



***Health Surveillance of People with Intellectual Disabilities:
What is there? What is possible?
Speaker and Facilitator Profiles***

Richard Balkus

Mr. Balkus is currently Associate Commissioner for Program Development and Research in the Office of Retirement and Disability Policy at the Social Security Administration. He previously served as Deputy Associate Commissioner for Disability and Income Assistance Policy. His current position includes research and analysis of disability issues and policies affecting the Supplemental Security Income and Social Security Disability Insurance programs. Mr. Balkus has published several papers in these areas. As Associate Commissioner for Program Development and Research, he represents the Commissioner of the Social Security Administration on the President's Committee for People with Intellectual Disabilities. Mr. Balkus also serves as a senior policy advisor to the United States Interagency Council on Homelessness.

Max Barrows

Max Barrows is an outreach coordinator with the Vermont statewide self-advocacy organization, Green Mountain Self-Advocates. In 2008, he was elected as a regional representative for the national organization, Self Advocates Becoming Empowered (SABE).

Lisa Belzak

Ms. Lisa Belzak works for the Public Health Agency of Canada. The mission of the Public Health Agency of Canada (PHAC) is to promote and protect the health of Canadians through leadership, partnership, innovation and action in public health. Surveillance at the national level is a core function of the Agency. Ms. Belzak is responsible for developing a new national surveillance system to monitor Developmental Disorders in Canada. She received her Master's in Epidemiology from the University of Toronto and has worked at the national level for the past 10 years developing a variety of surveillance systems for both infectious and non-infectious diseases.

Aaron Bishop

Mr. Bishop joined the National Council on Disability (NCD) staff in November 2010 as its Executive Director. He came to NCD with nearly 20 years of experience working with and for individuals with disabilities in both the service provision and public policy sectors. Prior to assuming his role at NCD, he was a Professional Staff Member for the U.S. Senate Health,

Education, Labor and Pensions (HELP) Committee for Senator Mike Enzi, where he handled disability related policy. Mr. Bishop also worked for Senator Judd Gregg on the HELP Committee, when the Senator chaired the committee. Mr. Bishop began his work on Capitol Hill through a Kennedy Foundation Public Policy Fellowship to specifically work on federal disability policy and legislation. Mr. Bishop's other professional experiences have included work for the Association of University Centers on Disabilities, the Waisman Center University Center for Excellence in Developmental Disabilities, and the Mental Health Center of Dane County.

Alexandra Bonardi

Alixé Bonardi studies trends and patterns in health and service outcomes for people with intellectual and developmental disabilities. Building on her clinical experience as a pediatric and adult occupational therapist, she has particular interest in research that informs policies that support people to live healthy and safe lives of their choosing. As Assistant Director of the University of Massachusetts Medical School / Shriver Center's Center for Developmental Disabilities Evaluation and Research (CDDER), she manages multiple projects that relate to promoting health and access to support services. She is principal investigator for the CDC/AUCD RTOI 2010 – Health Surveillance of Adults with Intellectual Disability project.

Coleen A. Boyle

Dr. Boyle serves as Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC. Dr. Boyle joined NCBDDD's Division of Birth Defects and Developmental Disabilities in 1988, first as Section Chief and later as Branch Chief and Division Director. In 2001, Dr. Boyle was named the Associate Director for Science and Public Health for CDC's newly created National Center on Birth Defects and Developmental Disabilities (NCBDDD). In October 2004, she was appointed the Director of the Division of Birth Defects and Developmental Disabilities. Before joining CDC in 1984 to work on the Agent Orange studies, Dr. Boyle was a faculty member in epidemiology at the University of Massachusetts, Program in Public Health. As part of the Agent Orange staff, Dr. Boyle served as the principal investigator for the Vietnam Experience mortality studies and as senior epidemiologist for a large, multi-centered cancer case-control study. Her interest and expertise is in the epidemiology and prevention of birth defects and developmental disabilities. She is the recipient of the CDC Charles C. Shepard Award for scientific excellence in 1997 and 2004 and has authored or co-authored more than 100 peer-reviewed and other scientific publications.

