

2015 LDI Call for Proposals Senior Fellow Cover Sheet

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Mechanism of Support (please select one)
X Pilot Project Grant (Maximum budget of \$20,000)
Working Group Support (Maximum budget of \$10,000)
Title of Proposal: "Recovering Inside? Ethical Challenges in Correctional Mental Health Care"
Amount Request: \$20,000
Does this project involve the use of any of the following:
X Human subjects or animals? [Focus groups]
Radioactive material/radiation producing equipment?
Investigational new drugs or new devices?
Potentially infectious agents, including human blood or tissue?
Carcinogens?
In vitro formation of recombinant DNA?
Note: As a condition of funding, PIs of all approved proposals must submit a letter from the university office of research administration that on the content of the conten
Signatures
Principal Investigator:
Department Chair: Date:11/4/2015

"Recovering Inside? Ethical Challenges in Correctional Mental Health Care"

A pilot project proposal to the Leonard Davis Institute of Health Economics

Principal Investigator

Dominic Sisti, PhD

Co-Investigator

Chris Feudtner, MD, PhD (CHOP, PSOM)

Confirmed Research Group Members

- 1. Kathleen Brown, PhD (Penn Nursing)
- 2. Philip Candilis, MD (St. Elizabeth's Hospital)
- 3. Samson Gurmu, MD (NJ State Corrections)
- 4. Michelle Joy, MD (PSOM)
- 5. Jonathan Moreno, PhD (PSOM)
- 6. Cyndi Reed Rickards, EdD (Inside-Out, Drexel University)
- 7. Andrea Segal, MS (PSOM)
- 8. Tyrone Werts (Inside-Out, Temple University)

If this proposal is funded, we will invite Nneka Jones Tapia, PsyD., Executive Director of the Cook County Department of Corrections. Appointed by Sheriff Tom Dart, Dr. Jones Tapia runs Cook County Jail and considers it a mental health care facility. We will also invite Jeffrey Metzner, MD, Program Director of Forensic Psychiatry at the University of Colorado School of Medicine, an authority on correctional and forensic psychiatry.

Abstract

We propose the creation of a yearlong pilot research project that aims to systematically identify and examine ethical issues related to mental health care provided in prisons and jails. This project is both novel and urgent. Bioethicists have largely overlooked the area of correctional mental health care despite the fact that there are currently over 1 million individuals incarcerated who have a mental illness and a significant subpopulation who have a serious mental illness such as schizophrenia or bipolar disorder. Key outcomes of this project will be threefold: (1) the collection and distillation of a research agenda for bioethicists to address overlooked issues in correctional mental health care to be published in a peer-reviewed journal, (2) the analysis of existing policies guiding correctional mental health care and those aimed at reducing the number of individuals with serious mental illness in prisons and jails, and (3) dissemination through publications and conference presentations at the American Psychiatric Association's Annual Meeting in May 2016 and the American Society for Bioethics and Humanities in October 2016.

Description

Synopsis

There are approximately 2.6 million people incarcerated in the US, which equates, by far, to the world's highest incarceration rate (~700/100,000 people). It is estimated that 50% of inmates of jails and prisons have a mental illness, and 15-20% have a serious mental illness (SMI). The reasons and causes of the criminalization of mental illness are manifold (1-3). We argue that a shadow health care system now exists behind bars in the US, with a substantial amount of behavioral health care delivered there.

Regrettably, biomedical ethicists have largely ignored this reality. We aim to change this fact.

By convening an interdisciplinary research group that includes bioethicists, clinicians, prison reform advocates, and (at least) one former inmate, we propose to develop a novel line of bioethics research to examine ethics and policy questions in correctional mental health care. In broad strokes, we know these issues will be related to inmate privacy, access to inpatient hospitalization, triage and caseloads, medication for institutional control, participation in research, reentry preparation, and the dual agency of mental health care providers.

As part of this project, we will examine current policies that guide correctional mental health care. Additionally, we will analyze interventions that aim to reduce the number of mentally ill individuals in prison.

