About the Editors

Jan Wallcraft is a consultant at the Centre for Recovery at the University of Hertfordshire. She has previously worked as Manager of the Service User Research Group for England (SURGE), part of the Mental Health Research Network (MHRN). She has written and presented on service-user involvement, recovery and alternatives to the biomedical model, and contributed to many publications. Her PhD was based on narrative accounts of first experiences of psychiatric hospital, which from her own experience she regards as a turning point, not always in the right direction.

Beate Schrank is a psychiatrist in training at the Medical University of Vienna, Department of Psychiatry and Psychotherapy. While she did a research degree in London (UK) she also had a position as a research worker at SURGE. It was then that she got to know the user movement and service user involvement in mental health research, which fundamentally reshaped her vision of research as well as mental health practice.

Michaela Amering is a Professor of Psychiatry at the Medical University of Vienna, Department of Psychiatry and Psychotherapy, with a focus of interest on psychosis, and the development of the families’ and the users’ movements. Her experience also includes work in community psychiatry and research in the UK and USA. She is currently serving as secretary of the AEP Section on Women’s Mental Health, and as secretary of the WPA Section on Public Policy and Psychiatry.
Chapter 1

Jan Wallcraft – see ‘About the Editors’ for author biography.

Mary Nettle lives in the UK and is self-employed as a Mental Health User Consultant. She has a particular interest in user-controlled research. She works as a Mental Health Act Commissioner ensuring that the rights of people detained under the Mental Health Act are upheld. She is chair of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP).

Chapter 2

Alison Faulkner is a freelance researcher, trainer and consultant in the mental health field. She has over 20 years’ experience of social research, mainly in the mental health field. She has worked for many of the national mental health voluntary-sector organisations in the UK, including the Sainsbury Centre for Mental Health, the Mental Health Foundation, Rethink and Mind. As a user of mental health services, Alison has experience of a range of services including acute inpatient care, crisis services and A&E, psychotherapy and medication. Alison is also a cat lover and one day would like to write a book on the lessons cats have to teach us about mental health.
Chapter 3

Angela Sweeney is an independent mental health survivor researcher. She has worked for a variety of mental health charities and universities on various research and teaching projects. She is currently completing a PhD at the Service User Research Enterprise (SURE, Institute of Psychiatry, King’s College London) in which she has used mixed methods to generate and test a user defined outcome measure of continuity of care.

Louise Morgan is a service user researcher based in London. She currently combines freelance work with a service user involvement post at a North London User group called BUG (Brent User Group). Prior to that, she worked for SURGE (Service User Research Group for England), the service user arm of the Mental Health Research Network, before leaving with the rest of her team in a protest resignation. She has also worked at the Service User Research Enterprise (SURE) at the Institute of Psychiatry.

Chapter 4

Bill (K.W.M) Fulford is Professor of Philosophy and Mental Health in the University of Warwick Medical School; an Honorary Consultant Psychiatrist and member of the Faculty of Philosophy, University of Oxford; Professor of Philosophy and Psychiatry and Co-Director of the Institute for Philosophy, Diversity and Mental Health at University of Central Lancashire (UCLan, UK). He is also Visiting Professor in Psychology, Institute of Psychiatry and King’s College, London University; and Special Adviser for Values-Based Practice in the Department of Health, London. He has published widely on philosophy and psychiatry and is Lead Editor of the journal Philosophy, Psychiatry, & Psychology and of a book series from Oxford University Press on International Perspectives in Philosophy and Psychiatry.

Jan Wallcraft – see ‘About the Editors’.
Chapter 5

**Jasna Russo** is a survivor researcher living in Berlin, Germany. She has a degree in clinical psychology and comes from former Yugoslavia where she has experienced forced psychiatric treatment. Jasna has worked on both collaborative research projects (at the Institute of Psychiatry, Kings College London), and on survivor-led and survivor-controlled projects (for the German organisation In Any Case, of which she is a founding member). She is also a Board member of the European Network of (ex-) Users and Survivors of Psychiatry.