Valerie Bradley

Ms. Bradley has been the President of the Human Services Research Institute since its inception in 1976. Ms. Bradley has directed numerous state and federal policy evaluations that have contributed to the expansion, enhancement and responsiveness of services and supports to people with disabilities and their families. She helped to design skills standards for human services workers, conducted a study to translate the experience with decentralization in Scandinavia to an American context, is the principal investigator of a national technical assistance initiative in quality assurance, and co-directs a national 25 state initiative on performance measurement, the National Core Indicators. She co-edited a book titled *Creating Individual Supports for People with Developmental Disabilities*, *Quality Enhancement in Developmental Disabilities*, and a recent book titled *Quality of Life for People with Intellectual*

and Other Developmental Disabilities. Ms. Bradley is the recent past Chair of the President's Committee on Persons with Intellectual Disabilities. She is also a Past President of the American Association on Intellectual and Developmental Disabilities.

Sue Carmichael

Sue Carmichael is part of the Valuing People Now delivery team, at the Department of Health for England to help make the Government's learning disabilities agenda happen. Her current remit is as the national lead on health and for people with the most complex needs. Dr. Carmichael is a learning disability nurse with a wide range of experience from institutional settings to community care, education and development, a trust nurse executive and now working in a policy setting in Government. She was part of the team that developed the Government's learning disability strategy, Valuing People and has worked in the Department of health since then. Ms. Carmichael also worked at South Bank University in their social work and learning disability nursing team.

Ron Chalmers

Dr. Chalmers has held the position of director general of the Disability Services Commission for the Government of Western Australia since November 2007, and prior to that held senior executive positions at the commission. Dr. Ron Chalmers has a background in teaching and educational administration. He became involved in disability services in 1991 as Local Area Coordinator Supervisor for the Upper Great Southern region. Dr. Chalmers has extensive experience in the development and expansion of Local Area Coordination and in the needs of people living in rural communities. He holds a PhD enquiring into the inclusion of children with severe and profound disabilities into mainstream schooling. He was a participant in the inaugural Australia and New Zealand School of Government Executive Fellows Program.

Errol Cocks

Dr. Cocks is Director of the Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, Curtin University of Technology in Australia. Following early career work in education and educational psychology with the WA Education Department, Dr. Cocks began work in the disability sector in 1970. He has held a number of additional roles in non-government and advocacy organizations in disability and mental health, having taught and developed undergraduate and postgraduate courses in social policy, human services, and disability studies in Australia, the UK, and the Middle East. Further, Dr. Cocks has extensive experience in the design and provision of training for health and human service workers that focused on service design and practices and the values base of services. This has included evaluation of services in the disability, aged, and mental health sectors in Australia and internationally.

Rosalyn Correa De Araujo

Dr. Correa is a cardiovascular pathologist trained at the National Heart, Lung, and Blood Institute. She is currently the Deputy Director of the Office on Disability. Prior to this position she served as the Director of the Office of the Americas Region in the Office of Global Health Affairs and the Secretary's Delegate to the U.S. Mexico Border Health Commission. Dr. Correa successfully led a Secretarial priority initiative on health diplomacy in Central America which

culminated in partnerships between HHS and foreign Ministries of Health in that region. As the Agency for Healthcare Research and Quality's former Director of Women's Health and Gender-Based Research, Dr. Correa expanded the women's health agenda to encompass a new field of inquiry – gender-based research – and received AHRQ Director's Award of Excellence for introducing a gender-based approach to health services research. As AHRQ's spokesperson in the Spanish language, she received AHRQ Director's Award of Merit for ensuring prevention and quality messages educated professionals and Hispanic communities. As a biomedical and a health services researcher, Dr. Correa has numerous scientific publications in peer-reviewed journals, as well as chapters in pharmacology textbooks, and consumer products.

Steven M. Eidelman

Mr. Eidelman is the University of Delaware's H. Rodney Sharp Professor of Human Services Policy and Leadership. He holds joint faculty appointments in the School of Urban Affairs and Public Policy and the Department of Individual and Family Studies and is a Senior Fellow in the Center for Disabilities Studies. Mr. Eidelman is the former Executive Director of the Joseph P. Kennedy Jr. Foundation, leading the organization to implement innovative projects, programs and cutting-edge policies. Prior to his appointment with the University of Delaware, Mr. Eidelman was the Executive Director of The Arc of the United States, an advocacy group for people with cognitive disabilities and their families, which has more than 900 state and local chapters and 100,000 members. Mr. Eidelman also served as Deputy Secretary for Mental Retardation in the Pennsylvania Department of Public Welfare.

