
Putting childhood disability on the map

A symposium cosponsored by Columbia University and UNICEF



COLUMBIA UNIVERSITY EPIDEMIOLOGY
SCIENTIFIC SYMPOSIUM



Columbia University
MAILMAN SCHOOL
OF PUBLIC HEALTH

SEPTEMBER 25, 2013

Dear colleagues,

Welcome to today's symposium, *Putting childhood disability on the map*.

This event, cosponsored by UNICEF, is one in a series of Columbia University Epidemiology Scientific Symposia (CUESS), which are dedicated to exploring cutting-edge scientific topics in epidemiology and population health. The series brings together leaders in the field and aims to explore state-of-the-science and to push the research agenda forward.

Future symposia will include *Philosophy and medicine: Explanation and prediction in the social sciences* on November 22, 2013.

Today's symposium brings together national and international research, policy, and government leaders for a full day of talks and discussion addressing such topics as: why childhood disability should be an international priority, disability rights for children, building capacity for assessment, working across the health, education and welfare sectors, and taking to scale interventions to both prevent child disability and to support children living with disability. I hope that you will find the ensuing conversation stimulating and informative.

Thanks go to Dr. Leslie Davidson and Dr. Claudia Cappa for all their work organizing today's event, to the speakers who join us today to share their perspectives, and to the staff members who work together to make it all go smoothly.

Warm regards,

A handwritten signature in cursive script that reads "Sandro Galea".

Sandro Galea, MD, DrPH
Gelman Professor and Chair
Department of Epidemiology

AGENDA

8:30 – 9:00 CHECK-IN AND BREAKFAST

9:00 – 9:15 WELCOMING REMARKS AND OVERVIEW OF THE DAY

Sandro Galea, MD, DrPH

Claudia Cappa, PhD

Leslie Davidson, MD, MSc

9:15 – 9:55 MOVING TOWARDS INCLUSION: WHERE ARE WE NOW?

Maureen Durkin, PhD, DrPH

9:55 – 10:20 ENSURING INCLUSIVE SERVICES: LEAVING NO ONE BEHIND

Javed Abidi

10:20 – 11:20 PANEL DISCUSSION UNICEF: AN AGENDA FOR ACTION

Strategic Opportunities for Interventions in the Lifecycle

Rosangela Berman-Bieler, MA

Evidence and Advocacy: The State of the World's Children 2013

Abid Aslam, MA

Priorities for Data Collection

Claudia Cappa, PhD

11:20 – 11:35 BREAK

11:35 – 12:00 TOWARDS INTERNATIONALLY COMPARABLE STATISTICS ON DISABILITY: THE WASHINGTON GROUP AND UNICEF COLLABORATION

Jennifer Madans, PhD

12:00 – 12:40 BUILDING CAPACITY TO MAKE ASSESSMENT POSSIBLE IN LOW INCOME COUNTRIES

Michael Boivin, PhD, MPH

12:40 – 1:30 LUNCH

1:30 – 1:50 EXCLUSION, INCREASED VULNERABILITY TO HIV/AIDS INFECTION: THE CASE OF DEAF AND HARD OF HEARING LEARNERS IN SOUTH AFRICA

Sumaya Mall, PhD

1:50 – 2:30 BRINGING MENTAL HEALTH AWARENESS INTO THE CLASSROOM: A MODEL THAT ENGAGES CHILDREN TO SUPPORT EACH OTHER

Christina Hoven, MA, MPH, DrPH

2:30 – 2:45 BREAK

2:45 – 3:10 ARE WE MAKING PROGRESS IN SOCIAL INCLUSION? A PROPOSAL FOR A MULTI-DIMENSIONAL INDEX FOR THE INCLUSION OF CHILDREN WITH DISABILITIES

