

BIOGRAPHICAL SKETCH

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NAME: Kevin T. Mintz, PhD

eRA COMMONS USER NAME (credential, e.g., agency login): MINTZ.KEVIN

POSITION TITLE: Postdoctoral Fellow

EDUCATION/TRAINING (*Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.*)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Harvard University	BA	05/2012	Government
The London School of Economics and Political Sciences	MSc	09/2013	Political Theory
Stanford University	PhD	09/2019	Political Science
National Institutes of Health, Clinical Center Department of Bioethics	Postdoctoral Fellow	07/2021	Bioethics
Stanford University	Postdoctoral Fellow	present	Ethical, Legal, and Social Implications of Genetics and Genomics

A. Personal Statement

I have expertise in political theory, clinical bioethics, and special education as well as my lived experience of CP. As the first research scholar at the Stanford School of Medicine who lives with cerebral palsy, my scholarship to-date focuses on using methods in political theory and clinical bioethics as tools to investigate the barriers people with disabilities confront in accessing social life, education, healthcare, and biomedical research. My time at the Stanford Center for Biomedical Ethics has initiated my empirical training in the Ethical, Legal, and Social Implications of Genetics and Genomics (ELSI) to explore how the tools and methodologies of these disciplines can be used to promote health equity for individuals with disabilities.

Building upon my existing expertise and experience, my long-term goal is to become an independent investigator who uses deliberative democratic methodologies to inform how precision medicine can meet the diverse needs of disability communities. Innovations in precision medicine are rapidly changing scientific understandings of the causes of and potential treatments for disabling conditions. Alongside potential benefits of PMR initiatives come a diversity of perspectives on the role PMR and precision medicine should play in treating or curing disabling conditions. However, little is known about the perspectives of disability communities towards emerging PMR into conditions that have not historically been understood as genetic, including CP. New strategies are needed for prospectively aligning the values of researchers, people with disabilities, and those who care for them in emerging PMR on disabling conditions. Existing literature on disability inclusion and anti-ableism in PMR provides insufficient guidance on how to facilitate consensus among the perspectives of researchers, people with disabilities, their caregivers, and clinicians. Drawing on extensive, semi-structured interviews and a validated process for facilitating deliberative democratic engagement, this project will yield insight into how to bring together the perspectives of precision medicine researchers, members of the CP community, and clinicians specializing in the care of CP to maximize the potential benefits and minimize the potential harms of PMR-CP.

Relevant articles

1. Cho M, Duque Lasio M, Amarillo I, **Mintz K**, Bennett R, Brothers K. "Words matter: The language of difference in human genetics." *Genet Med* 2023; 25(3):100343. Epub 2022 Dec 15. PMID: PMC9991958.
2. **Mintz K**. Serendipity and social justice: How someone with a physical disability succeeds in clinical bioethics. *Narrat Inq Bioeth.* 2022; 12(3): 1-9. PMID: PMC10583395.
3. **Mintz K**. Paying attention to the mouse behind the curtain: Dilemmas of disability justice in a lawsuit against Disney. *Soc Theory Pract.* 2021; 47(4): 687-715.
4. **Mintz K**, Jardas E, Shah S, Grady C, Danis M, and Wendler D. Enrolling minors in COVID-19 vaccine trials. *Pediatrics* 2021; 147(3): e2020040717. PMID: PMC7919110.

B. Positions, Scientific Appointments, and Honors

Scientific Appointments

2024 - present	Social Sciences Research Scholar, Stanford University
2021 - 2024	Postdoctoral Fellow, Stanford University
2019 - 2021	Postdoctoral Fellow, Department of Bioethics, National Institutes of Health

Teaching Experience (both paid and voluntary)

August 2021 – Present	Stanford University, School of Medicine and Program in Human Biology
July 2020 – June 2021	George Mason University, Department of Philosophy
March & May 2021	Stanford University, Sexual Health Peer Resource Center
October 2016 – March 2017	Stanford University, Department of Political Science
March 2016 – March 2017	San Francisco Sex Information
March & November 2015	St. Thomas University
August 2009 – December 2011	Harvard Graduate School of Education

Educational Consulting

July 2011 – October 2011	Harvard Graduate School of Education
January 2009 – May 2012	Thomas Hehir & Associates