Eric Emerson

Dr. Emerson is Co-Director of the English specialist public health observatory on intellectual disability. He is also Professor of Disability & Health Research at Lancaster University (UK) and Visiting Professor at the University of Sydney. His research addresses the health and social inequalities faced by people with disabilities and, in particular, people with intellectual and developmental disabilities. He is responsible for liaison between the International Association for the Scientific Study of Intellectual Disability (IASSID) and the World Health Organization. He previously held appointments at the University of Manchester, University of Sydney, University of Kent at Canterbury and in a range of health care organizations in the UK and Canada. His current research interests include understanding the social, cultural and economic bases of the health and social inequalities faced by disabled children, their families and adults with intellectual or developmental disabilities, building resilience among and improving the physical and mental health of disabled children, their families and adults with intellectual/developmental disabilities, and policy and practice relating to disabled children, their families and adults with intellectual/developmental disabilities as well as disability in low and middle income economies.

Glenn Fujiura

Dr. Fujiura is a faculty member of the Department of Disability and Human Development at the University of Illinois at Chicago, where he serves as the Director of Graduate Studies for the MS program, and as Associate Dean for Academic Affairs for the College of Applied Health Sciences. His research includes studies of fiscal structure and demography of the disability service system, on family policy, evaluation of long-term care services, poverty and disability, ethnic and racial issues in disability, and on the statistical surveillance of disability. Current

research projects include a methodological study of the reliability and validity of self-reported health among persons with intellectual disabilities, secondary analysis of the demographics of family support, a latent class modeling analysis of knowledge utilization by recipients of ADA related technical assistance, and demographic analysis of racial and ethnic disparities in accessing health care among Americans with disabilities in conjunction with the Oregon Health Sciences University. Dr. Fujiura is a member of the National Academy of Sciences Committee on the External Evaluation of the National Institute on Disability and Rehabilitation Research and was recently appointed editor-in-chief of the journal, *Intellectual and Developmental Disabilities*.

Michael Fox

Dr. Fox is the Associate Director for Science in the Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. Dr. Fox received a ScD, with a major in health policy and management, from the School of Hygiene and Public Health at The Johns Hopkins University. He has graduate degrees in Studies in Behavioral Disabilities and Biostatistics and Clinical Epidemiology from the University of Wisconsin and Medical College of Wisconsin. Dr. Fox's publications appear in *Health Affairs*, *Journal of Ambulatory Care Management*, the *American Journal of Public Health*, the *Journal of Poverty*, the *Journal of Disability Studies*, *Medical Care*, the *Journal of Health and Social Policy*, the *Journal of Family and Community Health*, *Kansas Journal of Law and Public Policy*, *Kansas Policy Review*, and the *Journal of Rehabilitation*. Dr. Fox's teaching and research interests are in the areas of public health, disability and health policy. He has taught courses on Medicare and Medicaid, analysis, and health policy in the MHA and doctoral programs, and taught Public Health Administration in the Master of Public Health program for more than 10 years.

Anne Fracht

Anne Fracht is the current President of Massachusetts Advocates Standing Strong (MASS). Ms. Fracht began her journey as a self-advocate in 1997 when she joined MASS, and became its second chairperson in 2002 until 2005. An Administrative Aide at Vinfen since 1996 and a former member of Vinfen's Human Rights Committee, Fracht serves on the Board of Directors of The ARC of Greater Boston and represents MASS on numerous steering committees at the state and national level. She has received several prestigious awards including the 2002 Ruth M. Batson Advocate of the Year Award along with Senate and House citations.

Matthew Janicki

Matthew P. Janicki, is research associate professor of human development at the Institute of Disability and Human Development at the University of Illinois at Chicago, and serves as director for technical assistance for the Rehabilitation Research and Training Center in Aging with Developmental Disabilities at the University. Formerly, he was director for aging and special populations for the New York State Office of Mental Retardation and Developmental Disabilities in Albany. Dr. Janicki was a Joseph P. Kennedy, Jr. Foundation's Public Policy Leadership Fellow, spending a sabbatical year at the National Institute on Aging and the United States Senate. He is the author/editor of numerous books and articles in the area of aging, dementia, public policy, and rehabilitation with regard to people with intellectual and

developmental disabilities and has lectured and provided training in aging and intellectual disabilities around the world. He is a fellow of the American Psychological Association and the Gerontological Society of America. Dr. Janicki served as the chair of the United States International Council on Mental Retardation and Developmental Disabilities and as the founding chair of the Aging Special Interest Research Group for IASSID. Currently he serves as one of the executive officers of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and is the editor-in-chief of IASSID's Journal of Policy and Practice in Intellectual Disabilities.

