

Symposium Contributors

INTRODUCTION TO THE SYMPOSIUM

Russell Shuttleworth holds a BA and MA in Anthropology from California State University, Sacramento, a Master's Degree in Social Work from San Francisco State University, and a Ph.D. in Medical Anthropology from the University of California, San Francisco-Berkeley. He has worked for many years as a personal assistant for disabled men. For his dissertation, he conducted ethnographic fieldwork in the East San Francisco Bay Area with men with cerebral palsy on their search for sexual intimacy. Dr. Shuttleworth is currently an Ed Robert's Postdoctoral Fellow in Disability Studies at the University of California, Berkeley where he co-teaches the course Anthropology and Disability. He also teaches the innovative course Disability and Sexuality at San Francisco State University. Dr. Shuttleworth has published widely in the areas of disability studies, disability and sexuality studies and the anthropology of disability.

Linda Mona is a licensed clinical psychologist who has conducted research and lectured on disability-related topics around the country for the past 13 years. Dr. Mona has worked in a variety of settings conducting both clinical work and research. Most of her clinical and research interests have focused on sexuality and people with disabilities. She obtained her BA in psychology from UCLA and both her masters and doctoral degrees in clinical psychology at Georgia State University. She completed both internship and postdoctoral work at the VA Palo Alto Healthcare System. Dr. Mona has advocated for the inclusion of disability status in university diversity curriculum and has been the energy behind positive changes for university students with disabilities within academic, administrative, and service domains. She has received national recognition by the American Psychological Association, the Association on Higher Education and Disability, and the Society for the Scientific Study of Sexuality for her research and service-related work focusing upon persons with disabilities. Furthermore, Dr. Mona has published her work in numerous academic publications. She worked at the World Institute on Disability as a research associate for over two years where she conducted disability policy research and is advocated for disability rights at the local, state, and national levels. Dr. Mona also worked as Visiting Assistant Professor at Pacific Graduate School of Psychology where she taught Cross Cultural issues in psychology and supervised Students' clinical work. Outside of her academic and clinical roles, Dr. Mona works as a disability content consultant with a variety of internet companies. Currently, Dr. Mona is a Staff Psychologist with the VA Long Beach HealthCare System where she works as a rehabilitation psychologist within the spinal cord injury service.

DISCRIMINATION, SEXUALITY AND PEOPLE WITH SIGNIFICANT

DISABILITIES: ISSUES OF ACCESS AND THE RIGHT TO SEXUAL EXPRESSION IN THE UNITED STATES

Holly Wade is a doctoral candidate in the joint doctoral program in special education at University of California, Berkeley and San Francisco State University. She is currently Board president for the Committee on Sexuality, a non-profit organization that advocates for people and policy around sexuality issues for people with developmental disabilities.

ADVENTURES IN CHILD-REARING: THE SEXUAL LIFE OF A CHILD GROWING UP WITH DOWN SYNDROME

Susan Fitzmaurice began her interest in disability studies with a series of small gray easily overlooked biographies in her elementary school that included Helen Keller, Dorothea Dix, Susan B. Anthony, and Jane Adams. These women inspired her to spend thousands of hours volunteering her time with numerous disability-focused organizations. She began in 1968 as a candystriper at the age of fourteen with the infamous Plymouth State Home and Training School on a ward for children labeled profoundly and multiply handicapped that was considered a model of progressive thinking for its time. Susan obtained her B.Ph. in Interdisciplinary Studies in Societal Realities from Thomas Jefferson College in 1975, a B.A. in Psychology from Grand Valley State University in 1998, and a M.S. in Rehabilitation Counseling, with a substantial added focus on Disability Studies, from Syracuse University in 2001. Currently, she acts as the Americans with Disabilities Act coordinator for the city of Dearborn promoting the full integration and participation of persons with disabilities in all areas of economic, political, and community life. Her son, Teddy Fitzmaurice, began his education in Ann Arbor as one of the first official inclusion students in Michigan. He has been a participating member of Not Dead Yet and Self-Advocates Becoming Empowered. He is looking forward to his high school graduation in 2003.

