

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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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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Joel D. Corcoran has been Executive Director of Clubhouse International since 1997. Prior to that he worked in various positions in the field of mental health since 1981. Clubhouse International is an organization working to end social and economic exclusion for people with mental illness. The Clubhouse model provides pathways to meaningful social inclusion, work, and wellbeing. Clubhouses are voluntary and empowering organizations where individual choice and multiple opportunities to succeed are the standard. The model has gained international recognition, scaling to more than 300 Clubhouses in thirty countries. In 2014 Clubhouse International and its partner Fountain House were recognized as an exemplary organization working to “alleviate human suffering” with the Conrad N. Hilton Humanitarian Prize. Joel is a passionate champion for the rights of people living with mental illness, and the importance of their involvement in the design of services and systems that support dignity, opportunity, and recovery.

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Vandana Gopikumar has worked extensively with homeless and poor persons with severe mental illness for three decades. She cofounded The Banyan and The Banyan Academy of Leadership in Mental Health, which have serviced over 3,000 homeless individuals and a million low-income households, including those from indigenous communities. Models developed at The Banyan are located within a social justice framework and are therefore collaborative and informed significantly by the wisdom of experiential experts. She uses case studies, ethnographies, and oral histories to better understand mental ill health attributions, identity, “social withdrawal,” “recovery” and hope. She is passionate about promoting peer-led care, leadership, advocacy and research.

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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

psychiatry residents and fellows, medical and other professional students, and other allied health professionals.

Sally Souraya is a senior service development manager at Implemental. She is involved in systems evaluations and capacity-building programs supporting the development and implementation of mental health strategies and services in different countries. Sally's areas of interest are advocacy, rights-based approaches, and models of empowerment and participation of people with lived experience. Her experience includes working as an occupational therapist, Mental health Technical Advisor, CRPD Trainer and Advocacy Consultant with local and international organizations in the Middle East and North Africa (MENA) region and China. Her work focused on empowering people with disabilities, promoting their rights and enhancing their social participation and involvement in their care. She also conducted research on involvement of people with schizophrenia in decision-making relating to their care in Ethiopia. Sally is involved in policy analysis and research on Stigma as part of the INDIGO network. She is also supporting the implementation of the mental health law in Qatar. Sally has an MSc in global mental health from King's College London and the London School of Hygiene and Tropical Medicine, and an international master's in public health from Tsinghua University in China.

Michael Ashley Stein is the Cofounder and Executive Director of the Harvard Law School Project on Disability, and a visiting professor at Harvard Law School since 2005. Considered one of the world's leading experts on disability law and policy, Dr. Stein participated in the drafting of the UN Convention on the Rights of Persons with Disabilities; works with disabled peoples' organizations and nongovernmental organizations around the world; actively consults with governments on their disability laws and policies; advises a number of UN bodies and national human rights institutions; and has brought landmark disability rights litigation globally. Professor Stein has received numerous awards in recognition of his transformative work, including the inaugural Morton E. Ruderman Prize for Inclusion; the inaugural Henry Viscardi Achievement Award; and the ABA Paul G. Hearne Award. His authoritative and pathbreaking scholarship has been published worldwide by leading journals and academic presses, and has been supported by fellowships and awards from the American Council of Learned Societies, the National Endowment for the Humanities, and the National Institute on Disability Rehabilitation and Research, among others. Dr. Stein holds an extraordinary professorship at the University of Pretoria's Centre for Human Rights, is a visiting professor at the Free University of Amsterdam, and teaches at the Harvard Kennedy School of Government. He earned a JD from Harvard Law School (where he became the first known person with a disability to be a member of the *Harvard Law Review*), and a PhD from Cambridge University. Professor Stein previously was Professor (and

Cabell Professor) at William & Mary Law School, taught at New York University and Stanford law schools, and was appointed by President Obama to the United States Holocaust Memorial Council.

Kanna Sugiura has an MD (Tokyo Women's Medical University), MScPH (London School of Hygiene and Tropical Medicine, and PhD (the University of Tokyo). As a psychiatrist and a researcher, she took part in a randomized controlled trial on suicide prevention, quantitative research on physicians' attitudes towards coercion, and qualitative research on involuntary psychiatric admission and supportive decision-making. Her global work was in Fiji, Equatorial Guinea and India, and she also worked at the WHO and the Japanese Ministry of Foreign Affairs, where she developed a toolkit on a rights-based approach to mental health services (WHO MINDbank, *QualityRights*, and WHO PROMind), drafted Japanese Global Health Policy, and chaired the G7 Progress Report health chapter. She is currently working as a psychiatrist, researcher, and a university lecturer (medical anthropology) in Japan.

