

MENTAL HEALTH, LEGAL CAPACITY, AND HUMAN RIGHTS

Since adoption of the Convention on the Rights of Persons with Disabilities and the interpretive General Comment 1, the topic of legal capacity in mental health settings has generated considerable debate in disciplines ranging from law and psychiatry to public health and public policy. With over 180 countries having ratified the Convention, the shifts required in law and clinical practice need to be informed by interdisciplinary and contextually relevant research as well as the views of stakeholders. With an equal emphasis on the Global North and Global South, this volume offers a comprehensive, interdisciplinary analysis of legal capacity in the realm of mental health. Integrating rigorous academic research with perspectives from people with psychosocial disabilities and their caregivers, the authors provide a holistic overview of pertinent issues and suggest avenues for reform.

Michael Ashley Stein is the Executive Director of the Harvard Law School Project on Disability, and a visiting professor at Harvard Law School. Considered one of the world's leading experts on disability law and policy, Stein participated in the drafting of the UN Convention on the Rights of Persons with Disabilities; works with disabled peoples' organizations and non-governmental organizations around the world; actively consults with governments on their disability laws and policies; advises an array of UN bodies and national human rights institutions; and has brought landmark disability rights litigation globally.

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Mental Health, Legal Capacity, and Human Rights

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CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press
978-1-108-83885-6 — Mental Health, Legal Capacity, and Human Rights
Edited by Michael Ashley Stein, Faraaz Mahomed, Vikram Patel, Charlene Sunkel
Frontmatter
[More Information](#)

CAMBRIDGE UNIVERSITY PRESS

University Printing House, Cambridge CB2 8BS, United Kingdom
One Liberty Plaza, 20th Floor, New York, NY 10006, USA
477 Williamstown Road, Port Melbourne, VIC 3207, Australia
314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre,
New Delhi – 110025, India
103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of the University of Cambridge.

It furthers the University's mission by disseminating knowledge in the pursuit of education, learning, and research at the highest international levels of excellence.

www.cambridge.org

Information on this title: www.cambridge.org/9781108838856

DOI: 10.1017/9781108979016

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First published 2021

A catalogue record for this publication is available from the British Library.

Library of Congress Cataloging-in-Publication Data

NAMES: Stein, Michael Ashley, editor. | Mahomed, Faraaz, 1985– editor. | Patel, Vikram, editor. | Sunkel, Charlene, editor.

TITLE: Mental health, legal capacity, and human rights / edited by Michael Ashley Stein, Harvard Law School, Massachusetts; Faraaz Mahomed, Wits University; Vikram Patel, Harvard Medical School; Charlene Sunkel, Global Mental Health Peer Network.

DESCRIPTION: Cambridge, United Kingdom ; New York, NY : Cambridge University Press, 2021. | Includes bibliographical references.

IDENTIFIERS: LCCN 2021010113 (print) | LCCN 2021010114 (ebook) | ISBN 9781108838856 (hardback) | ISBN 9781108972451 (paperback) | ISBN 9781108979016 (ebook)

SUBJECTS: LCSH: Mental health laws. | Mental health policy. | Convention on the Rights of Persons with Disabilities and Optional Protocol (2007 March 30)

CLASSIFICATION: LCC K3608 .M468 2021 (print) | LCC K3608 (ebook) | DDC 346.01/30874–dc23

LC record available at <https://lccn.loc.gov/2021010113>

LC ebook record available at <https://lccn.loc.gov/2021010114>

ISBN 978-1-108-83885-6 Hardback

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The Banyan Authors – Chapter 7 is authored by five human service professionals from The Banyan. All five of us are engaged with mental health systems in one way or the other as mental health professionals, peer leaders, policy level contributors, researchers, and social entrepreneurs.