DOING THE WILD THING: SUPPORTING AN ORDINARY SEXUAL LIFE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Carol Hamilton (BA, MEd) is a part time Ph.D. student enrolled in the School of Social Work and Social Policy, Massey University, New Zealand. She also works in the disability field as a trainer of Community Support Workers.

WHOSE SEX IS IT ANYWAY?: FREEDOM OF EXPLORATION AND EXPRESSION OF SEXUALITY OF AN INDIVIDUAL LIVING WITH BRAIN INJURY IN A SUPPORTED INDEPENDENT LIVING ENVIRONMENT

Karen Shue, Ph. D., C.Psych. is a psychologist practicing in neuropsychology and brain injury rehabilitation. She is President and Director of Learning at ABI Possibilities Inc., a provider of long-term living support services.

Ana Flores, O.T. Reg. (Ont.) is an Occupational Therapist and Director of Member Services at ABI Possibilities Inc.

INCORPORATING SEXUAL SURROGACY INTO THE ONTARIO DIRECT FUNDING

PROGRAM

Born and raised in Canada, Lawrence Shapiro is a student in the Disability Studies Program at Ryerson University in Toronto, Ontario. He has conducted presentations on disability at both the Society of Disability Studies Conference recently held in Oakland, California, and also at the first Queer Disability Conference held at San Francisco State University last spring. He is currently researching material for a documentary film on issues faced by women with disabilities in the developing world.

SEX, DISABILITY AND MOTHERHOOD: ACCESS TO SEXUALITY FOR DISABLED MOTHERS

Corbett Joan O'Toole is the Director of the Disabled Women's Alliance which provides training and organizes conferences on women and disability. Author of numerous articles in peer reviewed journals, including *Journal of Lesbian Health*, *Peabody Journal of Education*, *Sexuality and Disability*, and *Disability Studies Quarterly*. She recently co-authored a chapter on disabled lesbian health for the forthcoming medical textbook, *Women with Disabilities: A Comprehensive Guide to Care* edited by Dr. Sandra Welner.

LEISURE: A PATHWAY TO LOVE AND INTIMACY

David Howard, M.S.W., C.T.R.S. is a doctoral student in the Rehabilitation Science Ph.D. program at the University of Florida's College of Health Professions. He received his undergraduate and Masters degrees from the University of Utah in Therapeutic Recreation and clinical Social Work respectively.

Mary Ellen Young, Ph.D., C.R.C. is an Assistant Professor, Department of Rehabilitation Counseling, College of Health Professions, University of Florida, Gainesville, Florida. She was previously an Assistant Professor Center for Research on Women with Disabilities, Department of Physical Medicine and Rehabilitation, Baylor College of Medicine, and Associate Director, Brain Injury Research Center, The Institute for Rehabilitation and Research, Houston, Texas.

FREAK FUCKER: STEREOTYPICAL REPRESENTATIONS OF SEXUALITY IN BRITISH DISABILITY ART

From 1993-2000 Ronda Gowland worked as a personal assistant for disabled people. Subsequently, this led to further research in 1999 examining the 'Representations of Disability in Art and Literature for her BA Honours 'Art and Design History' degree dissertation at the Southampton Institute of Higher Education, England. Presently working as Programme Assistant and access representative for the John Hansard Gallery Education Department at the University of Southampton, she is currently studying for a Masters degree in Arts Management at the University of Portsmouth.

"SOMETHING IN YOUR BELLY" - FANTASY, DISABILITY AND DESIRE IN

MY ONE-LEGGED DREAM LOVER

Kath Duncan (kmd@ozemail.com.au) is a forty-something physical freak dynamo who works as a free-lance journalist/writer in radio, print and television. She struggles with her resistance to most things academic although she holds a BA (Communications) from the University of Technology in Sydney, a BA (Hons) degree from Southern Cross University, and a post-grad certificate in Sound from the Australian Film TV and Radio School. She gets off on exploring edgy and taboo topics including: masturbation, death, masculinity and housework, people who want to be disabled and a whole lot of stuff that keeps getting her into trouble. Born with two full-length limbs and half her left arm and right leg, Kath gets twice as much wear out of a pair of socks.