Jasna’s articles have been published in various different anthologies. Her research reports include *Taking a Stand: Homelessness and Psychiatry from Survivors’ Perspective* (together with T. Fink, Berlin 2003); *From One’s Own Perspective: Users’ Experiences of Person Centred Care* (together with F. Scheibe and A. K. Lorenz, Berlin 2007).

**Peter Stastny** is Senior Psychiatrist at South Beach Psychiatric Centre. A dissident psychiatrist, he is the author of numerous scholarly papers on psychosocial treatments, advance directives, self-help and empowerment, film history and mental health, and subjective experiences. He has served as expert witness and consultant in legal cases involving standards of care, involuntary treatment, and issues of dangerousness.

Peter has spearheaded innovative programs such as peer specialist services, peer-run businesses, and transitional living groups. He has directed and produced several documentary films addressing mental health subjects. In 2003, Peter was a founder of the International Network of Treatment Alternatives for Recovery (INTAR).

With Darby Penney, he was guest curator of a major exhibit at the New York State Museum in 2004, ‘Lost Cases, Recovered Lives: Suitcases from a state hospital attic’ and in 2006, Peter and Darby produced a book by the same title (Bellevue Literary Press, New York).

Jasna and Peter met each other in Dresden, Germany at the WPA thematic conference on coercion in 2006. This chapter is their first joint piece of work and they wish to thank the editors for this opportunity.

Chapter 6

**Kim Hopper** is Research Scientist at the Nathan Kline Institute for Psychiatric Research, and Professor of Clinical Sociomedical Sciences at Columbia University Mailman School of Public Health. He also co-directs the NIMH-funded Center to Study Recovery in Social Contexts. Kim is most interested in cross-cultural studies of psychosis, alternative perspectives on psychiatry as social practice, and user efforts to enhance participation, and is currently working on adapting Amartya Sen’s capabilities approach for use in public mental health.
Alisa Lincoln is an Associate Professor of Health Sciences and Sociology and has adjunct appointments at the Boston University School of Public Health and the Division of Psychiatry, Boston University School of Medicine. Her research interests focus on public urban mental health. She was the Principal Investigator of a SAMHSA-funded project which opened and evaluated a Safe Haven Shelter, now known as the Dudley Inn, for people who are chronically homeless, and struggling with both severe mental illness and substance abuse problems. This project included a consumer-driven evaluation. Currently, she is working on two NIMH-funded projects on psychiatric emergency-room care. The first studies staff perspectives of psychiatric emergency-room care and the impact of the culture and climate of a busy, public urban psychiatric emergency room. The second award allowed for the creation of The Boston Community Academic Mental health Partnership (B-CAMHP) a community-based participatory action-research group focused on mental health.

Chapter 7

All authors of this chapter work at the Program for Recovery and Community Health at Yale University in New Haven (USA).

Larry Davidson is a Professor of Psychiatry and Director of the Program for Recovery and Community Health of the School of Medicine and Institution for Social and Policy Studies at Yale University. His research and teaching interests focus on processes of recovery, the active role of the person in pursuing recovery, and the active role of people in recovery in transforming mental-health systems to promote recovery-oriented care.

Priscilla Ridgway is an Assistant Professor of Psychiatry at the Yale Program for Recovery and Community Health. Her work experience in the field of mental health ranges from being a psychiatric aide, case manager, and advocate for psychiatric inpatients, program director in an innovative psychosocial rehabilitation agency, and co-ordinator of research and planning for a state mental-health department. For the last 20 years she has worked within organisations committed to innovation and building recovery-paradigm knowledge, including the Center for Psychiatric Rehabilitation at Boston University, the University of Kansas Office of Mental Health Research and Training, and Advocates for Human Potential, Inc. Her work has always concerned human rights, recovery, services that support recovery, and amplifying the voice of mental health consumers. She considers her personal experience of recovery from brain trauma and post traumatic stress disorder as an important background that has taught her a lot in relation to her work.

2Substance Abuse and Mental Health Services Administration (SAMHSA).
Timothy Schmutte is a clinical psychologist and Associate Research Scientist at the Yale Program for Recovery and Community Health. In his role as the program manager for the evaluation of the federally-funded Connecticut Mental Health Transformation Grant, he works with state departments, advisory councils, and advocacy groups on developing strategies for increasing the level of consumer, youth, and family involvement in system transformation and program evaluation.