George Jesien

Dr. Jesien is the Executive Director of the Association of University Centers on Disabilities (AUCD) which represents national networks of Universities Centers conducting research, training and service for and with people with disabilities and their families. He has had over 30 years of experience in the disabilities field in various capacities including school psychologist, project manager, course faculty, and director of state and federally funded programs for children with special needs and their families. He has worked in educational agencies, Head Start, university settings and a foundation. Previous positions include serving as the executive director of the Joseph P. Kennedy, Jr. Foundation, director of the Early Intervention Program at the Waisman Center at the University of Wisconsin-Madison and executive director of the Portage Project. Dr. Jesien was awarded a Joseph P Kennedy, Jr. Foundation Public Policy Fellowship to work with the US Senate Subcommittee on Disability Policy working on disability related legislation. He has served as the president of the National and State Divisions for Early Childhood of the International Council for Exceptional Children and received outstanding service awards at the state and national levels.

Ruth Katz

Ms. Katz serves as Deputy to the Deputy Assistant Secretary for the Office of Disability, Aging and Long-Term Care Policy, in the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. She oversees a range of policy and research activities related to disability and aging. With over 25 years of experience with disability and long-term care issues, these include: managed care and other health and long-term care delivery systems--financing, structure and quality; home and community-based services; nursing home and post-acute care financing and quality; Medicare, Medicaid and private insurance policy related to people with disabilities and chronic conditions; alternative residential systems; and health information technology as it relates to post-acute and long-term care.

Michael Kerr

Dr. Kerr is a Professor of Learning Disability Psychiatry and Honorary Consultant in Neuropsychiatry at Cardiff University. Dr. Kerr initially trained as a general practitioner before training in psychiatry. Dr. Kerr's clinical practice is in the types of epilepsy associated with learning disability and in the assessment and treatment of epilepsy and psychiatric disorder. He has published widely on the subject of health care delivery for people with a learning disability, including a range of studies on the management of epilepsy and the delivery of Health Checks. Dr. Kerr is particularly interested in how employment can improve the health of people with a

learning disability. He is on the council of the International Association for the Scientific Study of Intellectual Disability. Dr. Kerr also chairs the Epilepsy Action Wales advisory board and works as a medical advisor to the Rett Society and Epilepsy Bereaved.

Gloria Krahn

Gloria Krahn is the Director of the Division of Human Development and Disability at the National Center on Birth Defects and Developmental Disabilities (NCBDDD). She joined the CDC after 25 years as an academic clinician, researcher, teacher and administrator. Her early work in child development was followed by an interest in disabilities and development across the lifespan. Dr. Krahn is widely regarded as a national and international expert in the field of disability and public health. Her publications and lectures have bridged the fields of child development, childhood-onset disability, health status measurement and health promotion among adults with disabilities. Dr. Krahn's research has been funded by the NIH, the U.S. Department of Education, the Maternal and Child Health Bureau at HRSA, and the CDC. Dr. Krahn is the author of numerous publications related to disability and child development, and she is the co-editor of the first major textbook on Disability and Public Health.

K. Charlie Lakin

K. Charlie Lakin is Director, Research and Training Center on Community Living, University of Minnesota. Dr. Lakin has 40 years' experience in services to individuals with intellectual and developmental disabilities as a teacher, researcher, consultant and advocate. He has directed numerous research and training projects and has authored or co-authored 300 publications based on that work. He frequently consults with state, federal and international agencies in matters of policy, research and evaluation. Among recognitions for his work are appointments by President Clinton to the President's Committee on Persons with Intellectual Disabilities, the American Association on Intellectual and Developmental Disabilities Dybwad Humanitarian Award, the University of Minnesota's Outstanding Community Service Award and the Distinguished Research Award of The Arc of the United States.

Sharon Lewis

Sharon Lewis is the Commissioner of the Administration on Developmental Disabilities. Well known as an effective advocate, Sharon has a proven track record in championing disability issues, while working for a better quality of life for all. Sharon has worked more than 10 years at local, state and national levels. She originally came to Washington, DC to serve as a Joseph P. Kennedy, Jr. Foundation Fellow, working for Senator Chris Dodd's HELP Subcommittee on Children and Families. In 2007, she joined Chairman George Miller's Education & Labor Committee staff as Senior Disability Policy Advisor, where she worked on disability-specific policy issues including the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the Rehabilitation Act. Furthermore, Sharon addressed disability concerns in other legislation before the Committee including the Higher Education Act, the reauthorization of the Elementary and Secondary Education Act, Head Start, and the Workforce Investment Act. More recently, Sharon crafted the "Keeping All Students Safe Act" on behalf of Chairman Miller, a bill that passed the House in March 2009 and limited the use of restraint and seclusion in schools. She was also chosen to serve on President Obama's Transition Team with

responsibility for reviewing the Office of Special Education and Rehabilitative Services and related policy issues.