Gerard Goggin (g.goggin@uq.edu.au) is a late thirties-something not quite straight academic who is a Postdoctoral Research Fellow at the Centre for Critical and Cultural Studies, University of Queensland. Gerard enjoys subverting the dominant paradigm, pushing the envelope, queering the pitch, and generally stirring things up. He has a forthcoming book, *Digital Disability: The Social Construction of Disability in New Media* (Rowman & Littlefield) in collaboration with Christopher Newell, University of Tasmania.

DISABLED SEX AND THE MOVIES

Leslie Harris is a journalist and copy editor in Johannesburg, South Africa. This is an expanded version of a paper delivered at the Society for Disability Studies conference held in June 2000 in Chicago.

FORBIDDEN WEDDING: MOVIE REVIEW

Mitchell Tepper, Ph.D. M.P.H. is Founder and President of The Sexual Health Network and SexualHealth.com. Dr. Tepper is an internationally recognized sexuality educator, researcher, author, and advocate dedicated to ending the silence around issues of sexuality and disability. His years of research at Yale University, Rutgers University, and the University of Pennsylvania have served as the basis for numerous professional, academic, and public presentations, articles, and chapters. Publications include: *Lived Experiences that Impede or Facilitate Pleasure and Orgasm in People with Spinal Cord Injury*; *Providing Comprehensive Sexual Health Care in Spinal Cord Injury Rehabilitation: Continuing Education and Training for Health Professionals*. He writes regularly for *Love Bites*, a monthly column in *New Mobility* magazine and *iCan.com*. Dr. Tepper also serves on the editorial board of the *Journal of Sexuality and Disability*; the Board of Directors of the American Association of Sex Educators, Counselors and Therapists (AASECT); The Sexuality Information and Education Council of the United States; and the International Society for the Study of Women's Sexual Health (ISSWSH). He is a regular guest lecturer at the Yale University School of Medicine. Dr. Tepper has a Master's degree in Public Health

from Yale University and a Ph.D. in Human Sexuality Education from the University of Pennsylvania. In addition to academic credentials, Dr. Tepper, who grew up with Crohn's Disease and acquired a spinal cord injury at age 20, brings a lifetime of first-hand experience with chronic illness and disability to his work.

VOICES

Lorre Leon Mendelson, CEO of en-LIGHTNING Consulting, recently relocated from the San Francisco Bay Area to Nashville, Tennessee where she works as Advocate for Individuals with Mental Illness for Tennessee Protection and Advocacy, Inc. Lorre is a mental health/disability advocate/activist, educator, national presenter, and author. Her poetry and articles have been published in the U.S., Canada and on the web including in *Disability Studies Quarterly*, Special Issue: Hidden Disabilities, Volume 20, Number 3, Summer Issue 2000. Co-authored article for special issue of *Women and Therapy* with a focus on anxiety disorders in the lives of women. She graduated from High School in Washington, DC, then, moving to Colorado, obtained a B.A. in Social Science at Colorado State University, Ft. Collins, Colorado in 1975.

As an advocate and activist, Lorre works with full energy and enthusiasm educating people about their rights, advocating for people with mental illnesses, ending prejudice and discrimination, and working collaboratively with others to achieve these goals. Lorre presents nationally on ending hate, educating the media, voting access for people with mental illnesses and other disabilities, successful employment for people with disabilities, and serves as a resource on an international basis for people with OCD and other mental illnesses. Trained by the NMHA and Ken Steele in the Voter Empowerment Project, Lorre implemented this in Northern California and has begun voter activities in Tennessee for people with disabilities.