Carolina Cuevas Melo

3:10 – 3:35 AUTISM SPEAKS AND THE GLOBAL AUTISM MOVEMENT: AWARENESS, ADVOCACY AND SCIENCE

Andy Shih, PhD

3:35 – 4:05 AUDIENCE DISCUSSION TAKING IT TO SCALE: PUTTING CHILDHOOD DISABILITY ON THE MAP

4:05 – 4:20 CLOSING REMARKS AND SUMMARY

Leslie Davidson, MD, MSc

HOSTS



CLAUDIA CAPPA, PhD

STATISTICS AND MONITORING SPECIALIST, STATISTICS AND MONITORING SECTION, DIVISION OF POLICY AND PRACTICE, UNICEF

Claudia Cappa, PhD is currently working as Statistics and Monitoring Specialist in the Statistics and Monitoring Section, Division of Policy and Practice, at the UNICEF headquarters. She is the focal point for data collection, data analysis and methodological work on child disability and on child protection from violence, exploitation and abuse. The support for these activities includes elaboration of survey questionnaires and data collection tools, data analysis, production of reports and publications, as well as delivery and dissemination of final results. Prior to joining UNICEF, she was working at the University of Geneva and at the Institute for Social Studies of the International Labour Organization (ILO). Claudia Cappa holds a MA and a PhD in Development Studies from the Graduate Institute of International and Development Studies, Switzerland.



LESLIE L. DAVIDSON, MD, MSc

PROFESSOR OF EPIDEMIOLOGY AND PEDIATRICS, MAILMAN SCHOOL OF PUBLIC HEALTH AND COLLEGE OF PHYSICIANS AND SURGEONS, COLUMBIA UNIVERSITY

Leslie L. Davidson is Professor of Epidemiology and Pediatrics at the Columbia University Medical Center's Mailman School of Public Health and College of Physicians and Surgeons, where she currently leads the doctoral programs in Epidemiology. Dr. Davidson worked throughout her career in the broad area of Maternal and Child Health. Since 1984, she has been involved in studying the epidemiology of disability in children in low and middle income countries. She was a member of the team of researchers evaluating the Ten Questions, a screen for use in low and middle income countries which have very limited capacity for identification, assessment and treatment of neurodevelopmental disability. She is currently the principal investigator for a NIH funded cohort study of neurodevelopmental disability in preschool children in KwaZulu-Natal, South Africa (the Asenze Study) and a Co-Investigator of an NIH funded study in Benin assessing neurodisability in children whose mothers were anemic during pregnancy. Other research interests include the prevention of violence. She trained in Pediatrics at Columbia, in Epidemiology at the London School of Hygiene and in child mental health research through a post-doctoral fellowship at the Institute of Psychiatry in London.

PARTICIPANTS



JAVED ABIDI

WORLD CHAIR, DISABLED PEOPLE'S INTERNATIONAL

Javed Abidi is the pioneer of the cross-disability movement in India. In 1993, he founded the Disabled Rights Group to work specifically on cross-disability issues, particularly the drafting and passage of the Disability Act 1995. He has formed the one and only cross – disability network across India called National Disability Network (NDN) with a reach in more than 300 districts.

He was instrumental in setting up of National Centre for Promotion of Employment for Disabled People (NCPEDP) in 1996 and has been its Director since 1997.

He has successfully led several path breaking advocacy initiatives in India, including the drafting and enactment of the Disability Act of 1995, inclusion of disability as a separate category in Census 2001, India's ratification of CRPD in 2007, inclusion of disability in the Five Year Plans, and setting up of a separate Department of Disability Affairs.

With his election as DPI's World Chair in October, 2011, Abidi is now also focused on the global disability movement. He strongly believes that the voice of disability should always first focus on the global South where nearly 800 million of the world's 1 billion people with disabilities live.



ABID ASLAM, MA

EDITOR, THE STATE OF THE WORLD'S CHILDREN, DIVISION OF COMMUNICATION, UNICEF

Abid Aslam is the editor of 'The State of the World's Children,' which UNICEF publishes annually. Prior to joining UNICEF in 2011, he was an award-winning journalist specializing in international economic governance, development, and humanitarian affairs. He has provided policy and communications advice to international organizations and philanthropies and instructed graduate students and working journalists.