Awards and Grants

2023	The Society for Philosophy and Disability Anita Silvers Essay Prize
2023	Postdoc JEDI Champion Award, Office of Postdoctoral Affairs, Stanford University
2022	The Stanford University Grant Writing Academy's Jump Start Award for Excellence in Research for Postdoctoral Scholars
2021	Stanford University Maternal & Child Health Research Institute and Department of Pediatrics, Undiagnosed Diseases Network Seed Grant
2018	Stanford University, Office of the Vice Provost for Graduate Education Diversity Dissertation Research Opportunity Award
2018	The Kinsey Institute for Research in Sex, Gender, and Reproduction at Indiana University, John Money Fellowship for Scholars of Sexology
2017 - 2019	Stanford University's Diversifying Academia, Recruiting Excellence Graduate Fellowship
2016 - 2017	Stanford University's McCoy Family Center for Ethics in Society, Graduate Fellow
2012	The Peter Wilson Graduate Award Presented by Harvard College
2011	Parent to Parent of Miami (FL) "Journey of Dreams" 7 th Annual IMPACT Award
2008	Miami Herald Silver Knight Award Recipient for Social Sciences

Professional Memberships

American Society for Bioethics and Humanities
American College of Medical Genetics and Genomics
American Society of Human Genetics
Society for Disability Studies

C. Contributions to Science

1. Investigated Research Ethics for Pediatric Populations and Individuals with Disabilities

People with disabilities are often excluded from biomedical research. This exclusion can be attributed to at least two factors. First, medical researchers often consider individuals with disabilities to be non-ideal participants in general health research because of how impairments significantly alter bodily function. Second, medical researchers frequently worry about how various disabilities may interfere with informed consent. While a postdoctoral fellow, first in the Department of Bioethics at the National Institutes of Health and currently at the Stanford Center for Biomedical Ethics, I have written three first authored publications focusing on research ethics and people with disabilities. Collectively, my publications in this area highlight common ethical tensions between disability inclusion in clinical research and the inclusion of pediatric populations. Research with participants in these populations focuses on ethical questions about what constitutes informed assent and how to protect participants from harm while not denying them access to the benefits of clinical research. Resolving these questions satisfactorily will help ensure that sixty one million Americans and approximately one billion people with disabilities worldwide will not be unfairly excluded from the research enterprise or denied the benefits of new medical interventions because medicine has not adequately studied the impact of these interventions on underlying health conditions. My proposed research builds upon these contributions to consider the ethical and political challenges associated with designing emerging PMR initiatives that take into account the needs and perspectives of people with disabilities and those who care for them.

- a) **Mintz K**, Gammer B, Khan AJ, Shaub G, Levine S, and Sisti, D. Physical disability and psychedelic therapies: An agenda for inclusive research and practice. *Front Psychiatry* 2022; 13:914458. doi: 10.3389/fpsy.2022.914458. PMID: PMC9174510
- b) **Mintz K**, Wasserman D. Research ethics and intellectual disability: Finding the middle ground between protection and exclusion. In: Reynolds, JM and Wieseler C, eds. *The Disability Bioethics Reader*. 1st ed. Routledge. 2022: 282-291.
- c) **Mintz K**, Jardas E, Shah S, Grady C, Danis M, and Wendler D. Enrolling minors in COVID-19 vaccine trials. *Pediatrics* 2021; 147(3): e2020040717. PMID: PMC7919110.

2. Identified Equity and Access Barriers to the Benefits of PMR and Precision Medicine

Research and innovations in precision medicine pose barriers of equity and access for members of disability communities. My most recent co-authored publications have grappled with the ethical question of how best to identify and remove these barriers in three distinct contexts: emerging smart toilet technologies for precision health, inclusive language use in genetics and genomics, and PMR into rare and undiagnosed diseases. While the experience of people with disabilities is only a part of the ethical and social considerations in these articles, contributing to them has solidified my commitment to using methodologies within ELSI to identify strategies for making PMR and precision medicine more responsive to the values and preferences of disability communities.

- a) Ge T, Rahimzadeh V, **Mintz K**, Park W, Martinez-Martin N, Liao J, Park S. "Passive monitoring by smart toilets for precision health." *Sci Transl Med* 2023; 15(681):eabk3489. Epub 2023 Feb 1. PMID: PMC10311987.
- b) Cho M, Duque Lasio M, Amarillo I, **Mintz K**, Bennett R, Brothers K. "Words matter: The language of difference in human genetics." *Genet Med* 2023; 25(3):100343. Epub 2022 Dec 15. PMID: PMC9991958.
- c) Halley M, Young J, Tang C, **Mintz KT**, Lucas-Griffin S, Maghiro A, Ashley E, Tabor H. "Genomics research with undiagnosed children: Ethical challenges at the boundaries of research and clinical care." *J Pediatr* 2023; 261:113537. Epub 2023 Jun 2. PMID: PMC10527480.