Hélène Ouellette-Kuntz

Hélène Ouellette-Kuntz is an Associate Professor in the Departments of Community Health & Epidemiology and Psychiatry at Queen's University in Kingston, Ontario, Canada. She is also appointed to a community-based agency for persons with intellectual disabilities in Southeastern Ontario (Ongwanada) where she works as an epidemiologist. Through the Division of Developmental Disabilities in the Department of Psychiatry at Queen's University, Hélène works with a multidisciplinary team providing service, teaching and research related to the health of persons with intellectual disabilities. She has recently undertaken doctoral studies in Health Geography at Queen's University. Hélène is the Director of the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities. This extensive research partnership, involving a dozen researchers and over 40 community agencies that support approximately 4,000 individuals with intellectual disabilities, is funded by the Social Sciences and Humanities Research Council of Canada. The research partnership is focusing on the impact of community integration policy across a service system (see www.seocura.org). She is also the Director of a national study of the epidemiology of autism through the Autism Spectrum Disorder Canadian-American Research Consortium which is funded by the Canadian Institutes of Health Research.

Julie Petty

Julie Petty played a leading role in building the self-advocacy movement in Arkansas. She was state coordinator of People First of Arkansas from 1998 to 2007, and served as chair of Self Advocates Becoming Empowered (SABE) from 2006 to 2008. She is a graduate of the University of Arkansas and holds a degree in journalism. She is a consultant with Human Service Research Institute (HSRI), and has led projects on self-advocacy and youth leadership. In her current role she works as a Disability Specialist with the Partners for Inclusive Communities/Arkansas' University Center on Disabilities and works with Arkansas People First.

Ismaila Ramon

Ismaila Ramon joined NCBDDD-CDC, as an Association of University Centers on Disability (AUCD) Surveillance and Epidemiology Fellow. Ramon is a member of the Disability and Health Branch in the Division of Human Development and Disability. He works the DHDD branch to identify health disparities and to engage in epidemiological research to identify risk and protective factors for those disparities. Before joining CDC, Ramon worked as an Injury and Disability Program Epidemiologist with the Kansas Department of Health and Environment providing epidemiologic support to statewide injury and disability programs. He is a member of the Council of State and Territorial Epidemiologists, American Association on Health and Disability, and the American Public Health Association. He is also an adjunct professor with Kaplan University and has served on the Kansas State Planning Committee for the Prevention of Sexual and Domestic Violence. Ramon received a bachelor's degree in Human Anatomy from Ahmadu Bello University in Nigeria and a Master of Public Health degree in epidemiology from the University of Oklahoma. He is currently working on his doctoral degree in Public Health.

Laverdia Roach

Laverdia Taylor Roach serves as Director of the President's Committee for People with Intellectual Disabilities (PCPID) within the Administration for Children and Families (ACF), United States Department of Health and Human Services. The Committee, established and continued by Executive Order, has the responsibility to provide advice and assistance to the President of the United States and the Secretary of Health and Human Services, through the Commissioner of Administration on Developmental Disabilities, on a broad range of topics related to intellectual disabilities. As Director of the President's Committee for People with Intellectual Disabilities, Mrs. Roach serves as policy advisor to the Commissioner of Administration on Developmental Disabilities, Assistant Secretary for Children and Families, and the Secretary of HHS in matters relating to the field of intellectual and related disabilities and citizens diagnosed with these disabilities. She is responsible for management, direction, and oversight of the day-to-day operations of the President's Committee, assuming the leadership role for supervision of staff and administrative functions; and planning, implementing, monitoring, and evaluating special initiatives, including the preparation of the Committee's mandated Annual Report to the President. She represents the Committee in constituency group and interagency collaborative activities, on ad hoc committees, and at special meetings in the private and public sector with a stated purpose to improve the quality of life that is experienced by citizens with intellectual disabilities.

Sue Swenson

Sue Swenson serves as deputy assistant secretary in the Office of Special Education and Rehabilitative Services in the US Department of Education. She served as commissioner for developmental disabilities in the Clinton administration, and as executive director of both the Kennedy Foundation and The Arc. She is the mother of young man with profound levels of intellectual disability.