & Lecturer on Law at Harvard Law School. He holds a J.D. from Harvard Law School, *magna cum laude*, and a B.A. from Cornell University, *summa cum laude*.



# **Megan Wright**

Professor of Law, Medicine, Sociology, and Bioethics, Penn State Law

**Title**: Planning for Cognitive Decline: Combining Formal Supported Decision Making and Power of Attorney

**Description**: Individuals planning for loss of capacity may want the benefits of supported decision making as long as they retain some decisional abilities coupled with the guarantee that someone can act on their behalf if they lose all decisional abilities. This presentation will discuss combining a written supported decision-making agreement with a power of attorney form in one document, addressing potential benefits and drawbacks of the proposed legal tool.

**Bio**: Megan S. Wright is a Professor of Law, Medicine, Sociology, and Bioethics at the Pennsylvania State University, a Visiting Lecturer in Law at Yale Law School, and an Adjunct Assistant Professor of Medical Ethics in Medicine at Weill Cornell Medical College.

