

BIOETHICS BULLETIN

NIH CLINICAL CENTER DEPARTMENT OF BIOETHICS

INTERVIEW WITH DAN BRUDNEY

Visiting scholar & professor of philosophy speaks about his experience at the NIH Department of Bioethics

Dan Brudney, Professor of Philosophy at the University of Chicago, joined the NIH Department of Bioethics for the Spring 2018 semester as a visiting scholar to work on Kantian autonomy and a moral basis for bedside decision-making. Before Dan leaves the department in June, the Bulletin interviewed him to learn more about his main projects and favorite experiences with the department.

Q: What is your previous experience in bioethics, and why were you interested in coming here?

Twelve years ago I began to participate in the clinical ethics program at the University of Chicago Medical Center. Eventually, I began to publish and to give talks in bioethics. However, my central institutional affiliation has always been in a philosophy department, so I jumped at the opportunity to spend a semester working at a top-flight bioethics department. It has provided me with my first opportunity to spend all my time on bioethics, as well as to gain exposure to the range of empirical work done in American bioethics.

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THE DEPARTMENT VOLUNTEERED TO PROVIDE DINNER TO GUESTS AT THE CHILDREN'S INN IN FEBRUARY AND MARCH. SPECIAL THANK YOU TO CAROLINE HUANG FOR COORDINATING THESE EVENTS.

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CHRISTINE'S CORNER



Greetings from the NIH CC
Department of Bioethics!

The Department of Bioethics continues to thrive with thought-provoking research, great fellows, and continued demand for high quality consultation across the NIH, despite major changes over the last year or so at the Clinical Center, the NIH, and in the U.S.

Happenings in the Department of Bioethics

We have had three wonderful, very engaged, and exciting visiting scholars this year:

1. Rebecca Dresser, Professor Emerita from Washington University School of Law, in Fall 2017.

Rebecca's current projects are of great interest to us: advance care planning for persons with dementia, including planning for assistance with dying, and the importance of incorporating the voices of experienced research participants into research ethics;

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CAROLINE HUANG: CHRONIC PAIN & OPIOID USE DISORDERS

During the fellowship, my research has primarily explored ethical issues arising in the management of chronic pain and opioid use disorders. Both these conditions are current public health crises: Chronic pain affects up to 100 million Americans and costs society up to \$635 billion per year, while opioid use disorders affect an estimated 2.1 million Americans and contributed to roughly 42,000 overdose deaths in 2016.

With my mentor David Wasserman, I have had the opportunity to work on two main conceptual projects. One paper introduces a practical framework designed to support clinicians as they help chronic pain patients make individualized management decisions. A second paper considers the challenge that chronic pain poses for disability theory and policy. Two other projects involve collaborations outside of NIH. In partnership with fire department officials, I have planned a qualitative study to investigate the impact of opioid-related overdoses on first responders. I have also started working with a clinical ethicist and fellow chronic pain patient to examine the ethical implications of prescription opioid limits, particularly for Medicare recipients.

These projects fit neatly within the NIH's focus on addressing both chronic pain and opioid use disorders through clinical care and research. Going on rounds with the Pain and Palliative Care team provided a close-up look at how pain specialists work with research teams to manage patients' pain and help the Clinical Center navigate issues such as the nationwide intravenous opioid shortage. In addition to established networks such as the NIH Pain Consortium, the NIH just launched the HEAL (Helping to End Addiction Long-Term) Initiative, which aims to prevent addiction through enhanced pain management and improve treatments for opioid use disorders. Our fearless leader, Christine Grady, also recently served on an NIH working group that issued a report on "Ethical considerations for industry partnership on research to help end the opioid crisis" to the Advisory Committee to the Director.

CHRISTINE'S CORNER, CONTINUED

2. Tom Shakespeare in February 2018. Tom is a sociologist and Professor of Disability Research on the medical faculty at the University of East Anglia and a member of UK's Nuffield Council on Bioethics. We learned so much from Tom's work on disability ethics, and on prenatal testing.

3. Dan Brudney, Professor of Philosophy, University of Chicago, is with us for Spring semester 2018. Dan is focusing, among other things, on challenging puzzles related to what it means to respect autonomous decision making in the clinical setting. (More about Dan in another part of the newsletter, pages 1,4).

We are thrilled that Annette Rid will be joining us in September 2018 through a position at Georgetown University. Annette is trained as a physician, is a former NIH fellow, and has recently been Associate Professor in Bioethics and Society at King's College in London. Her work covers a number of areas including international research ethics, research with pregnant women, risks in research, and others. Fortunately, no other faculty have left since Seema Shah and Frank Miller. Unfortunately, a hiring freeze has made it impossible to hire anyone to federal service. Renee Goodman has integrated beautifully into the Department as our Program Specialist, and helps us to keep the trains running smoothly.