Principal Objectives, Significance, Impact

The objectives for this pilot project are threefold: (1) the collection, distillation, and publication of a research agenda for bioethicists to address overlooked issues in correctional mental health care, (2a) the analysis of policies inside jails and prisons that guide mental health care and (2b) policies outside of jails and prisons aimed at reducing the number of incarcerated individuals with serious mental illness, and (3) dissemination of the work group's findings in peer-reviewed papers and conference presentations.

The first key objective of this pilot project will be to develop a research agenda for bioethicists to begin to examine the ethical challenges of providing mental health care inside prisons and jails. Professional medical ethicists have largely ignored this medical setting—a lack of attention that is evidenced by the significant gap in the literature. The writing on ethics in correctional mental health care has been limited to a few book chapters and one anthology. (4, 5) There is only one journal of record in correctional health care—the quarterly *Journal of Correctional Health Care*—and there is no evidence of a sustained engagement with this field by bioethicists. Given the magnitude of the problem and increasing national attention to the suboptimal treatment of incarcerated mentally ill individuals, we believe that our work in this area has the potential for significant scholarly and policy impact.

The second objective will be to systematically examine the current policies guiding correctional mental health care, pinpointing policies that may lead to ethically questionable practices on the inside. On the outside, mental health courts are now often viewed as primary access points for intensive mental health care. Some argue that these diversion programs actually perpetuate the abdication of caring for mentally ill individuals from the health care system to the criminal justice system. We will study and assess this possibility. We will analyze how federal policy proposals—particularly "The Helping Families in Mental Health Crisis Act of 2015" (H.R. 2646)—may improve access for individuals with SMI to help them avoid prison.

The third objective will be to broadly disseminate the findings of the research group in a peer-reviewed bioethics journal. Members of our research group will present early findings at the American Psychiatric Association's Annual Meeting in May 2016 and, tentatively, the American Society for Bioethics and Humanities in October 2016. We will ask all research group members to present information about this project to their respective professional societies and communities, in both formal venues (conferences, publications) and through social media. We will leverage our close working relationship with mental health reporters to amplify this project's impact, with the goal of attracting the attention of funders. The support of the Leonard Davis Institute will be acknowledged in all published work, presentations, and media interactions.

Research & Data Collection Plan

In phase one, the research group will hold two 2-hour discovery meetings to develop a preliminary conceptual map of ethical issues, develop focus group structures, and qualitative prompts.

In phase two, a series of focus groups (3-5) will be facilitated to develop an "ethics map" of salient issues in correctional mental health care from the perspective of providers and inmates. Focus groups will include various stakeholder groups from the community, workers from correctional facilities, inmates or their surrogates, and clinicians. Using qualitative methods—including freelisting and open-ended survey prompts—emergent themes will be examined and analyzed. These data will be used to both supplement the working group's deliberations and will provide empirical relief to the conceptual findings of the group.

In phase 3, the research group will convene two 2-hour meetings to analyze focus group data, finalize the ethics agenda, and develop policy proposals.

Next Steps

In fall 2016, we will seek continuing support based upon the findings of the research group. There are several promising philanthropic avenues for funding, including the Greenwall Foundation, the Ford Foundation, Open Society Foundations, and the Rosenberg Foundation.

Timetable

The research group will begin work in January 2016 and proceed through three phases:

- 1. January April 2016: Research and discovery, focus group planning
- 2. May September 2016: Focus group execution
- October December 2016: Analysis of focus group data, writing and submission of manuscripts(s)

Budget

	Description	Cost
Project manager	Defray salary of research coordinator who will conduct literature review, and assist with IRB submission, focus group facilitation, manuscript preparation, & dissemination of relevant materials to work group members.	\$7,000
Administrative coordinator	Defray cost of assistance with meeting scheduling, focus group coordination, media relations, & social media management.	\$7,000
Research group meetings	Defray costs of four working group meetings, conference travel, & participant honoraria.	\$3,000
Focus group meetings	Cost for focus group supplies, remuneration of participants, recording, transcription, and coding.	\$3,000
Total		\$20,000