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Dorrit Cato Christensen worked as a pediatrician for ten years, then as teacher of Danish as a foreign language at a school for refugees and the Danish Center for Torture Victims. In 1972 she gave birth to her lovely daughter Luise, who would be in the psychiatric treatment system for twelve years. Ms. Christensen participated in all sorts of forums around Luise's treatment. For many years she was a member of the municipal psychiatric forum in Copenhagen, representing as a relative of a mentally ill person. She set up relatives' groups – for example, at Luise's different residential centers. All that stopped when Luise sadly died in 2005. A few years after Luise's death she started an association called Dead in Psychiatric Care (DiP), where she was chair. Her presidency lasted until she stepped down in November 2020. As chair, she was a member of three different public associations on psychiatry. In 2017 DiP became a member of Mental Health Europe (MHE) (Ms. Christensen is now an individual member of MHE). Over her ten years as chair of DiP, Ms. Christensen

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Charlotte Hanlon is a reader in global mental health and co-director of the WHO Collaborating Centre for Mental Health Research and Training, IoPPN, at King's College London and an adjunct associate professor at the Department of Psychiatry, Addis Ababa University (AAU) in Ethiopia, where she lives. The main focus of Dr. Hanlon's work is on service interventions, implementation research and systems strengthening to support increased access to mental health care in low- and middle-income countries, particularly for people with severe mental conditions. Ensuring involvement of people with lived experience and local communities is a key part of her work.

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Elizabeth Kamundia works as an assistant director in the Research, Advocacy and Outreach Directorate at the Kenya National Commission on Human Rights and leads the Commission's work on rights of persons with disabilities. She holds an LLD from the Faculty of Law, University of Pretoria (2019). Her thesis is entitled "Supported decision-making as a human rights principle in mental health care: An international and comparative analysis". She holds an LLM in international and comparative disability law and policy from the Centre for Disability Law and Policy National University of Ireland, Galway (NUI Galway). Elizabeth has worked as a disability rights consultant with users and survivors of psychiatry in Kenya. In this role, she led research on the link between peer support and the exercise of legal capacity by persons with psychosocial disabilities in the Kenyan context. In addition to a research background, Elizabeth also approaches mental health from the

perspective of a family member. Elizabeth has worked at the Centre for Disability Law and Policy, NUI Galway (Legal Researcher) and the Centre for Human Rights, University of Pretoria (Disability Rights and Law Schools Project Coordinator). She has also worked at the Commission on the Implementation of the Constitution of Kenya (Consultant on Disability) and the Committee of Experts on Constitutional Review, Kenya (Legal Researcher). Elizabeth is an advocate of the High Court of Kenya.

Arjun Kapoor is a Research Fellow at the Centre for Mental Health Law & Policy at the Indian Law Society, Pune, India. He holds a bachelor's degree in law from NALSAR University of Law, Hyderabad and a master's degree in psychology (psycho-social clinical studies) from Ambedkar University, Delhi. Previously, he was appointed as Law Clerk to the Supreme Court of India and assisted the Court in matters of constitutional law and public law. Subsequently, he worked with community lawyers and paralegals in Gujarat, India to develop socio-legal interventions on access to justice and socio-economic rights. At the Centre, he co-leads various projects on law, policy, and services reform for mental health and youth suicide prevention. He provides technical support and leads capacity initiatives for a range of stakeholders on implementation of the Mental Healthcare Act, 2017 and National Mental Health Policy, 2014 using rights-based approaches. He also works with various stakeholders in India's mental health system to build a repository of data and information on mental health laws, policies, and services to promote evidence-based policy making for mental health and suicide prevention.

Kimberly Lacroix has been leading the Seher Community Mental Health and Inclusion Program for the last three years. Having trained in psychoanalytic psychotherapy and clinical thinking, she engages with the question of community mental health from an intersectional and social justice perspective. Her research is informed by both practice and thinking about practices in mental health from a critical feminist and, more recently, disability rights perspective. Through her work under the Seher program she has been engaging in questions about disabilities and cross-disability research and advocacy.

Faraaz Mahomed is a clinical psychologist and public health scholar working in the field of mental health and human rights. He received an MA in clinical psychology from the University of the Witwatersrand, Johannesburg, South Africa and an MA in international policy from the Middlebury Institute of International Studies in Monterey, California as a Fulbright Scholar. He received a Doctor of Public Health degree from the Harvard School of Public Health, is a research associate at the Harvard Law School Project on Disability and the FXB Center for Health and Human Rights at Harvard, and a visiting research fellow at the Center for Applied Legal Studies at the University of the Witwatersrand. He has worked as a researcher with the Office of the UN Special Rapporteur on the Right to Health and as

a research consultant on financing for rights-based approaches to mental health in the Global South with the Open Society Foundations. He previously held the positions of Senior Researcher for Equality at the South African Human Rights Commission and Clinical Psychologist in community health settings in Johannesburg and Cape Town, South Africa, and currently holds the position of Program Officer in Mental Health and Rights at the Open Society Foundations.