Maria O’Connell is an Assistant Professor of Psychiatry and Director of Research and Evaluation at the Yale Program for Recovery and Community Health. She has been involved in local and national recovery-oriented system transformation efforts and is the lead developer of the Recovery Self-Assessment (RSA), a tool designed to assess perceptions of the degree to which a variety of objective recovery-oriented practices are manifest in mental health and addiction service-agencies. Her research interests include recovery and recovery-oriented systems of care, psychiatric advance directives, and self-determination among adults with mental illness.

Chapter 8

Both authors work at the Center for Mental Health Services Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services (USA).

Paulo Del vecchio is currently the Associate Director for Consumer Affairs within the Office of the Director at the Federal Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration in the U.S. Department of Health and Human Services. In this capacity, he manages the Center’s precedent-setting activities in addressing consumer participation and education, issues of discrimination and stigma, consumer rights, and others. He was the first Consumer Affairs Specialist hired by this Federal agency. In this capacity, he promoted consumer/survivor participation in all aspects of the Center’s policies and operations ranging from public education to efforts at researching effective strategies to address the needs of persons with mental illnesses.

A self-identified mental health consumer/survivor, Paolo del Vecchio has been involved in the consumer/survivor self-help movement for over a decade.
Crystal Blyler is a Social Science Analyst in the Community Support Program Branch, Division of Service and Systems Improvement of the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services. She earned her PhD in psychology with a specialization in experimental psychopathology. Prior to joining SAMHSA she conducted schizophrenia research on symptomatology, neurocognition, motor disorders, medication compliance, suicide, and residential alternatives to hospitalization.

As an evaluation specialist at SAMHSA, Dr Blyler has served as a project officer on a diverse range of initiatives, most recently focussing on the design and evaluation of mental-health systems transformation; a variety of evidence-based practice activities, and, most recently, design and evaluation of mental-health systems transformation. Before that, she worked at the Chestnut Lodge Research Institute in Rockville, MD, where she served as a therapist/treatment co-ordinator for people with serious mental illnesses in the hospital’s outpatient clinic. The consumer movement has been known to her since graduate school when she served on the Human Rights Committee for the Massachusetts Department of Mental Health in Cambridge, MA.

Chapter 9

Jean Campbell is a Research Associate Professor in the Department of Psychiatry at the University of Missouri School of Medicine – Columbia, USA, and directs the Program in Consumer Studies and Training at the Missouri Institute of Mental Health. As an internationally-known mental-health consumer researcher, speaker, and consultant, she is a forerunner in the effort to define recovery and well-being of mental health service recipients and to promote multi-stakeholder approaches in evaluation and service delivery. Currently, she is working with the Missouri Department of Mental Health to promote consumer-operated service programs as an evidence-based practice and is part of the national effort to develop the Consumer-Operated Services Program Evidence Based Practices KIT. Dr Campbell was the Principal Investigator of a co-ordinating centre for a large, multi-site federal research initiative to study the cost-effectiveness of consumer-operated programs as an adjunct to traditional mental health services. She was a consultant to the President’s New Freedom Commission on Mental Health and a contributor to the Mental Health Report of the Surgeon General.

Dr Campbell is best known for her ground-breaking consumer-directed research study of consumer well-being in California, The Well-Being Project (1989 – referred to in Chapter 9) and the supplemental award-winning documentary, ‘People Say I’m Crazy’. She has received the NAMI Lionel Aldridge Award (2008), the Silver Key Award from the Mental Health Association of Greater St. Louis, (2004), the New York Association of Psychiatric Rehabilitation Services Executive Directors Award (2003), the International Association of Psychosocial Rehabilitation Services Acknowledgement, (2000), and the Human Rights Diversity Enhancement Award from the University of Missouri-Columbia (1995).
**Chapter 10**

**Jonathan Delman** is the Executive Director of Consumer Quality Initiatives, Inc., a Massachusetts-based service user directed research and evaluation organization, located in Roxbury, Massachusetts, USA. He is a lead investigator on several research projects, including a recently awarded National Institute of Mental Health (USA) grant to the Boston University School of Public Health (BUSPH) to establish a service user driven community-based participatory action-research partnership, the Boston Community-Academic Mental Health Partnership (B-CAMHP).