Charlene Sunkel is a globally active voice for the rights of people with lived experience of mental health conditions and disorders. She's been working in the field of mental health, advocacy, and human rights since 2003. She authored several papers from a lived experience perspective published in renowned international medical journals. She has written and produced theatre plays and a short feature film on mental disorders to raise public awareness. Ms Sunkel had been involved in the review and drafting of various policies and legislation in South Africa and provided technical assistance to international mental health-related reports and documents. She serves on a number of national and international boards and committees. She is the Principal Coordinator for the Movement for Global Mental Health. Ms Sunkel is the Founder/CEO of the Global Mental Health Peer Network, which was officially launched at the fifth Global Mental Health Summit in 2018. Ms Sunkel was diagnosed with schizophrenia in 1991, which led to her passion and work in mental health advocacy and human rights. She received a number of awards for her work, with the latest award for Outstanding Achievement in Mental Health from the Swiss Foundation and the WHO.

George Szukler is Emeritus Professor of Psychiatry and Society at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. He was previously a consultant psychiatrist at the Maudsley Hospital (1993–2013), Medical Director of the Maudsley and Bethlem NHS Trust (1997–2001), and Dean of the Institute of Psychiatry, King's College London (2001–2007). He was a visiting professor in the Department of Sociology (BIOS Centre) at the London School of Economics (2005–2014). From 2007 to 2015, he was an associate director of the National Institute for Health Research Mental Health Research Network, with lead responsibility for Patient and Public Involvement. A major aim was to increase the

involvement in mental health research of service users and carers as partners in the conduct of research. His key research interests concern mental health law reform, methods of reducing coercion in psychiatric care, and questions posed by risk assessment in mental healthcare.

Andrew Turtle is a mental health consumer, thought leader and advocate. Along with degrees in Chinese medicine and public health, Andrew has designed the successful website known as the Mental Health Navigation Tool and has been on numerous committees on a local, state, and global level. Andrew is currently the chairperson of the Nepean Blue Mountains Primary Health Network (NBMPHN) Consumer and Carer Committee at a local level and the Australian representative on the Global Mental Health Peer Network (GMHPN) on a global level, and works as an intensive support worker with One Door Mental Health at Frangipani House, a drop in centre providing a range of individual and group based activities for people with severe and persistent mental health.

Alberto Vásquez Encalada works as Senior Advisor at the Center for Inclusive Policy (CIP). Previously, he was the Research Coordinator for the Office of the UN Special Rapporteur on the rights of persons with disabilities. He is a Peruvian lawyer and holds a LLM in disability law and policy from the National University of Ireland, Galway. He has worked extensively on disability rights and mental health law at national, regional, and international levels. As the president of the Peruvian NGO Society and Disability, SODIS, he participated in the Peruvian Congress' Special Committee for reviewing the legislation related to the legal capacity of persons with disabilities, and was actively involved in the drafting and advocacy related to the adoption of that milestone reform. He is also a member of the Latin-American Network of Psychosocial Diversity.

Adrian D. Ward is a recognized national and international expert in adult incapacity law. While still practising, he acted in or instructed many leading cases in the field. He has been published in several languages, and his books include the standard texts on adult incapacity law in Scotland. He has been continuously involved in law reform processes. As consultant to the Council of Europe, he completed in 2018 a review of implementation throughout Europe of Council of Europe Recommendation (2009)11 on principles concerning powers of attorney and advance directives for incapacity. His report "Enabling Citizens to Plan for Incapacity," which includes proposals for future action and initiatives at European level, was adopted and accepted, and published by the Council at www.coe.int/en/web/cdcj/activities/powers-attorney-advance-directives-incapacity. Prior to that he was a member of the core research group of the Three Jurisdictions Project, which assessed compliance of the UK jurisdictions with the UN Convention on the Rights of Persons with Disabilities, and made recommendations to UK government bodies. He has addressed the UN Committee on the Rights of Persons with Disabilities at

the UN in Geneva and has had ongoing contact with members of the Committee. He is frequently in demand as keynote speaker at major international conferences. He is an expert adviser to the Centre for Mental Health and Capacity Law, Edinburgh Napier University, and a research affiliate with Essex Autonomy Project. He has been founder chairman of NHS Trusts and a Mental Health Association, and has also engaged in service delivery projects overseas. He has been convener of the Mental Health and Disability Committee of the Law Society of Scotland since 1989. His awards include an MBE for services to the mentally handicapped in Scotland; national awards for legal journalism, legal charitable work, and legal scholarship; and the lifetime achievement award at the 2014 Scottish Legal Awards. At the 2017 Law Society AGM he was the first person since 2009 to be made an honorary member of the Law Society of Scotland. He has advised in several countries as Expert Adviser on Mental Health Law and Practice to the WHO, and as Expert in Incapacity Law in projects promoted by European Union. He has assisted and acted as adviser to various projects at home and abroad, including with the Hague Conference on Private International Law and the European Law Institute. He is one of the four principal authors and editors of *The International Protection of Adults* (Oxford University Press), the principal international textbook on its subject. He has assisted with the planning and delivery of all Judicial Institute (previously Judicial Studies Committee) courses on adults with incapacity since the Act of 2000 was passed.

