



***May 23-26, 2011***

***Hyatt Bethesda, Bethesda, MD***

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

**Meeting Proceedings**



# Health Frontier for Intellectual Disabilities

May 23, 2011-May 26, 2011

Bethesda, Maryland

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# Health Frontier for Intellectual Disabilities

## *Executive Summary*

May 23, 2011-May 26, 2011

Bethesda, Maryland

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Nearly 4 million Americans are estimated to have intellectual disabilities (IDs). The Health Frontier for Intellectual Disabilities set of meetings covered three key themes: surveillance, training, and research. The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) in collaboration with the Association of University Centers on Disabilities (AUCD), with support from Administration on Developmental Disabilities (ADD) under Contract #HHSP23320082917YC to AUCD, convened a meeting to consider the need for, potential uses of, and possible methods of conducting population surveillance of the health status of adults with ID. AUCD, The Mountain Area Health Education Center (MAHEC), the Physical Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability (IASSID), American Academy of Developmental Medicine and Dentistry (AADMD), Wal-Mart Foundation, and North Carolina Council on Developmental Disabilities collaborated to convene a meeting on health professional education in intellectual and developmental disabilities. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function through the National Institute on Disability and Rehabilitation Research (NIDRR) convened a meeting on lifespan health and function of adults with intellectual and developmental disabilities; translating research into practice.

### Health Surveillance of People with Intellectual Disabilities: What is there? What is possible?

#### *People with Disabilities Can Lead Long, Healthy Lives*

The impetus for this meeting derives from the U.S. Surgeon General's 2002 report on "Bridging the Gap" that established the critical need for better surveillance information on the health of persons with intellectual disabilities. This report "developed to help expand knowledge, understanding, and action by a broad range of people and groups," is the same directive for partners who are continuing the work toward defining health status and needs of people who have IDs.

A meeting on methodological issues was held in September 2009 in conjunction with IASSID's Roundtable on International Collaboration to Improve the Health of Individuals with Intellectual Disabilities (ICID) in Kingston, Ontario, Canada. A second working meeting of representatives

from the government, research, and advocacy communities was held in February 2010 in Washington, DC, to identify approaches toward implementation. This third meeting held in May 2011 drew a broad audience interested in health surveillance, health professional education, and research trends related to ID.

A panel of federal agency representatives from the Administration on Developmental Disabilities (ADD), President's Committee for Persons with Intellectual Disabilities (PCPID), Office on Disability (OD), Office of Special Education and Rehabilitation Services (OSERS), and the Social Security Administration (SSA) presented on the utility of data and generating data. This panel preceded a panel of self-advocates representing Self-Advocates Becoming Empowered, Partners for Inclusive Communities/Arkansas' University Center on Disabilities, Arkansas People First, and Massachusetts Self Advocates Standing Strong. Each panelist provided perspective by sharing their experiences with the health care system including challenges and successes. A panel of data analyzers provided an overview of the National Core Indicators effort first before describing the various challenges inherent in identifying people with ID as a first step before then attempting to describe their health status on a population level. A team from the University of Massachusetts Medical School Center for Developmental Disabilities Evaluation and Research and the Human Services Research Institute collaborating as part of a Research Topics of Interest (RTOI) project funded through the AUCD-CDC Cooperative Agreement has been working to establish an operational definition of ID and detailed activities of their project advisory group to date.

Two workgroups formed for in-depth discussions on two topics: a) research and methods and b) data and policy. The research and methods workgroup discussed several key themes including definitional issues, specificity, person-first language, eligibility as a basis for identification, and data linkages. The data and policy workgroup focused heavily on the availability of necessary data and also the ability to assemble available data and present it successfully in the current political climate. An international panel of participants described the data systems, political environments, success stories and challenges in Australia, Canada, and the United Kingdom.