ROSANGELA BERMAN-BIELER, MA

CHIEF, DISABILITY SECTION, DIVISION OF PROGRAMMES, UNICEF

Rosangela Berman-Bieler is a Brazilian disability rights advocate for more than 35 years. Rosangela has joined UNICEF in February 2011 as Senior Adviser on Children with Disabilities and is currently serving as Chief of the UNICEF Disability Unit under the Gender, Rights and Civic Engagement Section, Program Division, in New York Headquarters. Living in the U.S. since 1995, her recent jobs have been for the World Bank, IADB, UNDP and other UN and international agencies. She is also the founder of the Inter-American Institute on Disability and Inclusive Development working to promote Human Rights and inclusiveness in the Latin America Region, and also in Portuguese speaking countries in Africa and Asia.



MICHAEL BOIVIN, PhD, MPH

PROFESSOR OF PSYCHIATRY AND NEUROLOGY/OPHTHALMOLOGY, MICHIGAN STATE UNIVERSITY

ADJUNCT ASSOCIATE PROFESSOR OF PSYCHIATRY, THE UNIVERSITY OF MICHIGAN

A former Fulbright research scholar to the DR Congo (1990-91) and Uganda (2003-04), Dr. Boivin presently leads several NIH-NICHD sponsored studies in Uganda pertaining to the neurocognitive rehabilitation in children surviving severe malaria and early caregiver training to enhance cognitive and psychosocial development in children with HIV. He is also a co-investigator on a pediatric study of the neuropsychological effects of konzo disease from poorly processed cassava in the DR Congo. Over the past 25 years Dr. Boivin has pioneered the application of neuropsychological assessment in gauging the neurocognitive impact of public health risk factors and interventions in African children. Much of this work is encompassed within a book he recently co-edited entitled *Neuropsychology of Children in Africa: Perspectives on Risk and Resilience* released by Springer Publishing in May, 2013.



CAROLINA CUEVAS MELO

MANAGER OF PUBLIC POLICY FOR SOCIAL INCLUSION, FUNDACIÓN SALDARRIAGA CONCHA

Carolina Cuevas Melo is a lawyer of the University of the Andes, with postgraduate studies at the Institute of Comparative Law in Paris and the University of Paris II - Panthéon Assas. She is currently pursuing a Master's in Development Practice Management at the Universidad de los Andes in Bogotá.

As manager of public policies for social inclusion at Fundación Saldarriaga Concha, Ms. Cuevas Melo advises the design of inclusive public policies and the proposal of a multidimensional Index of social inclusion. She is also promoting Public-private partnership to strengthen the inclusion of children with disabilities and the independent living and access to opportunities for different excluded social groups.

She also worked as advisor for Colombia's Vice-President, during the negotiation of the Convention on the Rights of Persons with Disabilities at the UN, and participated in the design of National Programme for Citizen Service at the Departamento Nacional de Planeación of this country.



MAUREEN DURKIN, PhD, DrPH

PROFESSOR OF POPULATION HEALTH SCIENCES AND PEDIATRICS, UNIVERSITY OF WISCONSIN-MADISON

Maureen Durkin is an epidemiologist, Professor of Population Health Sciences and Pediatrics, and Waisman Center investigator at the University of Wisconsin School of Medicine and Public Health. She received her undergraduate degree and PhD in anthropology from the University of Wisconsin-Madison, and her MPH and DrPH degrees in epidemiology from Columbia University. Her research interests include the epidemiology, prevention, antecedents and consequences of neurodevelopmental disabilities and childhood injuries. She has contributed to the development of cross-cultural methods for screening for developmental disabilities and methods for surveillance of childhood injuries, and has directed international studies of the prevalence and causes of neurodevelopmental disabilities in low and middle income countries. She has also directed cohort studies of neuropsychological outcomes of neonatal brain injuries associated with preterm birth and with metabolic disorders detected on newborn screening, and is currently principal investigator of the Wisconsin site of the Center for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network.



