Three interconnected meetings focusing on the health needs of persons with intellectual disabilities

**MAY 23, 2011**

### Meeting 1:

**Health Surveillance of People with Intellectual Disabilities:**

*What is there? What is possible?*

**May 23-24, 2011**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:00am</td>
<td>Continental Breakfast / Meet and Greet</td>
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<tr>
<td>8:30am</td>
<td><strong>Welcome and Meeting Orientation</strong></td>
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<tr>
<td></td>
<td>- Dr. Coleen Boyle, Acting Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention</td>
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<td>- Dr. Glenn Fujiura, Associate Dean, College of Applied Health Sciences, Associate Professor and Director of Graduate Studies, Department of Disability and Human Development, University of Illinois at Chicago</td>
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<tr>
<td>9:00am-10:15am</td>
<td><strong>Federal Plenary Panel: Utility of Data and Generating Data</strong></td>
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<td></td>
<td><strong>Moderator:</strong> Dr. Michael Fox, Division on Human Development and Disability, NCBDDD/CDC</td>
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<td><strong>Panelists:</strong></td>
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<td></td>
<td>- Sharon Lewis, Commissioner, Administration on Developmental Disabilities</td>
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<td>- Laverdia Roach, Acting Executive Director, President’s Committee for Persons with Intellectual Disabilities</td>
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<td>- Dr. Rosaly Correa De Araujo, Office on Disability, US Department of Health and Human Services</td>
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<td>- Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services, US Department of Education</td>
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<td>- Richard Balkus, Associate Commissioner, Office of Program Development and Research, Office of Retirement and Disability Policy, Social Security Administration</td>
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<td>- Ruth Katz, Deputy to the Deputy Assistant Secretary of the Office of Disability, Aging, and Long-Term Care Policy</td>
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<tr>
<td>10:15am-10:30am</td>
<td><strong>Break</strong></td>
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<td>10:30am-11:15am</td>
<td><strong>Self-Advocate Panel</strong></td>
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<td><strong>Moderator:</strong> Dr. George Jesien, Association of University Centers on Disabilities</td>
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<td><strong>Panelists:</strong></td>
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<td>- Max Barrows, Outreach Coordinator, Green Mountain Self Advocates &amp; Vice-President, Self-Advocates Becoming Empowered</td>
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<tr>
<td>11:15am-12:15pm</td>
<td><strong>Data Analyzers</strong>&lt;br&gt;Moderator:&lt;br&gt;Dr. Glenn Fujiura, Associate Dean, College of Applied Health Sciences, Associate Professor and Director of Graduate Studies, Department of Disability and Human Development, University of Illinois at Chicago&lt;br&gt;Panelists:&lt;br&gt;Valerie Bradley, President, Human Service Research Institute&lt;br&gt;Dr. Charlie Lakin, Director, Research &amp; Training Center on Community Living, University of Minnesota&lt;br&gt;Ismaila Ramon, Disability Surveillance and Epidemiologic Research Fellow, NCBDDD/CDC</td>
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<tr>
<td>12:15pm - 1:00pm</td>
<td><strong>Networking Lunch</strong></td>
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<tr>
<td>1:00pm-2:00pm</td>
<td><strong>RTOI presentation: Operational Definitions</strong>&lt;br&gt;Alexandra Bonardi, MHA, OTR/L, Assistant Director, Center for Developmental Disabilities Evaluation and Research, Center for Health Policy and Research, Instructor, Department of Family Medicine and Community Health</td>
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<tr>
<td>2:00pm-2:15pm</td>
<td><strong>Break</strong></td>
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<tr>
<td>2:15pm-3:30pm</td>
<td><strong>Workgroup 1: Research and Methods</strong>&lt;br&gt;<em>Judiciary Room</em>&lt;br&gt;Facilitator: Dr. Matthew Janicki, Research Associate Professor of Human Development at the Institute of Disability and Human Development at the University of Illinois at Chicago, Director for Technical Assistance for the Rehabilitation Research and Training Center in Aging with Developmental Disabilities at the University</td>
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<tr>
<td>2:15pm-3:30pm</td>
<td><strong>Workgroup 2: Data to Policy</strong>&lt;br&gt;<em>Cabinet Room</em>&lt;br&gt;Facilitator:&lt;br&gt;Aaron Bishop, Executive Director, National Council on Disability</td>
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<tr>
<td>3:30pm-3:45pm</td>
<td><strong>Break</strong></td>
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<tr>
<td>3:45pm-4:45pm</td>
<td><strong>Workgroup Reports</strong></td>
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<tr>
<td>5:00pm</td>
<td><strong>Networking Reception</strong></td>
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### May 24, 2011