Several key steps were identified to move surveillance efforts forward:

- Synthesize knowledge and ensure that it is held in an accessible repository of information
- Obtain funding and improve packaging of this cause
- Move forward with pilot state or regional projects
- Ensure the inclusion of international experiences and practices

## Health Professional Education in Intellectual and Developmental Disabilities

### *Health Care Professionals Are Responsible for Treating the Whole Person, Not Just the Disability*

An overarching theme throughout this meeting was infusing in health professionals the basic understanding that people with ID have the same rights as everyone else; to live a healthy life. A self-advocate panel including representatives from the North Carolina Council on Developmental Disabilities and Special Olympics answered several questions about their personal experiences with health professionals and provided best practice suggestions for partnering with people with ID to achieve better health outcomes. The AADMD spoke about the National Curriculum Initiative in Developmental Medicine (NCIDM) and distributed draft competencies. This project was initiated by three different groups, MAHEC, AADMD, and the Family Medicine Education Consortium. Participants from the United Kingdom, Australia, Canada and the Netherlands each provided an overview of health professional education (related to people with intellectual disabilities) in their respective countries as well as an analysis of curriculum building lessons learned followed by an overview of medical education around people with intellectual and developmental disabilities (I/DD) in the United States.

AADMD reviewed the process that has culminated in the NCIDM. This curriculum is meant to be a toolbox of goals and objectives in an ideal environment for educating medical students. Goals include core knowledge, intermediate and advanced level. These goals relate to the six core competencies of the Accreditation Council for Graduate Medical Education.

Dr. Correa-de-Araujo encouraged participants with several opportunities under the affordable care act and a list of reasons the Department of Health and Human Services (DHHS) OD has an interest in assisting with the development of curricula in this area. Special Olympics provided information on their web-based database of health care providers meant to prepare health professionals to support the health and well-being of people with I/DD).

Dr. Krahn reviewed current data on health disparity and ID providing a conceptual framework for understanding health equity and social determinants. A timely update was provided by Barbara Kornblau on the Health Resources and Services Administration's (HRSA) Negotiated Rulemaking Committee on Medically Underserved Populations and Health Professional Shortage Areas. She reminded the audience that this designation is a first step rather than a panacea. Dr. Lois Nora provided recommendations for promotion curriculum development in I/DD framing this task as one of leadership change. Ms. Heaton suggested a tiered curriculum model with a specific three phase approach to enhancing training in family medicine.

Future efforts are contingent upon sustained partnership between health professionals, researchers, and the university community. Communicating the need for training and keeping the issue visible is essential.

## Lifespan Health and Function of Adults with Intellectual and Developmental Disabilities: Translating Research into Practice

### *The Research Horizon*

Drs. Krahn and O'Hara provided a foundation for the beginning of the research meeting with their summation of both the Health Surveillance and Health Professional Education meetings. Dr. Krahn noted that multiple major issues in ID had arisen, that the purpose of good data is to drive practice and policy but in the long run it is to improve health outcomes of people with ID. Going forward from the surveillance meeting there will be three next steps: 1) planning for and linking electronic health records to build a strong database, 2) collecting data about social and life circumstances to learn more about the larger context in which people with ID live, and 3) designing quality health promotion activities. Work is in progress to establish people with ID as a Medically Underserved Population. The self-advocate presence reminded the audience that they are the experts in their own lives. Champions are needed who can move these major themes forward, create opportunities and open up new possibilities.

Dr. Tamar Heller reviewed emerging research trends in lifespan health and function: transition, environmental factors, siblings, increasing longevity, the recognition of a disability studies-social model approach to understanding the experience of people with disabilities, and some unfavorable policy trends. Two research projects on health disparities were presented by Dr. James Rimmer (Longitudinal Health and Intellectual Study on Obesity and Health Risk Behaviors) and Dr. Glenn Fujiura (Self-Reported Health-Related Quality of Life by Persons with ID). Dr. Rimmer described a longitudinal study examining the health behaviors and health outcomes in adults with ID, including changes across time in the prevalence of six health behaviors: physical activity, diet and weight control, oral health, smoking, alcohol consumption, and social participation. The aim of Dr. Fujiura's study was to develop a function-free, health-related quality of life instrument that would not penalize people with disabilities automatically.

Two research projects on health promotion practices and one intervention model were presented. Dr. Beth Marks (Sustainable Health Initiative Programs: Translating Knowledge through Interactive Distance Learning (iShip)), explained that the goal of the iShip project was to assess the effectiveness of the Health Matters program using an interactive distance learning (IDL) training model for staff working in multiple community-based organizations serving adults

with ID. As paid caregivers, direct support professionals (DSPs) are key in promoting sound health practices for people with ID. Dr. Kelly Hsieh (Identification of Falls Risk in Adults with ID) showcased research which determined the prevalence of falls among adults with ID living in community settings, compared adults with ID with non-fallers, measured the reliability of strength/balance instruments in adults with ID, and compared these instruments to those used in the general population. Research next steps include examining the relationship between falls and strength and balance measures as well as investigating the relationship between musculoskeletal markers and falls. Dr. Thomas Prohaska reviewed the common characteristics of evidence-based programs for successful translation and recommended using the RE-AIM framework for evaluating overall public health impact of evidence-based programs.