Our fellowship program and IRB internship program are flourishing. We had IRB interns from Peru, Zimbabwe, and Malawi for Fall 2017, an intern from the Blackfoot Nation in Spring 2018, and are in the process of selecting our Fall 2018 class with help from Reidar Lie. In May, we held our 4th annual Mid-Atlantic Regional Bioethics Fellows Workshop with Johns Hopkins and Penn, and several former fellows were featured!

It is hard to believe, but we are scheduled for our next quadrennial review by the Board of Scientific Counselors in January, and so will be gearing up over the next several months to showcase our research.

Happenings at the CC and NIH

The Clinical Center has seen many organizational changes, including a new CEO (started January 2017) and a new COO (started March 2018). There is a strong focus on patient safety and each day starts with a patient safety huddle. A new two-suite hospice unit is being built at the CC for patients who are at the end of life. The Bioethics Consultation Service continues to be an active and valued contributor to CC clinical care and clinical research.

I am still working with the NIH Coordinating Committee on Bioethics Research and Training, which is trying to promote and coordinate funding for bioethics research across the NIH. Although bioethics research funding remains challenging, several NIH ICs support some bioethics research. In addition to ongoing opportunities through the NHGRI ELSI program, the NIH BRAIN initiative published neuroethics research RFAs in both 2017 and 2018, and funded several R01s. The All of Us cohort study of the Precision Medicine Initiative is set to launch very soon.

I hope that each of you is healthy, happy, and productive. I recently challenged our group to identify the top three most important current issues in bioethics, please challenge yourself! We love to hear from you about your many adventures and accomplishments. Please remember that you are always welcome to visit, join us for tea, give a talk, collaborate with us on a project, or check us out on twitter (@NIHBioethics)!

Interview with Dan Brudney, continued



Q: What are some of your projects while you are here?

For a dozen years I participated in the weekly case conference discussions at the University of Chicago Medical Center. Over those years I was impressed with the care and the subtlety of clinicians' treatment of the ethical issues that arise in particular cases. However, the moral conceptual vocabulary with which clinicians discussed those cases often seemed impoverished.

Moreover, at times the clinicians justifiably departed from standard bioethical models (say, about how decision-making is supposed to happen at the bedside) but seemed reluctant to

admit doing so, i.e., reluctant to admit that the standard models have basic flaws. I think that at times this led them to make problematic bedside decisions. Some of my past work has consisted in analyzing the flaws in the bedside decision-making models and making proposals for reform. At the NIH I have been continuing that work.

Q: How does your work in bioethics connect to your work in political philosophy?

That is part of what I have been trying to understand during my time here. I am not yet clear on the connection, but I suspect that it goes through an understanding of the context and criteria for the legitimate exercise of power. Bedside decision-making is in part about power. It is about who gets to make a decision that is likely to have great practical consequences for at least one individual. And so it is about the conditions under which this or that person should have the decision-making power, and, with the surrogate, it is about the criteria that constrain the exercise of that power, i.e., make it not arbitrary. These are the categories of the political philosopher.

Q: What has been the most stimulating part of your time at the NIH Department of Bioethics?

I have benefited greatly from talking with everyone in the Department. I knew a couple of the faculty beforehand, and so I was not surprised at how enjoyable and useful it has been to talk with them. However, the Fellows have been an unexpected delight. It is a remarkable group. They are smart, interesting and able to converse productively on a wide range of bioethical topics. They are quite impressive. Perhaps the most unexpectedly stimulating thing has been tea-time! I have truly enjoyed the conversations that I've had with fellows and faculty as we have munched carrots, celery and other (almost overly) healthy snacks.

INTERVIEW WITH JOESPH MILLUM, PHD

Department member Joseph Millum speaks about his recently published book “The Moral Foundations of Parenthood.”