Steven Manning is a Fort Wayne, Indiana native who has been a member of the Carriage House Clubhouse in Fort Wayne since 2002. Prior to joining the clubhouse, he was hospitalized several times. He went through a stint of homelessness, and there were about four suicide attempts. After becoming involved regularly at Carriage House, Mr. Manning experienced a wonderful transformation; in about ten years he was able to complete his master's degree in secondary education. He also started a video production company, a business venture that continues to grow and improve. Steven's love for performance on stage and screen has resulted in him receiving roles in feature-length movies. His most recent film, entitled *I Only Want You*, is currently in production in southern Indiana. Steven will play the role of Sheriff Hap Jenkins in this intense drama. It will be his fourth movie and largest role so far. Steven says, "without my faith and without the love and support from members and staff at the Carriage House, there's absolutely no way I would be living such a wonderful life. It will be my life's work to be an advocate for men, women, and children, who suffer from severe and persistent mental illness; helping them experience all the love, support, and opportunities that they deserve to have."

Jonathan Martinis is the Senior Director for Law and Policy for the Burton Blatt Institute at Syracuse University, leading its efforts to ensure that older adults and people with disabilities have access to the services and support they need to lead independent, inclusive lives.

Tina Minkowitz is a lawyer based in the United States who works on the international human rights of persons with disabilities, focusing on the rights of persons with psychosocial disabilities and the universal right to legal capacity. She contributed significantly to the drafting of the Convention on the Rights of Persons with Disabilities, in particular to Articles 12 and 14, among others, and was among the leaders of the International Disability Caucus. Ms. Minkowitz participates in the global movement of users and survivors of psychiatry and persons with psychosocial disabilities, and represented the World Network of Users and Survivors of Psychiatry in the CRPD drafting process and in other UN processes for some years afterwards. In 2009 she founded the Center for the Human Rights of Users and Survivors of Psychiatry, which she still serves in the capacity of President. She regularly contributes to the work of the Committee on the Rights of Persons with Disabilities and other UN human rights mechanisms, and has contributed to the work of the OAS on legal capacity and support measures. She maintains contact with networks in all parts of the

world and provides advice and support to disabled people's organizations in their work of implementing and monitoring the Convention. She received an LLM in Public International Law from the University of Oslo, and has written numerous articles, blog posts, and advocacy papers related to legal capacity and related issues.

Melita Murko is a psychologist from Bosnia and Herzegovina with over twenty years of experience in the field of mental health at the national, regional and international level. Two largest projects she worked on in the past were the Mental Health Project for south-eastern Europe, implemented under the Stability Pact's Social Cohesion Initiative from 2002 to 2008, and the WHO European Declaration *Better health, better lives: children and young people with intellectual disabilities and their families*, endorsed by the Regional Committee in Azerbaijan in 2011. Since June 2016 Melita has been working for the WHO Regional Office for Europe as a technical officer with the Mental Health Programme.

Iregi Mwenja is a mental health advocate with childhood lived experience. He grew up in rural Kenya where he faced the social challenges of growing up with undiagnosed ADHD. He received his diagnosis as an adult, a revelation that became a turning point in his life. Though an accomplished wildlife biologist, he left a well-paid job as a country director of an international NGO to establish a mental health nonprofit: Psychiatric Disability Organization (PDO). PDO works to foster mental healthcare for the socially disadvantaged in Kenya. Through PDO, thousands of Kenyans have received affordable mental healthcare and the much-needed social support.

Joyce Nato obtained her MD degree from the University of Nairobi (Kenya) and an MMed (Psych) from the University of Nairobi (Kenya). She worked with the Ministry of Health at all levels, including national level, where she was head of the division of noncommunicable diseases (NCDs). She later joined the WHO Country Office as the National Professional Office (NPO) in charge of prevention and control of NCDs, mental health, disability, tobacco control, and violence and injury prevention. In 2006, she held brief for the Regional Advisor on Tobacco Control for a period of seven months (April to October 2006) in Brazzaville, Congo. She has supported the government to prioritize NCDs. Some of the achievements include ratification, domestication and implementation of the WHO Framework Convention on Tobacco Control. Documents in place include the National NCDs Prevention and Control Strategy, Mental Health Policy, Injury and Violence Prevention Strategy, Cancer Control Strategy and Cancer Treatment Guidelines, and the Physical Activity Action Plan. She's a member of the recently launched Mental Health Task Force to look into issues of mental health in the country following a presidential directive.