Alicia Ely Yamin is currently a Lecturer on Law and Senior Fellow on Global Health and Rights at the Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School and Adjunct Senior Lecturer on Health Policy and Management at the Harvard TH Chan School of Public Health. She devotes much of her time to advocacy as Senior Advisor on Human Rights at the global health justice organization, Partners In Health. Yamin's 25+-year career at the intersection of global health and human rights has bridged academia and activism, as well as law and global health/development. She has lived and worked in Latin America and East Africa for half of her professional life, working with and through local advocacy organizations.

Edwina Zoghbi is a public health professional whose work focuses on matters of mental health and noncommunicable diseases. Edwina has been working at the WHO in Lebanon since 2013. She provides support in the development and implementation of the national mental health strategy, in particular the integration of mental health into primary health care, the Quality Rights project, national awareness campaigns, and various capacity building for health and mental health professionals. Edwina holds a BA in psychology, BS in nutrition, and MPH in public health from the American University of Beirut.

Preface

The aim of this volume is to engage critically with the subjects of legal capacity and human rights for people with psychosocial disabilities, and the closely related subjects of coercion in mental health and supported decision-making. Our book is the culmination of an effort to solicit multiple, diverse, and often varying perspectives on an issue that intersects with numerous academic disciplines, clinical practices, and lived experience perspectives.

Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), a number of academic works have engaged with subjects such as law reform, rights-based clinical practice and supported decision-making in light of the provisions of Article 12 of the CRPD and General Comment 1 on Article 12 issued by the Committee on the Rights of Persons with Disabilities. However, to our knowledge, our use of an interdisciplinary and global approach with engagement of the academy, clinical practitioners, legal scholars, and people with lived experience (with a resultant total of sixty-three authors from twenty-one countries, ten of which are low- and middle-income countries) to engage critically with issues of legal capacity and supported decision-making is unique, and especially so for the divergence of views presented. Such an approach is also necessary because, as the chapters illustrate, the provisions of Article 12 and General Comment 1 have implications for law and policy, for economics, for clinical practice, for community-driven practices, for research, and – most important of all – for rights-based advocacy.

We were especially careful to include – and feel very fortunate to have a pathbreaking section dedicated to – the voices and perspectives of people with psychosocial disabilities and their caregivers. In fact, at least twenty-two authors represented in this volume, including editors, count themselves as people with psychosocial disabilities or as caregivers. Participation is a central tenet of the CRPD, embodied by the principle of “Nothing About Us Without Us,” and we hope that we have given due attention to this principle, and centralized it at the core of this volume. Certainly, this work would be not be complete without the lived

experiences of individuals with psychosocial disabilities. The book is intended to be critical and dialogical; to simultaneously engage with conceptual thinking as well as practical implementation; to expound on existing research while also recognizing the need to be forward looking. As editors, we have endeavored to help individual chapter authors make their arguments as clearly and strongly as they could, while remaining agnostic as to the content of their contributions. We are grateful to each of the contributors but do not endorse, as editors, any particular view presented.

Our contribution exists in a continuum of efforts that have been undertaken in recent years, heavily influenced by an interdisciplinary workshop held at the Harvard Law School Project on Disability and sponsored by the Weatherhead Center for International Affairs, which was attended by many of the authors represented in the volume's chapters. The workshop was a useful precursor to the work presented here, because it embraced a similar dialogical approach, and sought to build an interdisciplinary and diverse community of thought partners who continue to grapple with the tensions around issues of legal capacity, as is evident in the book, and in the individual and collective work of contributors. As was clear then, this volume makes equally clear: there are no formulaic answers to many of the questions that have arisen in recent years. Even so, it is also abundantly clear that there is no shortage of critical engagement, constructive dialogue and innovation in the field of mental health practice free of all forms of coercion and inclusive of supported decision-making, and this will ultimately be the determinant of progress in a field that is rapidly evolving.