References

- 1. Sisti DA, Segal AG, Emanuel EJ. Improving long-term psychiatric care: bring back the asylum. JAMA. 2015;313(3):243-4.
- 2. Blair TR, Espinoza RT. Medicare, medicaid, and mental health care: Historical perspectives on reforms before the US congress. JAMA. Online First, October 19, 2015. Epub October 19, 2015. doi: 10.1001/jama.2015.13328.
- 3. Lamb HR, Weinberger LE. The shift of psychiatric inpatient care from hospitals to jails and prisons. Journal of the American Academy of Psychiatry and the Law. 2005;33(4):529-34.
- 4. Konrad N, Völlm B, Weisstub DN. Ethical Issues in Prison Psychiatry: Springer; 2013.
- 5. Trestman R, Appelbaum K, Metzner J. Oxford Textbook of Correctional Psychiatry: Oxford University Press; 2015.

BIOGRAPHICAL SKETCH

NAME	: SISTI	DOM	IINIC.
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eRA COMMONS USER NAME (agency login): SISTID

POSITION TITLE: Assistant Professor of Medical Ethics

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Villanova University	BS	05/1996	Biology
University of Pennsylvania	MBe	12/2000	Bioethics
Georgetown University	Fellow	05/2008	Clinical Bioethics
Michigan State University	PhD	08/2010	Philosophy/Bioethics

A. Personal Statement

My role in this pilot project is that of PI. This project aims to build an ethics and policy program on correctional mental health care. I am an assistant professor of medical ethics and psychiatry. I direct an extramurally funded research program, the Scattergood Program for Applied Ethics in Behavioral Health Care, which focuses on the ethical, legal, and policy dimensions of mental health care. My research includes philosophical analyses that aim to clarify the concept of mental disorder, answering the ethical, legal, and social challenges of diagnostic category creation and revision, such as in the recent revision of the DSM and NIMH's RDoC initiative. I have worked in close collaboration with psychiatrists, biomedical researchers, social scientists, and philosophers and have published several peer-reviewed papers that integrate the methods of these disciplines. I am coeditor of a reader on the ethics of behavioral health care. I have developed and twice taught a graduate level course, "Ethics in Mental Health Care". I hold a secondary appointment in the Department of Psychiatry, where I developed and teach the ethics curriculum for residents across four years of training. I have mentored one psychiatry resident and we have published two papers together. For the past five years, I have organized and facilitated an ethics track for the American Psychiatric Association's annual meetings. Because of these experiences I fell well prepared to lead this project. My recent scholarship related to psychiatric health services and particularly long-term psychiatric care touches on issues relevant to correctional mental health care. I have been a guest lecturer in an Inside/Out course at Curran-Fromhold Correctional Facility. I am in a position now to begin to expand this area of ethics and policy research. Recent relevant publications include:

- 1. Sisti, Dominic A., and Arthur L. Caplan. "Accommodation without exculpation? The ethical and legal paradoxes of borderline personality disorder." *The Journal of Psychiatry & Law* 40.1 (2012): 75-92.
- 2. Sisti, Dominic A., Andrea G. Segal, and Ezekiel J. Emanuel. "Improving long-term psychiatric care: bring back the asylum." *JAMA* 313.3 (2015): 243-244.
- 3. Sisti, Dominic A. and Chethan Ramamurthy. "From Alienism to ACOs: Integrating Psychiatry, Again." *Psychiatric Services*, December (In Press)