Shain Neumeier is a lawyer, activist, and community organizer, as well as an out-and-proud member of the disabled, trans, queer, and asexual communities. Their passion on the issue of ending abuse and neglect of youth with disabilities in schools

and treatment facilities stems from their own experiences with involuntary medical treatment and bullying, and led them to go to law school. They have pursued their goal of using legal advocacy to address these problems ever since. Currently, Shain is a Trial Attorney in the Commitment Defense Unit of Massachusetts' Committee for Public Counsel Services' Mental Health Litigation Division. Shain previously worked with the Intersex & Genderqueer Recognition Project, the Autistic Women & Nonbinary Network, and the Community Alliance for the Ethical Treatment of Youth. They have volunteered with the Southern Immigrant Freedom Initiative, the People's Parity Project, and Capital Area Against Mass Incarceration. As a solo practitioner in Massachusetts, they specialized in defending disabled people against involuntary commitment and guardianship, and earlier worked on a series of cases against an abusive residential treatment facility in Oregon. Shain's writing appears in *Autistic Activism and the Neurodiversity Movement: Stories from the Frontlines, Resistance and Hope: Essays by Disabled People: Crip Wisdom for the People, Rewire News*, and *Loud Hands: Autistic People, Speaking*. Their work has been featured by the New England Center for Investigative Reporting, *American Bar Association Journal*, *Pacific Standard*, *The Nation*, WGBH, and MassLive. Among other honors, they were named the Massachusetts Bar Association's Outstanding Young Lawyer in 2018, the Self Advocacy Association of New York State's Self Advocate of the Year in 2017, and the Association of University Centers on Disabilities' Leadership in Advocacy Awardee in 2015. When not working, they're probably crafting, playing Dungeons & Dragons, listening to history podcasts, or watching Netflix with their partner and three feline roommates.

Gerald L. Neuman is the J. Sinclair Armstrong Professor of International, Foreign, and Comparative Law at Harvard Law School, and Director of its Human Rights Program. He teaches human rights, constitutional law, and immigration and nationality law. From 2011 to 2014, he was a member of the Human Rights Committee, the treaty body that monitors compliance with the International Covenant on Civil and Political Rights. He served previously on the faculty of Columbia Law School (1992–2006), and the University of Pennsylvania Law School (1984–1992). He is a member of the American Academy of Arts and Sciences.

Aikaterini Nomidou – Being an active carer to her brother who lives with schizophrenia and seeing the problems faced by families trying to cope with mental illness consequences – and the unfairness of the situations service users find themselves in – prompted Aikaterini to become actively involved in the mental health issues that affect vulnerable people and society as a whole. Following a degree in Italian language and literature at Aristotle University and a degree in law at Democritus University of Thrace, she received a postgraduate degree in mental health, law and human rights from the Indian Law Society. Her area of passion and expertise

includes the use of the WHO QualityRights toolkit and package of training and guidance modules to assess quality and human rights in mental health and social care facilities, and to build capacity among key stakeholders. Aikaterini is a practicing lawyer; WHO PFPS Champion for Greece; Secretary General of the Global Alliance of Mental Illness Advocacy Networks, GAMIAN-Europe; President of the Greek Federation of Associations/Organizations for Mental Health, POSOPSI; Vice-president of the Association for Mental Health and Alzheimer's disease, SOFPSI N.SERRON; and a visiting lecturer in compassionate care and course coordinator in health law at the Faculty of Medicine, University of Crete. She serves on the Mental Health Committee of the Greek Central Board of Health and the Permanent Mental Health Committee for monitoring the implementation of Greece's mental health strategic and operational plan, and is a member of EC Chafea and the Innovative Medicines Initiative (IMI) pool of patient experts. Aikaterini has worked with governments and organizations on mental health policies and legislation, including in Afghanistan, Qatar, United Arab Emirates, and Sierra Leone, and was a Fulbright scholar and fellow at the Salzburg Global Seminar on Health and Health Care Innovation in the 21st Century, Session 587: "Changing Minds: Innovation in Dementia Care and Dementia-Friendly Communities."