Dr. Heller provided background data on embracing family and community supports, followed by two research projects. Dr. Sally Magana (By Caring for Myself, I Can Care Better for my Family: a Pilot Health Education Intervention) described an intervention using the community health worker (Promotora de Salud) model in Latino communities supported by self-efficacy theory to assist mothers in improving their own health, as well as, train them to improve the health of other mother's in their community. Dr. Joy Hammel (Examining Environmental Barriers and Supports to Home and Community Participation with People with I/DD) tested environmental barriers and supports to home and community participation with people with I/DD by doing home audits in collaboration with peer mentors and access specialists.

An advocate panel responded to the research projects and their comments overlapped on several key points. The normalization of disability in the social world was appreciated because the environmental barrier—rather than the condition—is viewed as the problem. Several of the advocates valued the Promotora de Salud (community health worker) model used in targeting the Latino community as a way of honoring the family while also honoring cultural paths and social behaviors of the ethnic group. Several advocates also noted the importance of continuing to engage and support siblings.

Dr. Alan Factor spoke on the topic of bridging the aging and developmental disabilities networks noting several major programs that could potentially support collaboration including the Aging and Disability Resources Centers, Lifespan Respite Care Act, Affordable Care Act (ACA), and the National Alzheimer's Project Act. Dr. Matthew Janicki reviewed community supports efforts for adults with I/DD affected by Dementia. He described several goals of the National Task Group on ID and Dementia Practices: 1) defining best practices in technological and clinical practices that can be used by agencies in delivering supports and services to adults with ID affected by dementia, 2) updating existing AAIDD practice guidelines on care management of dementia among people with ID, and 3) identifying dysfunction indicators that

can be incorporated into a first-instance screening instrument. A report from this group is expected by late fall 2011/early winter 2012.

The meeting concluded with a federal and national organizations panel consisting of ADD, the Administration on Aging, National Council on Aging, American Network of Community Options and Resources (ANCOR), and NIDRR. Dr. Joe Caldwell of the National Council on Aging explored legislative opportunities for collaboration. Dr. Bob Hornyak of the National Council on Aging observed the many common themes between aging and disability networks. He encouraged the bridging of silos in partnerships that are desirable but challenging to overcome limitations imposed by law, regulation or lack of precedent. Sue Ellen Galbraith of ANCOR suggested that time-limited demonstrations and projects are not enough and that structural changes enacted through legislation and by other means are necessary. Sue Swenson then summarized effective collaboration as based on 1) communication, 2) coordination (share leadership), 3) cooperation, and 4) collaboration (share the work).

## The Health Frontier for Intellectual Disabilities

### *Forging Ahead*

Fulfillment of the public health objectives outlined over the course of these three meetings will require coordination and collaboration among federal agencies, researchers, university faculty, people with ID, and other stakeholders. The health status of people with ID is at times jeopardized by competing demands despite the centrality of this issue to the disability community. A strengthened system of surveillance supported by continued research and the development of quality curricula available to future healthcare professionals is necessary at this juncture to ensure the well-being of people with ID.

*For an agenda, participant list, speaker biographies, photos, and presentations from the meeting please visit:*

[http://www.aucd.org/template/event.cfm?event\\_id=2474&id=379&parent=379](http://www.aucd.org/template/event.cfm?event_id=2474&id=379&parent=379).

# Health Surveillance of People with Intellectual Disabilities: What is there? What's possible?

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*May 23, 24, 2011*

*Sponsors: NCBDDD, CDC (National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention), and Administration on Developmental Disabilities (ADD) under Contract #HHSP23320082917YC to the Association of University Centers on Disabilities (AUCD)*

**May 23, 2011**

## **Welcome and Meeting Orientation**

*Coleen Boyle, PhD, MSHyg, Director, NCBDDD/CDC*

Dr. Boyle welcomed everyone to the meetings and reminded the audience that this year is NCBDDD's ten year anniversary during which the center and their partners will be reflecting back on history through special 10 Years of Service events and activities to honor the achievement of this milestone of progress.