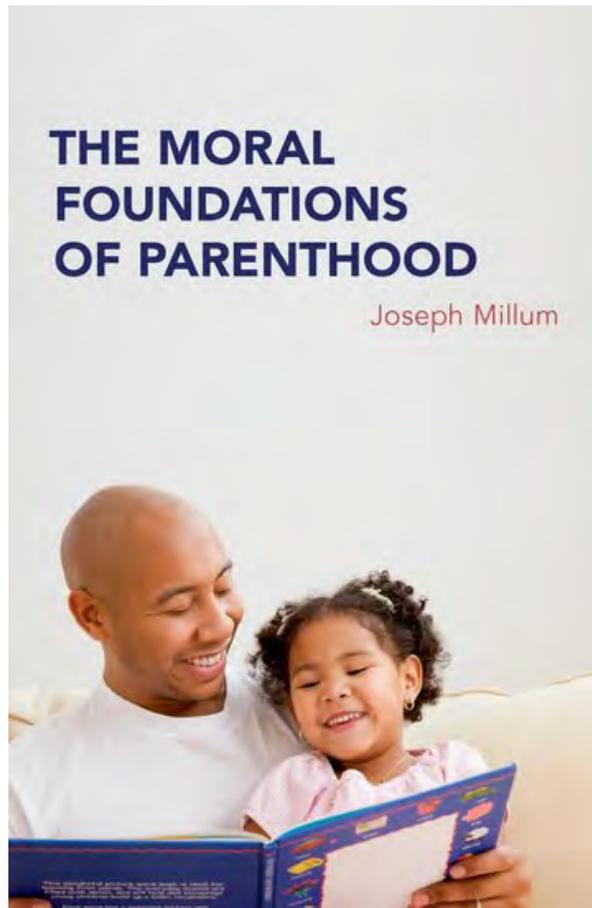
Tell us about your new book, “The Moral Foundations of Parenthood.”

The book is about how people become parents and what it means to be a parent, ethically speaking. I try to answer the questions of how someone can acquire parental rights and responsibilities and what those rights and responsibilities consist in.

Now, the answer to the question, *How does someone become a parent?*, might seem pretty obvious. (When I pose it, I sometimes get the impression that my audience thinks I need some remedial education in human biology.) But it only seems that way because of our paradigm for the normal way that people become parents. If a man and a woman conceive, she carries the child to term, and they raise the child in their joint household, then it’s clear who the parents are. But what about when the biological father isn’t the man in the couple? What about if they hire a surrogate to gestate a baby for them? What about a

same-sex couple who have a friend help them procreate? What about grandparents who raise their grandkids and want to see them or separated couples who dispute custody?

a specific religion? To volunteer them for medical research? May they privilege their own kids over others—such as by paying for private schools—and do they even have a duty to do so?



These cases are not so straightforward.

The questions just multiply when we look at the content of the rights and responsibilities. Do parents have the right to physically punish their children? To raise their children to believe

I think that we need a theory of moral parenthood to answer these questions. That’s what I try to develop in the book.

Why did you decide to write this book? Back when I was first teaching bioethics, we covered a lot of topics related to procreation: in vitro fertilization, surrogate mothers, sperm and egg donation, and so on. A lot of the class readings seemed to assume an answer to the question of who the

“real” parents were. But when I started reading about the ethics of parenthood, I felt that many writers didn’t dig that deep into the fundamental philosophical questions. So, it seemed like there was a gap in the literature.

At the same time, questions about the ethics of parenting seem to come up all the time. Most parents, in my experience, find themselves torn by parenting dilemmas. And the popular media is full of fascinating cases. For example, just the other day I was reading about a court case in Canada where a fostering agency had taken two children back from parents who refused to lie to them about Santa Claus and the Easter Bunny!

Who is the intended audience of the book?

It is a philosophy book, so I'm expecting the primary readership to be philosophers and philosophy students. On the other hand, I do think that the topic is interesting to a much wider group, especially within

bioethics and public policy. I tried to make it as friendly as possible to interested non-philosophers and it's full of real-life examples. While researching the book, I learned a lot from reading law review articles—maybe legal scholars will find something in it for them, too.

What has been the reception?

I'm still waiting for the first reviews to come out... It takes a little while with academic books. On the other hand, my dad received it well.

What do you plan to work on next?

On the ethics of parenthood, I'm planning to do some work on the concepts of abuse and neglect, which are really important for thinking about when the state can intervene

with parenting. I'm also going to proselytize my standard for parental decision-making, which I think is an improvement on the best-interests standard. And one day I'd like to write a more popular book on parenting ethics—I still hope to use the title *Just Kidding*...

On other topics, I have a co-edited volume coming out this year on priority-setting for global health spending and I'm writing a book with David DeGrazia, with the tentative title, *A Progressive Theory of Bioethics*.

Is there a way to get discounted copies of the book?

Thanks for asking! Yes, right here: <https://global.oup.com/academic/product/9780190695439/?&promocode=AAFLYG6>

INTERVIEW: RENEE GOODMAN



Tell us how you came to the NIH Department of Bioethics.