3. Addressed Structural Ableism in Medicine and Healthcare

Since 2014, much of my scholarship has focused on the ethics of care, intimacy, and sexual health for people with disabilities. More recently, I have built on this work to consider broader issues of disability accessibility in the context of medicine, public health, and healthcare. People with disabilities experience pervasive inequalities and discrimination in these domains. My articles in this area combine my training as a political theorist with clinical bioethics to demonstrate how the challenges people with disabilities confront in accessing these critical domains are matters of social justice. My proposed career development and research plans will enable me to extend this work to emerging PMR into disabling conditions, such as cerebral palsy.

- a) Solis C, **Mintz K**, Fenton K, Wasserman D, and Danis M. "Homecare in America: The Urgent Challenge of Putting Ethical Care into Practice," *Hastings Center Report* 2023. NIHMS: 1894612.
- b) **Mintz K**. Serendipity and social justice: How someone with a physical disability succeeds in clinical bioethics. *Narrat Inq Bioeth.* 2022; 12(3): 1-9. PMID: PMC10583395.
- c) **Mintz K**. "My blessed child doesn't need to know about that": How should sexual health educators confront the challenge of religious pluralism in working with individuals who have intellectual disabilities? *Ethics, Med. Public Health* 2018; 5: 8-17.
- d) **Mintz K**. Sexual Intimacy, Social Justice, and Severe Disabilities: Should Fair Equality of Opportunity in Health Extend to Surrogate Partner Therapy? *Journal of Philosophy. Science and Law* 2014; 14:4-15

4. Examined disability bioethics and its intersection with business and design

In 2017, I read a newspaper article about a series of lawsuits against Disney Parks & Resorts U.S. brought by individuals with moderate and severe autism spectrum disorder and their families. I subsequently cultivated a working relationship with the plaintiffs' attorney and interviewed seventeen of his clients. I did so without formalized training in qualitative or mixed methods research and without external funding. In light of the many health disparities and structural inequalities people with disabilities confront, the ability to receive access to Disney's theme parks might appear trivial in comparison. I illustrate the contrary, highlighting how access to leisure facilities like Disney theme parks can be a source of flourishing for individuals who are unable to have meaningful social experiences through other means.

My work on this case study provides ample evidence of my potential to develop into an independent scientific investigator because at each stage of the research process I took initiative, meticulously and persistently ensuring that the project continued. My perseverance led to a series of publications using the lawsuits to consider the extent to which large corporations like Disney should accommodate customers with intellectual disabilities. In 2023, I was awarded the inaugural Anita Silvers Essay Prize by The Society for Philosophy and Disability for my 2021 publication *Paying attention to the mouse behind the curtain: Dilemmas of disability justice in a lawsuit against Disney*. My work in this area solidified my commitment to an academic career in empirical bioethics and ELSI. A major issue in the Disney lawsuits was the extent to which appeals to the potential genetic etiology of autism spectrum disorder could be used to mitigate Disney's obligations to provide the plaintiffs with disability modifications. I plan to devote my career to being an independent investigator who uses empirical methods in ELSI and disability bioethics to ensure that genetics and genomics are used as tools to alleviate the health disparities and other social inequalities that individuals with intellectual and developmental disabilities confront.

- a) **Mintz K**. Paying attention to the mouse behind the curtain: Dilemmas of disability justice in a lawsuit against Disney. *Soc Theory Pract.* 2021; 47(4): 687-715.
- b) **Mintz K**. Universally designed urban environments: 'A Mindless Abuse of the Ideal of Equality' or a matter of social justice? In *Technology and the City, Philosophy of Engineering and Philosophy*, vol. 36. Springer; 2021: 177-200.
- c) **Mintz K**. Guests with Autism and Reasonable Accommodations at Disney. In *Business Cases in Ethical Focus*. Broadview Press; 2019: 179-189.
- d) **Mintz K**. Is Disney Disabling? *Disabil Soc* 2018; 33(8): 1366-1371.

Complete List of Published Work in MyBibliography

<https://www.ncbi.nlm.nih.gov/myncbi/kevin.mintz.1/bibliography/public/>