The book begins with an introduction by the coeditors, exploring the many unanswered questions and providing a background for what follows. Thereafter, the volume is divided into four parts. In the first, our contributors have focused on legal and conceptual issues related to universal legal capacity. Alicia Yamin has provided a thoughtful account of the way in which Article 12 interacts with the right to health, recognizing that the two are interdependent and indivisible. Likewise, Benjamin Barsky, Julie Hannah, and Dainius Puras have engaged with the way in which the universal right to legal capacity interacts with broader conceptual and practical reforms in thinking in the mental health field, illustrating the urgency of the need for a shift to noncoercive mental health models in the context of the COVID-19 pandemic. The chapter by Tina Minkowitz illustrates the way in which Article 12 symbolizes a broader recognition of the humanity and dignity of people with psychosocial disabilities, and issues a call for reparations from the psychiatric community.

Of course, there are many perspectives which view the provisions of Article 12 and General Comment 1 in a different light, and we have sought to include those as part of our commitment to dialogue. Examples include the chapter by Gerald Neuman, who suggests that the absolutist approach to legal capacity evident in Article 12 and General Comment 1 is tenuous and not in keeping with other approaches, including the approach of the United Nations Human Rights Council. Laura Davidson,

meanwhile, makes a case for ‘interim’ legislation that would reduce and potentially abolish coercive mental health practices, but which would likely be in tension with General Comment 1’s assertion that the right to equal recognition before the law is not subject to progressive realization.

Another counterargument is provided by Szmukler and Dawson, who argue that incapacity is a concept that extends beyond mental health and therefore suggest that laws and policies ought to focus on legislation related to the subject of incapacity on any ground, rather than being the purview of mental health law specifically. Similarly, Mrinalini Ravi and colleagues have argued that the binary between capacity and incapacity and between coercion and non-coercion is an acontextual and an asocial one, suggesting that while autonomy is indeed a fundamental right, it should not be viewed in isolation from the interdependence of people, the ways in which communities and families function, and the ways in which social contexts support or undermine it.

The second section of the book focuses on legal and policy reforms that have sought to domesticate the provisions of the CRPD. Alberto Vasquez shares an exposition of the content of reforms in the civil code in Peru, while also providing a very pragmatic account of barriers to the realization of the right to equal recognition before the law, including in national legislation in that country. Faisal Bhabha’s chapter engages with the subject of supported decision-making provisions at federal and provincial levels in Canada, illustrating the disparate nature of reforms and providing a clear indication of what can be done to mitigate these concerns. Similarly, the chapter by Pathare and Kapoor offers insight into the ways in which India sought to domesticate legal capacity provisions into the national Mental Health Care Act and examines the practicalities of implementation of the Act now that it has passed.

In providing an exposition of the reforms evident in Scottish legislation, Adrian Ward has shed light on some of the complexities that arise in regulating supported decision-making, while also demonstrating how Scotland has sought to navigate them. The role of civil society and disabled peoples’ organizations in driving legal reform is also evident in the chapter by Helene Combrink and Enoch Chilemba, which focuses on the complexities of introducing CRPD-compliant legislation in Zambia and Ghana. Similarly, Elizabeth Kamundia and Ilze Grobbelaar-du Plessis have noted the significance of consultative processes in the development of the Kenyan Mental Health Amendment Bill, while nonetheless expanding on the shortcomings of the Bill itself.

The third section of the book is dedicated to the practice of supported decision-making and noncoercive mental health care. It highlights innovative practices, while also expounding on research underway and research that is still needed. Bhargavi Davar and colleagues have shared their experiences of working in non-coercive, community-oriented ways to develop the practice they call the “circle of care” in Pune, India, illustrating the utility of this approach in crisis-support

intervention as well as decision-making. Likewise, Ulrike Jarkestig Berggren outlines the model of the “personal ombudsman” in Sweden, examining both its utility and the critical elements which make it useful. Two chapters have a transnational focus: Michelle Funk and colleagues provide an account of the World Health Organization’s Quality Rights Initiative, which aims to transform mental health systems to become rights affirming, including a specific emphasis on noncoercive measures. Similarly, the Clubhouse model is showcased in the chapter by Joel Corcoran, Cindy Hamersma, and Steven Manning. The model is an approach to psychosocial support in a community context, which the authors suggest can be adapted to various contexts and can be utilized as a means of supported decision-making.