After spending about 9 years as a federal contractor with NIAID in a Malaria research laboratory, I came to the Department of Bioethics on a whim! I say on the whim because I was not in a place where I actually wanted to change jobs. Finally after many years, the Malaria laboratory at NIAID had begun the process of transitioning my job from contractor to federal employee. As I began the application process for that transition, I saw this job announcement which peaked my interest a bit. The description of the job announcement was very short, the application open and close date was even shorter (maybe about 3 days to be exact). With the many years of experience in the federal government, to me that was a sure sign this job was intended for someone specific. Even with all of my assumptions and uncertainties, I pushed passed my fear and said to myself “oh what the heck, I’ll give a shot”, I applied! To my surprise several months later I received an email from Christine asking if I was still interested in this position and from there the journey begun!

What are your hopes for your time here?

My predecessor Becky Chen left big shoes for me to fill. One of my hopes is to continue what she and many others started many years ago. As trivial as it might sound the day to day management and operations of this Department is a big deal! There are so many different moving parts with many different areas to think about and oversee. My goal is to just make sure this place continues to have a positive and productive presence here at the NIH Clinical Center for many more years to come. There is also a wealth of knowledge here.... I love that when I come to work I not only have the opportunity to be a part of running this place, I’ve been privy to observing so many different and interesting bioethical issues come to life! For my own selfish reasons, I have hopes to continue to learn and hear about new ideas.

What do you most enjoy about working in the NIH Department of Bioethics?

The hospitableness of the people here in the Department, I think every guest or friend of the Department can attest to this! You all know exactly what I mean, it’s just a very unique place. With so many different disciplines, different views, and areas of expertise one might think it would become complicated... everyone seems mesh very well. That is a true testament to the integrity of the people here who make up this Department.

Until next time...

2016-2018 FELLOW BIOGRAPHIES



FROM LEFT TO RIGHT, CAROLINE HUANG, ROBERT STEEL, HALEY SULLIVAN, SOPHIE GILBERT, LEAH PIERSON, DAVID MILLER.

Sophie Gibert is a pre-doctoral fellow in the Department of Bioethics. She is originally from Boulder, Colorado, and graduated from Wellesley College in 2016, where she majored in Philosophy and designed a second, independent major in Biology and Society. During the fellowship, her research has focused on topics in clinical and public health ethics, especially those related to agency, motivation, and moral responsibility. Her current projects concern the ethics of manipulation and the role of apologies in institutional responses to medical error. In the fall, she will begin a PhD in Philosophy at the Massachusetts Institute of Technology.

Caroline Huang is a postdoctoral fellow in the Department of Bioethics. She completed an SB in Brain and Cognitive Sciences at MIT, followed by a DPhil (PhD) in Public Health at the University of Oxford. At Oxford, her dissertation examined ethical issues surrounding access to care for BRCA (breast cancer susceptibility genes 1 and 2) mutations, a topic inspired by Camp Kesem families. She also developed a debating course module for the MSc in Global Health Science and published and presented on topics including concussions, direct-to-consumer genetic testing, free will, medical ethics education, and nudge behavior. At NIH, she is researching ethical issues arising in the management of chronic pain and opioid use disorders.

David Miller is a pre-doctoral fellow in the Department of Bioethics. David grew up in Tallahassee, Florida and graduated from Florida State University with a BA in Religious Studies in 2015. From 2015-2016, David completed an MSc in Medical Anthropology at the University of Oxford as a Frost Scholar. At NIH, David works on issues surrounding clinical trial design and physician-assisted death. After his fellowship, David plans to attend medical school at the University of Pennsylvania.

Leah Pierson is a pre-doctoral fellow in the Department of Bioethics. She is originally from Arlington, Virginia and graduated from Brown University in 2016 with an independent major in Human Rights. During the fellowship, she has explored topics in global health ethics and has focused in particular on priority setting for health research. This summer, she will begin an MD/PhD in Global Health and Population at Harvard Medical School and the Harvard T.H. Chan School of Public Health.

Robert Steel is a post-doctoral fellow in the Department of Bioethics. He completed a BA in philosophy at Stanford and a PhD in philosophy at the University of Pittsburgh. He wrote his dissertation in epistemology, on the proper treatment of higher order evidence. At the NIH, he is now working on a cluster of issues surrounding population ethics. His current research interests include reproductive ethics, measures of welfare, the moral status of future people, and personal identity and survival.

Haley Sullivan is a pre-doctoral fellow in the Department of Bioethics. She is from Raleigh, North Carolina and graduated from Duke University in 2016 with a major in neuroscience. During the fellowship, she has worked on projects including the return of genetic incidental findings in low-resource research settings, pregnant women's views on prenatal whole genome sequencing and the right-not-to-know genetic information.