B. Positions and Honors

Positions and Employment

2002	Adjunct Instructor, Rutgers University-Camden, Camden, NJ
2003-2004	Adjunct Instructor, Villanova University, Villanova, PA
2005-2010	Research Associate, Center for Bioethics University of Pennsylvania,
2005-2010	Teaching Assistant and Course Instructor, Michigan State University
2010-2012	Senior Fellow, Center for Bioethics, University of Pennsylvania
2012-2013	Adjunct Assistant Professor of Ethics in Psychiatry, University of Pennsylvania School of Medicine
2013-present	Assistant Professor of Medical Ethics and Health Policy at the Hospital of the University of
	Pennsylvania, University of Pennsylvania School of Medicine
2013-present	Assistant Professor of Psychiatry, University of Pennsylvania School of Medicine (Secondary)
2015-present	Associate Fellow, Penn Center for Public Health Initiatives
2015-present	Senior Fellow, Leonard Davis Institute of Health Economics

Other Experience and Professional Memberships

1998-Present	American Society for Bioethics & Humanities (Chair, Mental Health Ethics Affinity Group,
	(2012- 2014))
2009-2013	American Philosophical Association (Member)
2009-Present	Association for the Advancement of Philosophy & Psychiatry (Member)
2010-2012	Data Safety Monitoring Board, PTSD Treatment Trial (DSMB Member)
2010-2013	Ethics Consultant, Protocol Development Team, Naltrexone vs. Buprenorphine Trial Design
	(Ethics Consultant)

2015-Present Group for the Advancement of Psychiatry (GAP) (Ittleson Consultant, Professionalism and

Ethics Committee)

2015-Present Multidisciplinary Association for Psychedelic Studies (MAPS) (Ethics Consultant)

Honors

2008 Michigan State University, Merit Fellowship

2009 American Society for Bioethics and Humanities, Early Career Scholar Support

2010 Michigan State University, Dissertation Completion Award
2011 University of Pennsylvania, LeadingSuccess Program

C. Contribution to Science

- 1. Advancing ethical long term psychiatric care: I coauthored a Viewpoint with Ezekiel Emanuel and Andrea Segal that was published in JAMA in January 2015. This paper, entitled, "Improving Long-Term Psychiatric Care: Bring Back the Asylum" created a firestorm of controversy evidenced by letters to JAMA and media interest. It was the central theme of an opinion piece in the New York Times in February 2015. As of September 23, 2015 this paper has garnered over 12,300 views and an Altmetric score of 223, placing it in the top 5% of all articles scored by Altmetric. It is fair to say that this short paper has significantly disrupted the status quo and conventional discourse about the appropriate role of psychiatric hospitalization and mass incarceration of individuals with serious mental illness.
- 2. Combined conceptual and empirical projects related to clinical ethics and professionalism in mental health care: Employing both conceptual analysis and empirical methods, I have sought to examine ethically questionable practices in clinical mental health care. An example is the forthcoming paper, "Diagnosing, Disclosing, and Documenting Borderline Personality Disorder: A Survey of Psychiatrists' Practices" in the *Journal of Personality Disorders*. The impetus of this research was anecdotal evidence that clinicians are not totally forthright with patients who have borderline personality disorder (BPD), which is a highly stigmatized mental disorder.
- 3. Translating philosophical theories into pragmatic arguments related to behavioral health research, treatment, and policy: In a series of papers I have aimed to translate and apply philosophical theories to real-life problems in behavioral health care. During the run up to the publication of the DSM-5, I was active and engaged in the conversation about the controversial category changes. I gave several talks at national conferences, both peer-reviewed and invited, and delivered grand rounds on the philosophical and ethical dimensions of revising the psychiatric nosology. My work at that time yielded a suite of peer-reviewed publications and editorials pertaining to the complexity of the concept of mental disorder and the DSM-5.