Piers Gooding’s chapter is a useful illustration of the ways in which research can and has contributed to progress in this field. It is also a useful indicator of what research is still required and what barriers exist in its conduction. The chapter by Schneiders et al. also focuses on research, particularly in relation to supported decision-making, conducted by the Saks Institute at the University of Southern California. It demonstrates the utility of the research itself, as well as its potential for broader transformation of mental health care systems. Stephanie Smith, meanwhile, demonstrates that much more needs to be done in the way of research and standard setting to make the CRPD a reality, particularly in resource-limited settings as far afield as Haiti, Rwanda, Liberia, Sierra Leone, Malawi, Lesotho, Peru, and Mexico.

The fourth section of our book focuses on the voice of lived experience in decision-making, both by documenting research efforts related to the experience of people with psychosocial disabilities and by accounts of their experience provided directly. Charlene Sunkel and colleagues in the Global Mental Health Peer Network provide first-person narratives of their experiences of coercion in mental health systems, of recovery, and of the value of peer support and collective advocacy from South Africa, Cameroon, Kenya, Australia, and Canada. Lydia Brown and Shain Neumeier illustrate the value of collective lived experience advocacy as well, but they focus on the United States and demonstrate very effectively how ableism and sanism collude with various other forms of discrimination to create “hypermarginalization.”

Dorrit Cato Christensen’s account of her daughter’s experience of involuntary treatment in Denmark is interspersed with an exploration of noncoercive methods that align with the CRPD, offering an emotional account that also calls for practical reforms. Similarly, Aikaterini Nomidou’s chapter focuses on the author’s own experience as a caregiver for a family member with a psychosocial disability and as an advocate for change in Greece and beyond. The chapter by Kanna Sugiura is a useful exploration of the varied perspectives of people with psychosocial disabilities in relation to coercion, decision-making, and involuntary admission into

mental health institutions in Japan and India, while the chapter by Sally Souraya and colleagues provides a similar account in the context of Ethiopia.

Through this breadth of chapters covering many countries and perspectives, we have sought to explore issues of legal capacity, supported decision-making, and coercive mental health treatment in a cross-cutting, comprehensive, and interdisciplinary manner. We acknowledge that it is not possible to engage with all perspectives in the space of one volume, but as the exegeses above demonstrate, there are vast amounts of knowledge and expertise contained in the chapters that follow. It is a testament to the significance of the subject matter that we have solicited work from so many parts of the world, and that we have garnered perspectives from practitioners and policymakers alike, and from advocates, researchers, and people with psychosocial disabilities alike too.

We express our sincere thanks to the colleagues and friends who have contributed to this volume, and to the editors and publishers at Cambridge University Press. We reiterate our gratitude to the Weatherhead Center for International Affairs for their workshop sponsorship. Special thanks are due to Juliana Restivo, Program Coordinator for the GlobalMentalHealth@Harvard Initiative for invaluable contributions made in coordinating both the volume and the workshop, and for superb work as our editorial assistant, and to Juliet Bowler, Senior Program Manager of the Harvard Law School Project on Disability for supporting the workshop. Readers are invited to learn more about these two research and advocacy centers and their work by visiting their respective websites: <https://globalhealth.harvard.edu/domains/global-mental-health-harvard/>; <https://hpod.law.harvard.edu/>.

Finally, we express also our very sincere hope that this volume will contribute to realizing a world in which people with psychosocial disabilities enjoy the same freedoms, rights and responsibilities as any other members of their communities and that coercion and discrimination in all experiences, most notably health care, are eliminated altogether. In the final analysis, this was – and remains – our singular aspiration.

Foreword

In times of pandemic, we should especially consider those who are most likely to be overlooked and left behind. Historically, persons with disabilities have been among those most excluded. Many persons with disabilities – including those with psychosocial disabilities – have been exposed to serious human rights violations, had their legal agency substituted by guardians and been denied the right to choose what is best for them.

Mental health systems that intimidate or coerce those that need help the most are bound to fail. Change will only come with equal recognition before the law of the legal agency of persons with disabilities. This must be combined with the availability of community-based services, including those that work to prevent sexual violence, and with concrete steps on ending institutionalization. Community-based services enable persons with disabilities to remain in their communities and to contribute to their own well-being.

Having legal agency allows for valid, free, and informed consent. It is the key to ending coercive treatment and ensuring that an individual can decide on services they can trust to support them best.

Realizing the rights of persons with disabilities is a matter of justice and an investment in our common future. We should be guided by human rights, and by persons with disabilities themselves, in line with the disability community's motto: "Nothing about us, without us".

I welcome the initiative of the group of scholars, mental health practitioners, human rights experts and persons with disabilities that has led to the publication of *Mental Health, Legal Capacity, and Human Rights*. Only by working together can we succeed. Building knowledge is the path to drawing the roadmap towards more just and inclusive societies.

António Guterres, The Secretary-General, United Nations