Sally-Ann Ohene is the National Professional Officer for Disease Prevention and Control in the WHO Ghana Country Office. She is responsible for noncommunicable diseases including mental health conditions and epidemic-prone diseases and provides technical and programmatic support to the Ministry of Health, multi-sectoral national stakeholders, UN agencies and other development partners in planning, policy and guideline development and program implementation.

Archana Padmakar has been a clinical psychologist working in the mental health sector for fifteen years. She has a doctorate from Vrije University, Amsterdam. Her PhD thesis focused on developing a framework for adaptive mental health systems for homeless women with mental health issues. She has completed MPhil in clinical psychology from Kasturba Medical College, Manipal. She has a licensing certification from the Rehabilitation Council of India. She has specialization in treating children, adults, and adolescents, utilizing a wide range of holistic psychological interventions and techniques that can provide every client with an individualized experience. She has experience of working in diverse clinical settings, such as with homeless persons with mental health issues, including in underprivileged communities; in inpatient and outpatient centers; with homeless women with mental health issues; and with support groups comprising caregivers. She also practices low-cost therapy for individuals, couples, and families. She currently heads the Emergency Care and Recovery Centre at The Banyan and its replication model across five districts in Tamil Nadu. Archana's expertise in recovery pathways for people with

mental health issues led her to research models of long-term care, continuity of care, and support structures that families would require as part of her PhD. She also works as a teaching faculty in Department of Applied Psychology at Banyan Academy of Leadership in Mental Health, teaching the masters of clinical psychology course.

Vikram Patel is the Pershing Square Professor of Global Health and Wellcome Trust Principal Research Fellow at the Harvard Medical School. He co-leads the GlobalMentalHealth@Harvard initiative. His work has focused on the burden of mental health problems, their association with social disadvantage, and the use of community resources for their prevention and treatment. He is a cofounder of the Movement for Global Mental Health; the Centre for Global Mental Health (at the London School of Hygiene & Tropical Medicine); the Mental Health Innovations Network; and Sangath, an Indian NGO which won the WHO Public Health Champion of India prize. He is a fellow of the UK's Academy of Medical Sciences and has served on the committee which drafted India's first National Mental Health Policy and the WHO High-Level Independent Commission for NCDs. He has been awarded the Chalmers Medal, the Samat Prize, the Pardes Humanitarian Prize, an Honorary OBE, and the John Dirk Canada Gairdner Award in Global Health. He was listed in *TIME Magazine's* 100 most influential persons of the year in 2015.

Soumitra Pathare is a consultant psychiatrist and Director of the Centre for Mental Health Law and Policy at the Indian Law Society, Pune, India. His primary interests are in the areas of mental health policy, scaling up mental health services, rights-based care, and legislation. He was a member of the Mental Health Policy Group appointed by Government of India to draft India's first National Mental Health Policy, released in October 2014. He has provided technical assistance to the Ministry of Health and Family Welfare, Government of India in drafting India's new Mental Health Care Act 2017, which takes a rights-based approach to mental health care and provides for publicly funded universal mental health care. He has served as a WHO consultant in many low- and middle-income countries, assisting in developing mental health policy and drafting and implementing mental health legislation. He was the Principal Investigator of QualityRights Gujarat project (2014–16), which implemented the WHO QualityRights program in six public mental health facilities in Gujarat. He has recently (2013–19) been involved in scaling up Atmiyata across Mehsana district, Gujarat, with a population of 1 million. Atmiyata is a project to improve access to mental health services in rural areas by training and mentoring women leaders of microcredit self-help groups to provide basic psychological interventions and access to social benefits for a defined rural population.

Kavita Pillai is Assistant Director, Training, at Bapu Trust for Research on Mind & Discourse, Pune. Her practice is informed by engagement with Eastern mind traditions, rights-based perspectives, and practices in psychosocial disability. She is a certified arts-based therapy practitioner and educator.

Dainius Puras is Professor of child psychiatry and public mental health at Vilnius University, Lithuania. From 2018 he is also Director of the Human Rights Monitoring Institute – NGO based in Lithuania. Positions he has held have included President of the Lithuanian Psychiatric Association, Dean of Medical Faculty of Vilnius University, President of the Baltic Association for Rehabilitation, and Chair of the Board of Human Rights Monitoring Institute. From 2007 to 2011 Puras was a member of the UN Committee on the Rights of the Child. From 2014 to 2020, Puras has been a UN Special Rapporteur on the right to physical and mental health. Puras has been actively involved in national and international activities in the field of developing and implementing evidence-based and human rights-based health-related policies and services, with special focus on children, persons with psychosocial and intellectual disabilities, other groups in vulnerable situations, and issues related to promotion of mental health and prevention of all forms of violence. His main interest is the management of change in the field of health-related services regionally and globally, with a main focus on operationalization of a human rights-based approach through effective policies and services.