D. Research Support

Ongoing Research Support

Sponsor: Greenwall Foundation

Dominic Sisti (PI) 07/01/2015-07/01/2016

The Prodromal Schizophrenia Ethical and Empirical Nexus: Normative Implications

Role: PI

Sponsor: The Thomas Scattergood Behavioral Health Foundation

Dominic Sisti (PI) 07/01/2013-06/30/2019

The Scattergood Program For Applied Ethics Of Behavioral Health Care: Phase 2

Role: PI

Completed Research Support

Sponsor: The Leonard Davis Institute

Arthur Caplan (PI) 01/01/2011-12/31/2011

Categories and Controversies: The Ethical Dimensions of the DSM-5

Role: Sub-PI; Project Lead

Sponsor: The Thomas Scattergood Foundation

Arthur Caplan (PI) 09/01/2010-12/31/2013

The Scattergood Program for Applied Ethics of Behavioral Healthcare

Role: Sub-PI; Program Director

BIOGRAPHICAL SKETCH

NAME: FEUDTNER, CHRIS

eRA COMMONS USER NAME (agency login): feudtner

POSITION TITLE: Professor of Pediatrics, Medical Ethics and Health Policy

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Princeton University, Princeton, NJ	BA	1985	Molecular Biology
Lancaster University, Lancaster, England	MA	1987	History of Science
University of Pennsylvania, Philadelphia, PA	MD	1995	Medicine
University of Pennsylvania, Philadelphia, PA	PHD	1995	History of Medicine
University of Washington, Seattle, WA	MPH	2000	Health Services

A. PERSONAL STATEMENT

Although I have devoted my career to pediatrics, my initial interests in medicine were in the field of psychiatry, and I have continued to be drawn to the clinical, social, cultural, and ethical challenges of providing adequate care for people with mental illness. My first published paper was on the history of the epidemic of shell shock among British troops in the First World War, and I have been involved in several studies of mental health issues and care for vulnerable children, most recently regarding the care of children with mental health conditions hospitalized for medical illnesses (in press). This background set of interests also combines, in the current proposal put forward by Dr. Sisti, with my concerns based on many conversations I have had with my wife (who is the medical director of Project H.O.P.E. in Camden) regarding the care of homeless individuals with mental illness who are often incarcerated for periods of time, disrupting their psychiatric care. For these reasons, I am keen to participate in this important project under the leadership of Dr. Sisti to map out the important ethical concerns regarding mental health care needs and treatment within the correctional system of justice. This project will change the dialogue about correctional mental health.

- 1. Feudtner C. "Minds the dead have ravished": shell shock, history, and the ecology of disease-systems. Hist Sci. 1993 Dec;31(94 pt 4):377-420. PubMed PMID: 11623374.
- 2. Rubin DM, Alessandrini EA, Feudtner C, Mandell DS, Localio AR, Hadley T. Placement stability and mental health costs for children in foster care. Pediatrics. 2004 May;113(5):1336-41. PubMed PMID: 15121950.
- 3. Guevara JP, Feudtner C, Romer D, Power T, Eiraldi R, Nihtianova S, Rosales A, Ohene-Frempong J, Schwarz DF. Fragmented care for inner-city minority children with attention-deficit/hyperactivity disorder. Pediatrics. 2005 Oct;116(4):e512-7. PubMed PMID: 16199679; PubMed Central PMCID: PMC1255962.
- 4. Matone M, Localio R, Huang YS, dosReis S, Feudtner C, Rubin D. The relationship between mental health diagnosis and treatment with second-generation antipsychotics over time: a national study of U.S. Medicaid-enrolled children. Health Serv Res. 2012 Oct;47(5):1836-60. doi: 10.1111/j.1475-6773.2012.01461.x. Epub 2012 Sep 4. PubMed PMID: 22946905; PubMed Central PMCID: PMC3513608.