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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>8:30am</td>
<td>Continental Breakfast and Networking with IASSID / Health SIRG</td>
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<tr>
<td>9:00am-9:15am</td>
<td><strong>Overview/Summary Day 1</strong></td>
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<tr>
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<td>Dr. Gloria Krahn, Director of the Division on Human Development and Disability, NCBDDD/CDC</td>
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<tr>
<td>9:15am-10:45am</td>
<td><strong>International Panel</strong></td>
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<td>Moderator:</td>
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<td></td>
<td>▪ Dr. Eric Emerson, Co-Director, Program Improving Health &amp; Lives: Intellectual Disabilities Observatory for England</td>
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<td>Panelists:</td>
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<td>▪ Dr. Ron Chalmers, Director General, Disability Services Commission, Australia</td>
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<td>▪ Dr. Errol Cocks, Director Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, Curtin University of Technology, Australia</td>
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<td>▪ Ms. Hélène Ouellette-Kuntz, Associate Professor in the Departments of Community Health &amp; Epidemiology and Psychiatry (Division of Developmental Disabilities) at Queen's University, Canada</td>
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<td>▪ Ms. Lisa Belzak, Epidemiologist, Health Surveillance and Epidemiology at Public Health Agency of Canada, Canada</td>
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<td>▪ Dr. Sue Carmichael, Office of the National Director for Learning Disabilities, National Lead for Health and People with Complex Needs, Valuing People Programme, Department of Health, United Kingdom</td>
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<td>▪ Dr. Michael Kerr, Professor of Learning Disability Psychiatry, Department of Psychological Medicine &amp; Neurology, Cardiff University, United Kingdom</td>
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<tr>
<td>10:45am-11:00am</td>
<td>Break</td>
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<tr>
<td>11:00am-11:25pm</td>
<td><strong>Wrap Up Open Mike</strong></td>
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<td>Moderator:</td>
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<td></td>
<td>▪ Steven M. Eidelman, H. Rodney Sharp Professor of Human Services Policy and Leadership Department of Human Development and Family Studies College of Education and Public Policy, Co-Director National Leadership Consortium on Developmental Disabilities University of Delaware</td>
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<tr>
<td>11:25am-11:45am</td>
<td><strong>Closing Remarks</strong></td>
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<tr>
<td></td>
<td>▪ Dr. Gloria Krahn, Director of the Division on Human Development and Disability, NCBDDD/CDC</td>
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### Meeting 2:

**Health Professional Education in Intellectual and Developmental Disabilities**  
**May 24 - 25, 2011**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>12:15pm-1:00pm</td>
<td>Health Professional Education Opening Lunch</td>
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<tr>
<td>1:00pm-1:15pm</td>
<td>Break</td>
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<tr>
<td>1:15pm-1:45pm</td>
<td>Welcome / Opening Remarks: Setting the Stage for “Closing the Gap”</td>
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<td>Specialized Health Professional Medical Education - Can it reduce health disparities?</td>
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<tr>
<td>1:45pm-1:55pm</td>
<td>National Curriculum Initiative in Developmental Medicine</td>
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<tr>
<td>2:35pm-2:50pm</td>
<td>Break</td>
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<tr>
<td>2:50pm</td>
<td>Australian Overview</td>
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<td>3:10pm</td>
<td>Canadian Overview</td>
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<tr>
<td>3:30pm</td>
<td>Netherlands Overview</td>
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<tr>
<td>4:05pm</td>
<td>United Kingdom Overview</td>
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<tr>
<td>4:25pm</td>
<td>United States Overview</td>
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<tr>
<td>4:45pm</td>
<td>Q&amp;A / Discussion</td>
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<td>5:05pm</td>
<td>Evaluations/ Adjourn</td>
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<tr>
<td>8:00am</td>
<td>Continental Breakfast</td>
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<tr>
<td>8:30am</td>
<td>Welcome and Introduction</td>
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<td></td>
<td>Rick Rader, MD, Vice President of Policy and Advocacy, AADMD</td>
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<tr>
<td>8:35am-10:00am</td>
<td>International Participants Panel—“Curriculum Building 101” - Lessons Learned</td>
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<td>Moderator - David Wood, MD, MPH, Professor, University of Florida College of Medicine - Jacksonville, Director, Jacksonville Health and Transition Services (JaxHATS)</td>
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<td>Robert (Bob) Davis, PhD, BS</td>
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<td>William F. Sullivan, MD, CCFP, PhD</td>
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<td>Ian Casson, MD</td>
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<td>Prof. Henny MJ van Schrojenstein Lantman-de Valk MD, PhD</td>
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<td>Marijke Meijer, MD</td>
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<tr>
<td>10:00am-10:15am</td>
<td>Break</td>
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<tr>
<td>10:15am-11:30am</td>
<td>National Curriculum Initiative in Developmental Medicine--Overview and Progress to Date</td>
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<td>Matthew Holder, MD, MBA</td>
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<td>Carl V. Tyler, Jr. MD, MS, CAQ-Geriatrics, CMD, Assoc. Professor, Medicine Institute, Cleveland Clinic Lerner College of Medicine Coordinator, Geriatric Education and Research</td>
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<tr>
<td>11:30am-12:00pm</td>
<td>Audience Feedback - Recommendations for NCIDM</td>
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<td>Moderator – Rick Rader, MD</td>
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<tr>
<td>12:00pm-1:00pm</td>
<td>Networking Lunch</td>
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<tr>
<td>1:00pm</td>
<td>Opening Remarks and Introduction</td>
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<td>Matthew Holder, MD, MBA</td>
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<td>Continuing the Call</td>
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<td>Rosaly Correa-de-Araujo, MD, MSc, PhD, Deputy Director, Office on Disability, US DHHS</td>
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<td>1:50pm</td>
<td>From Need to Action - “The View from Here”</td>
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<td>George S. Jesien, PhD, Executive Director, Association of University Centers on Disabilities</td>
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<tr>
<td>2:00pm</td>
<td>An Interdisciplinary Perspective – “What we know we know”</td>
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<td>Stephen Corbin, DDS, MPH, Senior Vice President, Special Olympics</td>
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<tr>
<td>2:20pm</td>
<td>Health Disparities - “The State of the State”</td>
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<td>Gloria Krahn, PhD, MPH, Director, Division of Human Development and Disability, Centers for Disease Control</td>
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<td>2:40pm</td>
<td>“Medically Underserved Population” Status - A Progress Report</td>
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<td>Barbara Kornblau, JD, OTR/L, Dean, School of Health Professions and Studies, University of Michigan – Flint, Member, HRSA’s Negotiated Rulemaking Committee on MUA/P and HPSA</td>
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<tr>
<td>3:00pm</td>
<td>Break</td>
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<tr>
<td>3:20pm</td>
<td>Promoting Curriculum Development in I/DD – “Challenges and Opportunities”</td>
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<td>Lois Nora, MD, JD, MBA, President Emeritus and Dean of Medicine Emeritus, Northeastern Ohio Universities College of Medicine, Member, Council of Academic Medicine</td>
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<td>3:40pm</td>
<td>Enhancing Training in Family Medicine – “Where do we go from here?”</td>
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### May 26, 2011

#### Meeting 3:
**State of Science Conference on Lifespan Health and Function of Adults with Intellectual and Developmental Disabilities: Translating Research into Practice**
May 26, 2011