Dr. Boyle stated that there is a growing awareness of both the health issues faced by adults with intellectual disabilities and the lack of population level data. The lack of good health surveillance information makes it difficult to identify needs and solutions, and evaluate interventions and clinical programs. She pointed out that this is the third meeting convened and should aim to move the earlier work forward—identifying gaps in the health surveillance system for people with intellectual disability (ID) and how to fill them. Dr. Boyle noted that many other countries are more aggressive in data collection and utilization than the United States and that the reactions from international participants should provide perspective to the disability organizations and advocates, federal agency representatives and researchers convened at the meeting.

*Glenn Fujiura, PhD, Associate Dean for Academic Affairs, Associate Professor and Director of Graduate Studies, College of Applied Health Sciences, Department of Disability and Human Development, University of Illinois at Chicago*

Dr. Fujiura encapsulated the conceptual framework that has served as a focal point for efforts to date. He pointed out that Dr. Gloria Krahn at NCBDDD has been the driving force and inspiration for these meetings and this movement with two key questions: What is the health status of people with intellectual disabilities? And why don't we know more?

He noted that these are particularly challenging questions given the unique characteristics of this population and the structure of our health data surveillance systems. The first meeting of this effort was held in September 2009, which addressed the need for and feasibility of obtaining this data. The determination was made that the will exists to collect data even if such collection is not achievable in the near term. The second meeting in February 2010 expanded the scope to include policy experts.

He posed a series of questions for the meeting discussion: How do you define the sample population, leverage and modify existing data, and incorporate the voices of those being surveyed? How can we integrate local and national data? Who are we talking about? What do we already know? What do we need to find out? What can we use that is already out there? How can we make it sustainable and move from data to health policy?

## **Federal Plenary Panel: Utility of Data and Generating Data**

*Moderator:*

- *Michael Fox, PhD, Division of Human Development and Disability, NCBDDD/CDC*

*Panelists:*

- *Laverdia Roach, MA, Acting Executive Director, President's Committee for Persons with Intellectual Disabilities (PCPID)*
- *Rosaly Correa-de-Araujo, MD, MSci, PhD, Office on Disability, US Department of Health and Human Services (DHHS)*
- *Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services, US Department of Education*
- *Richard Balkus, Associate Commissioner, Office of Program Development and Research, Office of Retirement and Disability Policy, Social Security Administration*
- *Ruth Katz, Deputy to the Deputy Assistant Secretary of the Office of Disability, Aging, and Long-Term Care Policy*

This federal panel represented sources of administrative data as well as sites for policy implementation—the beginning and end points of ID surveillance. Panelists emphasized a need for interoperability and collaboration amongst efforts; given the scarcity of resources public-private partnerships are vital. Many noted that while the Affordable Care Act (ACA) contains some promising provisions, data on participation and health outcomes is necessary and the ways in which data is interpreted will be of utmost importance.

*Laverdia Roach, Acting Executive Director, PCPID*

Ms. Roach described the role of PCPID as solely advisory to the secretary of the DHHS and the President. The committee maintains close relationships with offices and agencies authorized to make grants, carry out programs and deliver services. Committee members meet every 2.5 years and report to the President annually. The committee has 21 citizen members—parents, self-advocates, teachers and doctors, as well as, thirteen ex-officio members. The committee works with

representatives of thirteen cabinet-level departments to engage in meaningful dialogue about ways of working together to improve life for people with intellectual disabilities. She described Project Search; a disability hiring initiative PCPID is currently coordinating which provides high school seniors with an opportunity to experience the workplace. Disproportionate shares of students in this program have children or are expecting children. PCPID wants to learn more about the rate of teenage parenting as pregnancy at such a young age can adversely affect one's ability to maintain employment (among other things). PCPID has recently completed a report on dental care and Ms. Roach noted that it has been surprising to discover how many people with intellectual disabilities have poor health due to a lack of or inferior dental care. PCPID struggles with continuity in the makeup of its committee. Ms. Roach explained that while the committee meets every 2.5 years, the needs of people with intellectual disabilities continue each day. The committee needs researchers to share their findings so the recommendations presented in reports are backed by valid and reliable data. She noted that it would be helpful if population-specific data on people with ID were available in a centralized repository. The vision of PCPID is to discuss and develop an approach to successfully implementing a surveillance system that improves the ability to understand the health status and health needs of people with intellectual disabilities.