CHRISTINA HOVEN, MA, MPH, DrPH

PROFESSOR OF EPIDEMIOLOGY (IN PSYCHIATRY), COLUMBIA UNIVERSITY

Dr. Hoven is a child psychiatric epidemiologist. Much of her recent research has addressed the impact of parental exposure to trauma on their children. Her epidemiological investigation of 8,236 New York City public school children following the September 11th attack on the World Trade Center provided strong evidence for the parent-to-child “transmission” of trauma, indicated by elevated rates of psychopathology in children by level of parental exposure. These findings have led to numerous additional studies addressing this relationship; including children of 9/11 Evacuees and First Responders, and children of Criminal Justice System Involved parents. Most recently she is conducting a study addressing the long-term effects of direct exposure to the WTC attacks in children who were 0-12 on September 11, 2001. Internationally, Dr. Hoven’s research addresses mental health awareness and suicide intervention across diverse countries, cultures and languages, including several broad multi-country studies in Europe and Asia.



JENNIFER MADANS, PhD

ASSOCIATE DIRECTOR FOR SCIENCE,
NATIONAL CENTER FOR HEALTH
STATISTICS (NCHS)

Jennifer H. Madans, PhD, has been the Associate Director for Science, National Center for Health Statistics, since May, 1996 and is responsible for the overall plan and development of NCHS’s data collection and analysis programs. Since Dr. Madans joined the Center, she has concentrated her research efforts on data collection methodology, measurement of health and functioning and health services research. She has directed two national longitudinal studies (NHANES I Epidemiologic Follow-up Study and the National Nursing Home Follow-up Study) as well as the redesign of the National Health Interview Survey questionnaire. She is a founding member and chair of the steering committees for three UN sponsored initiatives to develop internationally comparable measures of disability and health. Dr. Madans is a graduate of Bard College (BA) and the University of Michigan (MA and PhD, Sociology). She completed a Postdoctoral Fellowship in the Department of Epidemiology and Public Health at Yale University.



SUMAYA MALL, PhD

FOGARTY AIDS INTERNATIONAL
TRAINING AND RESEARCH PROGRAM
FELLOW, COLUMBIA UNIVERSITY

Dr. Sumaya Mall completed her PhD at Stellenbosch University in 2012 on disability and HIV/AIDS. Her thesis was supervised by Prof Leslie Swartz with whom she is continuing postdoctoral research. Since completing her PhD, she has published several peer reviewed articles on disability and HIV/AIDS in local and international journals, has been interviewed on radio in South Africa and has written for the media in response to sexual abuse of disabled people in South Africa. She is currently a Fogarty postdoctoral trainee at Columbia University, where she will be working with Prof Leslie Davidson on further research on the disabling consequences of HIV/AIDS.



ANDY SHIH, PhD

SENIOR VICE PRESIDENT, SCIENTIFIC
AFFAIRS, AUTISM SPEAKS

Dr. Shih works closely with members of Autism Speaks' Board, Scientific Advisory Committee, senior staff and volunteer leadership to develop and implement the organization's research program. He oversees the etiology portfolio, which includes genetics, environmental sciences and epidemiology, as well as the Innovative Technology for Autism program, which supports the research and development of novel assistive technologies. Dr. Shih also leads Autism Speaks' international scientific development efforts, including the Global Autism Public Health Initiative, an international advocacy effort currently active in over 40 countries around the world that integrates awareness, research, and service development.

Dr. Shih's research background includes published studies in gene identification and characterization, virus-cell interaction, and cell-cycle regulation. He was instrumental in the cloning of a family of small GTPases involved in cell-cycle control and nuclear transport, and holds three patents on nucleic acids-based diagnostics and therapeutics. Dr. Shih is a resident of New York City, where he lives with his wife and two children.

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