<table>
<thead>
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<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:45am-8:15am</td>
<td>Continental Breakfast and Networking</td>
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<tr>
<td>8:15am-8:20am</td>
<td><strong>Welcome</strong></td>
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<tr>
<td></td>
<td>Dr. Tamar Heller, Professor, Head, Department of Disability and Human Development, University of Illinois at Chicago (UIC), Director of Rehabilitation Research and Training Center on Aging and Developmental Disabilities: Lifespan Health and Function (RRTCADD)</td>
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<tr>
<td>8:20am-8:40am</td>
<td><strong>Laying the Foundation for Research and Practice: Outcomes of the Meetings on Health Surveillance and Health Professional Education</strong></td>
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<tr>
<td></td>
<td>Dr. Glenn Fujiura, Associate Dean, College of Applied Health Sciences, Associate Professor, Department of Disability and Human Development, UIC, RRTCADD</td>
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<td>Dr. Gloria Krahn, Director, Division of Human Development and Disability, NCBDDD, CDC</td>
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<td>Dr. David O’Hara, COO, Westchester Institute for Human Health &amp; Development</td>
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<tr>
<td>8:40am-9:00am</td>
<td><strong>Emerging Research Findings on Lifespan Health and Function</strong></td>
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<td>Dr. Tamar Heller</td>
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<tr>
<td>9:00am-9:45am</td>
<td><strong>Health Disparities</strong></td>
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<td></td>
<td>Dr. James Rimmer Professor, Department of Disability and Human Development, Director of National Center on Physical Activity and Disability, RERC on Recreational Technology and Exercise Physiology for People with Disabilities, UIC, RRTCADD</td>
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<td></td>
<td>Dr. Glenn Fujiura</td>
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<td></td>
<td>Dr. Philip Davidson, Professor Emeritus of Pediatrics and Psychiatry, Strong Center for Developmental Disabilities, University of Rochester, RRTCADD</td>
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<tr>
<td>9:45am-10:15am</td>
<td><strong>Health Promotion Practices and Interventions</strong></td>
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<td>Dr. Beth Marks, Research Assistant Professor, Department of Disability and Human Development, Associate Director of Research, RRTCADD, UIC,</td>
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<td>Dr. Kelly Hsieh, Research Assistant Professor, Department of Disability and Human Development, Associate Director of Evaluation and Statistics, RRTCADD, UIC</td>
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<tr>
<td>10:15am-10:30am</td>
<td>Break</td>
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<tr>
<td>10:30am-11:25am</td>
<td><strong>Discussants</strong></td>
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<tr>
<td></td>
<td>Dr. I-Min Lee, Professor of Epidemiology, Harvard University</td>
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<td>Dr. Meindert Haveman, Professor of Special Education and Rehabilitation, University of Dortmund, Germany</td>
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<td>Dr. Thomas Prohaska, Professor, Community Health Sciences, Co-director of Center for Research on Health</td>
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<td>Time</td>
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| 11:25am-12:10pm | Embracing Family and Community Supports | Dr. Tamar Heller  
Dr. Sandy Magaña, Associate Professor, Social Work, Waisman Center, University of Wisconsin, Madison, RRTCADD  
Dr. Joy Hammel, Associate Professor, Occupational Therapy and Disability Studies, UIC, RRTCADD |
| 12:10pm-12:45pm | Lunch                                |                                                                                                |
| 12:45pm-1:30pm | Discussants                         | Dr. Eric Emerson, Co-director, Program for Improving Health and Lives: Intellectual Disability Observatory for England  
Gail Hunt, President and CEO, National Alliance for Caregiving |
| 1:30pm-2:10pm | Bridging the Aging and Developmental Disabilities Networks | Dr. Alan Factor, Research Assistant Professor, Institute on Disability and Human Development, UIC  
Matthew Janicki, Research Associate Professor, Institute on Disability and Human Development, UIC  
Associate Director for Training and Dissemination, RRTCADD |
| 2:10pm-3:00pm | Federal and National Organizations Panel | Robert Hornyak, Acting Director, Center for Policy, Planning, and Evaluation, Administration on Aging  
Sharon Lewis, Commissioner of the Administration on Developmental Disabilities  
Suellen Galbraith, Senior Policy Advisor, ANCOR  
Dr. Joe Caldwell, Director of Long-Term Services and Supports Policy, National Council on Aging |
| 3:00pm-3:15pm | Looking to the Future               | Dr. Tamar Heller                                                                          |
| 3:15pm-3:30pm | Closing Remarks                     | Sue Swenson, Acting Director of the National Institute on Disability and Rehabilitation Research, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services |