As a person with PTSD, depression and OCD, Lorre is strongly committed to education, awareness, and equal rights for people with and without mental illness working to end the prejudice and discrimination that pervades the social, educational, health, medical, vocational, and political structures for people with disabilities. Lorre works with the media to provide more accurate portrayals of people with mental illness and other disabilities through awareness and education. She received commendations from the State of California, Department of Rehabilitation, and SCCCED in 1997 for her work in the community, elected by the Santa Clara County Committee for the Employment of People with Disabilities (SCCED) as Disability Champion of the Year, 1997, organized and coordinated non-partisan political debate with disability representatives from national political parties, October 2000, nominated for California Secretary of State's "Hall of Fame" to honor voter outreach efforts going

above and beyond assisting with registering voters and encouraging voter participation, January 2001. In 2000, spearheaded voter registration drive for the Spirit of ADA National Torch Relay, June 17, San Francisco Bay Area and Voter Registration Volunteer activities with the Santa Clara County Registrar of Voters office helped increase voter registration in the year 2000 of over 35,000.

SEX, INTIMACY, AND MENTAL ILLNESS: A PERSONAL REFLECTION

Scott Snedecor has had a wide range of experiences in the mental health field. He has been a consumer of public and private mental health services. He has been in short and long term inpatient treatment. He is currently working as the Consumer Liaison for Multnomah County. He has been involved in mental health policy for about 7 years. He has served on the Regional Acute Care Advisory Council, the Multnomah County Adult Behavioral Health Advisory Council, the Oregon Office of Consumer Technical Assistance Advisory Council, The Dammasch Trust Advisory Council, the Attorney General's Task Force on Civil Commitment, the Mid-Valley Behavioral Health Care Network Quality Council, the IPS Plus Quality Assurance Committee, and the Tri-County Medical Transportation Advisory Board. He has written a wide number of articles on consumer/survivor issues, which have been published locally and nationally, including The Death of Mental Illness, Grief, Back-up; a model for Organizing, and Creative Disengagement; a Guide for Providers. He has been an educator for workshops on Sexuality and Mental Illness, Consumer Empowerment in Managed Care, Organizing Your Consumer Group, Using Psychiatric Advanced Directives, Becoming a Partner with your Prescriber, How to Create a Drop-in Center, Medications from a Consumer Perspective, Healthy Grieving, Using Affirmations, Consumers and Employment, and How to be an Effective Consumer Provider.

He has also been a key trainer for the Portland Police Crisis Intervention Team, the Clackamas County Sheriff's Deputies, and the Multnomah County Sheriff's Deputies on issues regarding Mental Health and Law Enforcement.

Professionally in the mental health and addictions fields, Scott has worked as an addictions counselor for adolescents, a project coordinator of a federal experimental addictions treatment program for homeless adolescents, a case manager for a consumer operated intensive outreach case management project, the team leader for the same project, a program manager of a consumer operated community mental health center, an outcomes interviewer, a psycho-social rehabilitation specialist, a residential treatment coordinator, a consumer technical assistance training coordinator, and a consumer affairs specialist. He received the 2001 Mental Health Award of Excellence from the Oregon Department of Human Services and the 2002 Garrett Smith Memorial Award for his work as a consumer advocate.

WHO'D FUCK AN ABLEIST?

Katie F. Ball is a front-line activist with twenty years

experience in the disability rights and social change movements. She is a qualified secondary teacher, a community development worker, a wife and a mum. She has worked in the phone sex industry and taught Politics of Disablement at Kangan-Batman TAFE. Totally fascinated by human sexuality, Katie upholds the right of all people with disabilities to social and sexual equality. She has spoken at many forums and written a library-based dissertation on the sociological analysis of sexuality and the disability rights movement. She is bi-sexual and describes herself as a raving nymphomaniac. Katie was featured in award-winning television documentary *Untold Desires* and her photos have been published in *Picture Magazine*. Katie has Kugelberg Welander Syndrome (Juvenile Spinal Muscular Atrophy) and uses an electric wheelchair for mobility. The trauma of institutionalisation at the age of fifteen has left her with Separation Anxiety Disorder, Generalised Anxiety Disorder and Anxious Attachment. She lives with depression and continues to suffer panic attacks as a result.