Jonathan has written several peer-reviewed articles and book chapters on the significant involvement of consumers in research, and has served on a variety of national and state policy committees, including the President’s New Freedom Commission subcommittee on acute care. Mr. Delman has lived with bipolar disorder for many years and is a long-time service user researcher and advocate. He is currently pursuing his doctorate (part-time) in Health Policy and Management at BUSPH.

**Alisa Lincoln** – see Chapter 6.

**Chapter 11**

**Virginia Minogue** works in the NHS as Head of the West Yorkshire Mental Health Research and Development Consortium (UK). Her specific areas of interest are service user and carer involvement in research and service development and planning, partnership working and mentally disordered offenders. She works particularly closely with service users and carers, involving them at all levels of the research agenda, and has published papers in this area and a training package. She was previously a Senior Lecturer in Community Justice in Sheffield. Prior to this she worked for a number of years in the Probation Service as a manager, researcher, Family Court Welfare Officer and probation officer. She is currently Chair of the Editorial Board for the journal *Mental Health and Learning Disabilities Research and Practice*. She is also Chair of a voluntary sector mental-health organisation which offers support, housing and employment services to adults with mental health problems and their carers.

**Chapter 12**

**Diana Rose** was educated at Aberdeen and London Universities, taking degrees in psychology, and social psychology. Her PhD was about representations of madness in the media. She has also been a mental-health service user all her adult life. After teaching in a university for ten years she was medically retired and spent ten years ‘living in the community’. During that time she became active in the
user movement. In 1996 she went to work for the Sainsbury Centre for Mental Health (London) and whilst there built on both her research and her consumer experience to develop User-Focused Monitoring (UFM), a model for evaluating mental health services which is wholly user-driven. She has now been co-director of the Service User Research Enterprise (SURE) at the Institute of Psychiatry in London for five years. This is an academic team but nearly all the staff have experience of psychiatric services and treatments and the research done by the team is intended to prioritise the experiences of service users. Leading projects include work on consumers’ perspectives on ECT, users’ perceptions of detention and compulsion and users’ experiences of acute wards.

Chapter 13

**Peter Beresford** is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University (UK). He is also Chair of Shaping Our Lives, an independent, service user controlled UK organisation and network and a long-term user of mental health services. He has a longstanding interest in issues of participation as a writer, educator, researcher and activist. In England he is a member of the Advisory Board of Involve, which works to support public and user involvement in health, public health and social care research and of the National Institute for Health Research. He is also a member of the Survivor Researchers Network and an active survivor–researcher.

Chapter 14

**Paddy McGowan**, from Omagh in County Tyrone, recovered from schizophrenia with the support of other survivors and professionals. He was involved in organising the first ‘Voices’ conference in Derry in November 1999. As a member of the Institute for Recovery in Mental Health and a prominent member of the International Network of Treatments Alternatives for Recovery (INTAR) he is respected as a leading and inspirational authority in creating alternatives to the so-called ‘medical’ or ‘maintenance’ model. Paddy set up the first user group in Ireland in 1994 and was the founder and first Chief Executive Officer of the Irish Advocacy Network. He has been involved in developing peer-advocacy training alongside staff awareness training in user empowerment and advocacy to an accredited degree level. He served on the National Disability Association’s Ad Hoc Focus Group on Mental Health and the Management Committee of the United Kingdom Advocacy Network. Paddy has also been instrumental in designing and implementing user-led research focusing on user-satisfaction with statutory mental health services throughout Ireland, including the Southern Health Board, which led to *Focusing Minds*, the locally-agreed interpretation and implementation of national mental health policy in the Southern Health Board, Ireland. He has been a member of many expert
mental health committees and working groups throughout Northern Ireland, gives lectures nationally and internationally, and in 2005 received the prestigious Social Entrepreneurs Ireland Award.