Mrinalini Ravi is Co-lead for the Sundram Fasteners Centre for Social Action and Research at The Banyan Academy. She holds bachelor's and master's degrees in psychology and mental health services research respectively. She's held several portfolios in the past decade, but holds her five-year stint managing a shelter for homeless men with mental health issues closest to her heart. Much of her learning comes from her clients, who were kind and patient enough to share their journeys with her and helped her to navigate her interests in working with vulnerable populations meaningfully. Her dream is to establish a recovery college and enable more students like her to benefit from peer-led education and research.

Barbara Regeer is Associate Professor of transdisciplinary strategies for sustainable development and system transformation at the Athena Institute for research on innovation and communication in the health and life sciences, Vrije Universiteit Amsterdam. Her research interests are in emerging innovative strategies for (sustainable) development, with a specific focus on the facilitation of multi-stakeholder processes, knowledge co-creation, social change, and mutual learning between all actors involved, in such areas as mental health care, child and youth care, disability mainstreaming, sustainable food systems, and integrated rural development. Besides publications in the mentioned areas in international peer-reviewed journals, she has (co)authored books on approaches to knowledge co-creation for sustainable development. She coordinates, and teaches in, various courses on (transdisciplinary) research methodology, science communication, policy processes and (social) innovation. She is director of the Graduate School for Transdisciplinary PhD Education at the Athena Institute.

Elyn R. Saks is Orrin B. Evans Distinguished Professor of Law, Psychology, and Psychiatry and the Behavioral Sciences at the University of Southern California Gould School of Law; Adjunct Professor of Psychiatry at the University of California, San Diego, School of Medicine; and Faculty at the New Center for Psychoanalysis. Professor Saks received a BA in philosophy from Vanderbilt University, where she graduated first in her class; an MLitt in philosophy from Oxford University, where she was a Marshall Scholar; a JD from Yale Law School, where she was an editor on the *Yale Law Journal* and recipient of the Francis Wayland Prize for her clinical work; and a PhD in psychoanalytic science from the New Center for Psychoanalysis, where she received the Jacques Brien prize. Saks has also received honorary doctorate degrees from Pepperdine University and from the Chicago School of Professional Psychology. Professor Saks teaches law and mental health to law students and psychiatry and psychology fellows at the USC Keck School of Medicine. She writes extensively in the area of law and mental health, having published some sixty articles and book reviews and four scholarly books. She has also published an award-winning memoir describing her life with schizophrenia, called *The Center Cannot Hold: My Journey Through Madness*. She is on a number of mental health boards. And she has been elected to the American Law Institute and she is a winner of a MacArthur Fellowship, also known as “the genius grant.”

Christopher Schneiders is the Director of the Saks Institute for Mental Health Law, Policy, and Ethics at USC Gould School of Law. He leads the development, planning, and implementation of the institute’s research and activities, including the annual spring symposium and the current supported decision-making research study for people with psychiatric disabilities. He also contributes to the academic efforts of Distinguished Professor Elyn Saks and the Saks Student Scholars. He is a founding member of the USC Alliance for Civic Engagement and serves on Pearson, Inc.’s Corporate Disability Mentoring Advisory Council.

Stephanie L. Smith is the Co-Director of Mental Health at Partners in Health (PIH), an Associate Psychiatrist at Brigham and Women’s Hospital (BWH), and an Instructor in Psychiatry at Harvard Medical School (HMS). She also holds affiliations with the Division of Global Health Equity at BWH, and the Department of Global Health and Social Medicine at HMS. In her role at PIH, Dr. Smith provides clinical, programmatic, and research support for mental health integration across all the PIH sites, including Rwanda, Liberia, Lesotho, Malawi, Mexico, Sierra Leone, Peru, and Haiti. Dr. Smith’s current research interests focus on evaluating outcomes and impact of task-sharing endeavors for mental health care across the PIH sites. Dr. Smith continues to provide clinical care as a consultation-liaison psychiatrist at the BWH, and actively teaches and mentors trainees at all levels, including