ALUMNI UPDATES

Danielle Bromwich is continuing her work as an Associate Professor of Philosophy at the University of Massachusetts, Boston. Since her last update, she has finished two papers with Joseph Millum on consent (published in *Ethics and Ergo*) and got a dog named Brambles.

Dena Davis celebrated Christmas 2017 in Oaxaca, and then (Coptic) Christmas on January 7, 2018 in Lalibela, Ethiopia.

Colleen Denny finished her OB/GYN residency and is now starting as an attending position (Assistant Clinical Professor of OB/GYN, New York University School of Medicine) at Bellevue Hospital in Manhattan, New York.

Greer Donley is now a law clerk for Judge Robert Sack on the U.S. Court of Appeals for the Second Circuit. In August, she will be starting as an Assistant Professor at the University of Pittsburgh Law School, and she reports being "thrilled" to settle down with her husband, Zeke Rediker, in their new house in Squirrel Hill.

From Catie Gliwa: Hi everyone! I'm excited to let you know that I just matched into OB/GYN residency at UCLA, so I'll be staying out here for another four years. I would love to catch up if you are ever in LA!

From Sarah Gollust: I am still working hard raising two boys (now age 4 and 7), being a tenured associate professor, and helping to run a new national research program, the Robert Wood Johnson Foundation Interdisciplinary Research Leaders. I am still deeply engaged in ethics through my teaching. I teach a one-credit core MPH course on public health ethics and my students always teach me new ways of thinking about tough public health problems. I think of my NIH colleagues from 15+ years ago often!

Former fellow Rob Hughes is currently in his third year in the Legal Studies and Business Ethics Department at Wharton, where he is working on the ethics of paying people to take risks, ethical limits on law enforcement, and the question when (if ever) it is morally permissible to treat fines or other legal sanctions as costs of doing business. After four years of long-distance with his partner Matt (including two years of the fellowship), Rob and Matt moved in together and are planning on getting married next summer.



Samia Hurst-Majno is still working as an Associate Professor of Bioethics and Chair of the Institute for Ethics, History, and the Humanities at the University of Geneva, which moved to a new location last fall (shortening her commute). Her husband, who she married in 2016 (see photo, left) is now head of surgery for the canton of Ticino. From Samia: "Facetime is wonderful, and Swiss trains are even better. We still have a room to host any of you who come through Geneva."

Stellah Imot is working as the IRB Administrator for the Makerere University School of Health sciences IRB in Uganda. She hopes to pursue bioethics at the masters degree level in the future.

Owen Schaefer and his wife, Poh Lin, welcomed a baby Han Schaefer into the world on July 4, 2017. Han weighed in at just under 4.5kg at birth, and has been keeping his parents busy. Owen describe him as "quite energetic and good-natured, in addition to acting as a good weight-training exercise machine for his parents." Owen is working as a Research Assistant Professor at Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore.



Seema Shah accepted an endowed chair in Pediatrics at Northwestern Medical School and a position as the Associate Director of the Bioethics Program at Lurie Children's Hospital beginning in September. She will be leaving her current position as an Associate Professor, University of Washington & Seattle Children's Hospital. Seema also plans to continue to collaborate with Ben Wilfond and her other colleagues in Washington; and she looks forward to hosting some NIH bioethics alumni who are in the Chicago area.

David Shalowitz finished training and moved to Winston-Salem, NC to join the faculty at Wake Forest University as an assistant professor, Gynecologic Oncology and Implementation Science. He continues to work on health policy in access to gynecologic cancer care while serving as vice chair of the Committee of Ethics of the American College of OB/GYN.

Will Smith and his fiancée, Valerie, are getting married in June then moving to Philadelphia, where Will will be starting his research track residency in Psychiatry at the University of Pennsylvania. He anticipates working on resource allocation and conceptual issues at the foundations of psychiatric science. Will recently published an article from his dissertation on resource allocation online first on the Journal of Medical Ethics and hopes to publish more articles from his dissertation over the next few years.



Roseanna Sommers graduated from Yale with a JD/PhD in Psychology after six years. She defended her dissertation, "Deformed Consent," which she says drew heavily on my experience at the NIH. She will be headed next to a two-year fellowship at the University of Chicago Law School to teach legal writing to first-year law students while continuing research on the psychological and legal complexities of consent. Roseanna also provided a video of her oral defense:

<http://www.roseannasommers.com/dissertation>.

Rebecca Wolitz and her husband recently welcomed a baby boy, Elijah Emmett, into the world. Rebecca is currently a fellow at the Center for Law and the Biosciences, Stanford Law School.