**Liam Mac Gabhann** qualified as a mental health nurse in 1988 and headed off from Ireland with his new found insights to change the world. Spending most of his early career in England with some brief sojourns in Australia and the Middle East, he consistently worked with people with psychotic illness, and concentrated on acute mental health care. He has been a nurse, researcher/practitioner and worked in practice/service development. In 2001 he returned to Ireland and now works as a lecturer, and in practice. He practises on an acute psychiatric admission ward and co-ordinates the Graduate Diploma/MSc in Health Care Practice/Nursing Practice, and also runs some interesting professional development courses at Dublin City University. His clinical research focus generally centres on the relationships and understandings of mental health professionals and service users in relation to mental health, illness and health care. He is the lead for a research programme ‘service user involvement in research’ with the aim of creating real partnerships with service users. He has a degree in health studies, a Masters in Sociology of Health and Health Care, and a taught Doctorate in Nursing Science.

**Chris Stevenson** trained as a psychiatric nurse in the UK and studied for a degree in psychology and sociology, working on a casual basis in practice. She became a community mental health nurse in a progressive service and learned family therapy ‘on the job’. She was challenged in her existing thinking about distress and began to see how patterns of communication, relating and cherished stories could keep the individual and family tied in to a way of living that was not satisfying or fulfilling. She moved from practice to academia, although she maintained her family therapy practice, joining a team with Jim Birch (an alternative psychiatrist) and Alex Reed, now a nurse consultant in family therapy. They immersed themselves in the postmodern/social constructionist therapy literature acknowledging that families are experts on their own lives and she wrote her PhD in the area.

Chris has also worked at University of Newcastle, with Phil Barker, where she led the research underpinning the Tidal Model of psychiatric/mental health nursing as an ‘in-system’ alternative to existing coercive nursing practices, whilst maintaining her family therapy life. She co-authored a good practice guide on involvement with members of the Irish Institute for Mental Health Recovery (IMHR), Kieran Crowe and Paddy McGowan.

As the first Chair in Mental Health Nursing in Ireland, she established a lectureship open to people with experience of service use.
Jim Walsh used mental health services for approximately 14 years. During that time he returned to education completing a degree in psychology at Queens University, Belfast and became actively involved in various mental health initiatives set up with the specific aim of improving the status of people experiencing psychological and emotional distress within mental health care systems. Later he became employed by a health trust in Northern Ireland; first as a Day Care Worker and later coordinating a partnership initiative – the Mental Health Alliance. He is involved in several local, national and international user and carer initiatives – the Irish Advocacy Network, the Institute for Mental Health Recovery, Mental Health Ireland, and the International Network of Treatment Alternatives for Recovery. He now works as a lecturer in mental health at the School of Nursing, Dublin City University.

Chapter 15

Sarah Hamilton is a senior researcher at Rethink, the leading national mental health membership charity in Great Britain. Sarah’s main current research interests are: the role and needs of family members and friends caring for someone with a mental illness; stigma and discrimination against people with a mental illness; and the relationship between debt and mental ill-health.

Chapter 16

Daniel B. Fisher life’s work is to inspire the hope and call forth the voice that helps people recover. This passion comes from his lived experience with mental illness. No-one would have guessed such a calling lay ahead when he obtained a PhD in biochemistry at the University of Wisconsin and carried out neurochemical research at the National Institutes of Mental Health into the possible biochemical basis of schizophrenia. Ironically, however, during the course of that work, he was himself diagnosed with schizophrenia at age 25, and hospitalized several times. In large part, his recovery from schizophrenia was based on the life-changing experiences he witnessed, and he decided he would dedicate the rest of his life to helping others recover from mental illness. To do so, he earned a MD from George Washington University, and was trained as a psychiatrist at Harvard Medical School. He has practised as a Board-certified, community psychiatrist at Riverside Community Care in Wakefield, Massachusetts, USA, for the last 25 years. But he yearned to bring about change
at a more extensive level. To do so, in 1992 he co-founded the National Empowerment Center and has served as its Executive Director since then.

Dr Fisher was a Commissioner on the White House New Freedom Commission on Mental Health. He won the Mental Health America’s Clifford Beers Award for Mental Health Advocacy in 2002, and he has helped organize the National Coalition of MH Consumer/Survivor Organizations, which acts as a voice for consumers in the development of national mental health policy.

Chapter 17

Jan Wallcraft and Beate Schrank – see ‘About the Editors’ for author biographies.