B. POSITIONS AND HONORS

Positions and Employment

1998 - 2000	Fellow, Robert Wood Johnson Clinical Scholars Program, University of Washington
2000 - 2002	Acting Assistant Professor, Department of Pediatrics, University of Washington
2001 - 2002	Assistant Professor, Department of Pediatrics, University of Washington
2002 - 2010	Assistant Professor of Pediatrics, University of Pennsylvania School of Medicine
2008 -	Director, Department of Medical Ethics, The Children's Hospital of Philadelphia
2010 -	Director, Academic General Pediatrics Fellowship, Penn School of Medicine
2010 - 2014	Associate Professor of Pediatrics, University of Pennsylvania School of Medicine
2014 -	Professor of Pediatrics, Medical Ethics and Health Policy, Penn School of Medicine
2015 -	Associate Division Chief, Division of General Pediatrics, The Children's Hospital of Philadelphia

Other Experience and Professional Memberships (select)

2009 - 2010	Member, Study Section for Healthcare Quality and Effectiveness Research, AHRQ
2010 -	Editorial board member, American Journal of Bioethics – Primary Research
2014 -	Chair, Executive Committee, Section of Hospice and Palliative Medicine, AAP
2014 -	Standing Member, Study Section for National Institute of Nursing Research, NIH

Honors (select)

2008	Steven D. Handler Endowed Chair of Medical Ethics, The Children's Hospital of Philadelphia
2011	Leonard Tow Humanism in Medicine Award, Arnold P. Gold Foundation
2011	Samuel Martin Health Evaluation Sciences Research Award, University of Pennsylvania
2012	CHOP Mentor Award, The Children's Hospital of Philadelphia
2013	Cunniff-Dixon Physician Award, The Hastings Center
2014	Fellow, The Hastings Center

C. Contribution to Science

Full list of 200+ published articles is available via MyBibliography:

- 1. Pediatric Palliative Care, Parental Decisionmaking: I have championed the conduct of prospective cohort studies of parental decision-making in pediatric palliative care, employing a mixed methods approach. Through these studies, we have substantially advanced our understanding of the "real time" psychology of how parents conceive of the decisions they are being asked to make, and the influence (and complexity) of emotions and a sense of duty to be a "good parent" on these decisions.
 - a. Hexem KR, Mollen CJ, Carroll K, Lanctot DA, Feudtner C. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. J Palliat Med. 2011 Jan;14(1):39-44. PubMed PMID: 21244252; PubMed Central PMCID: PMC3021326.
 - b. Renjilian CB, Womer JW, Carroll KW, Kang TI, Feudtner C. Parental explicit heuristics in decision-making for children with life-threatening illnesses. Pediatrics. 2013 Feb;131(2):e566-72. PubMed PMID: 23319524; PubMed Central PMCID: PMC3557409.
 - c. Hexem KR, Miller VA, Carroll KW, Faerber JA, Feudtner C. Putting on a happy face: emotional expression in parents of children with serious illness. J Pain Symptom Manage. 2013 Mar;45(3):542-51. PubMed PMID: 22926092; PubMed Central PMCID: PMC3510342.
 - d. Feudtner C, Walter JK, Faerber JA, Hill DL, Carroll KW, et al. Good-parent beliefs of parents of seriously ill children. JAMA Pediatr. 2015 Jan 1;169(1):39-47. PubMed PMID: 25419676.
- 2. Pediatric Palliative Care, Epidemiology and Health Services Research: Over the past 15 years, I have conducted (or collaborated on) most of the "big data" studies of pediatric palliative care, and have written the chapters on these topics in all of the major pediatric palliative care textbooks. This line of work has been instrumental in building the argument for the need for pediatric palliative care services, and characterizing the nature of these needs.
 - a. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, et al. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. Pediatrics. 2001 Jun;107(6):E99. PubMed PMID: 11389297.
 - b. Feudtner C, Feinstein JA, Satchell M, Zhao H, Kang TI. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. JAMA. 2007 Jun 27;297(24):2725-32. PubMed PMID: 17595273.
 - c. Feudtner C, Kang TI, Hexem KR, Friedrichsdorf SJ, Osenga K, et al. Pediatric palliative care patients: a prospective multicenter cohort study. Pediatrics. 2011 Jun;127(6):1094-101. PubMed PMID: 21555495.
 - d. Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, et al. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. Pediatrics. 2013 Dec;132(6):1063-70. PubMed PMID: 24190689.