*Rosalyn Correa-de-Araujo, MD, MSci, PhD, Office on Disability, US DHHS*

Dr. Correa-de-Araujo stated that public-private partnerships are critical to expand data and put it to meaningful use. The challenges include defining intellectual disability precisely, tracking people with ID who age out of the system, communicating appropriately with those surveyed, interpreting data, disseminating information and applying data clinically to improve lives. She explained that the Office on Disability (OD) has some focus on improving the health and wellness of everyone with disabilities. Under ACA, the OD is charged with expanding data collection and setting standards. To respond to this charge, Dr. Correa-de-Araujo noted, the OD put together a group to work on challenges with definitions of disability, with a primary focus on functional status; this group sent on recommendations to the DHHS Data Council. This group was guided by the following criteria in developing standards:

- They should be demonstrated to have worked well in practice
- They should represent minimum data standards
- The Office of Management and Budget (OMB) standards must form the basis for these standards
- In self-reports or surveys, disability questions are recommended as standard

A final decision from the Secretary of DHHS is expected soon and Dr. Correa-de-Araujo reminded the audience that this effort must overcome budget constraints as many ACA provisions are unfunded. In the American Community Survey (ACS), six questions address disability status. The OD is trying to expand those questions to provide more information about functional status. Under Section 4302 of

ACA, the Office must develop additional survey questions to assess access to care, treatment, acute and long-term care, identify providers with accessible facilities and equipment, and the number of employees trained in disability awareness. Questions are to be framed in ways that facilitate federal agencies' inserting questions approved by the DHHS secretary into *existing* surveys.

*Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services, US Department of Education*

Ms. Swenson encouraged the audience to think about the uses of data and the basic methods of disability support and intervention: revolution, rights, rehabilitation and remedy. Data are used for multiple reasons: reporting, counting, accounting, measuring, investigating, researching, describing, planning, marketing, organizing, politicizing and investing.

She posed the following question: What would it take for all doctors to understand that some portion of their patients will have ID and allow more time with these patients? She went on to review some of the statistics-0.42% of children with an Individualized Education Program (IEP) have traumatic brain injury (TBI) which amounts to roughly 25,000 kids nationwide. In addition, according to the CDC, 59,000 children in the United States are hospitalized for TBI-related injuries, and roughly 6,200 children die of TBI-related injuries annually. She noted that ideology is important as are system-wide supports for people with intellectual disabilities.

Ms. Swenson reminded the audience that market segmentation underlies life in the United States and described PRIZM, a market segmentation tool which sorts the population by life stage, affluence, urban density and more. A look at this segmentation data illustrates that, for many people, their only protein is what they catch or shoot. Poverty might have a larger effect on health status than any other factor. She suggested that researchers and government agencies with data sets that include zip codes, consider having it coded with PRIZM categories. Those who deliver health care services may begin to understand that people with ID live in all communities. She reminded those who research and advocate with data to ensure that their data meets accessibility standards.

*Richard Balkus, Associate Commissioner, Office of Program Development and Research, Office of Retirement and Disability Policy, Social Security Administration (SSA)*

Mr. Balkus described the Childhood Intellectual Disability (CID) cohort study, an SSA example of how administrative data can be used for longitudinal analysis. The study followed a group of children with ID over 10 years. SSA is modernizing its disability research file and as part of a multi-year effort, pulling together disability data from different systems and 20 years of disability claims. The design makes data accessible to researchers, and there is increased use of structure data from electronic folders. He noted that using electronic folders creates opportunity for mining data in an effort to

improve knowledge of disability applicant and beneficiary pools. The application builds predictive models to identify cases SSA can adjudicate quickly.

Mr. Balkus described several characteristics of the Supplemental Security Income (SSI) program for children, a program limited to those whose condition is expected to last 12 continuous months or result in death. There are income and resource limits, and benefits vary according to the child's living arrangement. For this project, there must be a primary diagnosis of CID and at least one monthly SSI payment in 1999. Participants must have been younger than 18 as of 12/31/99 and unmarried. The cohort started out with 329,000—about 25% of the population with intellectual disabilities. The definition includes an IQ of less than 70 with deficits in adaptive functioning. As of 2009, 16% of the cohort is still beneficiaries. Seventy-four percent of the cohort with ID has continuing eligibility, while 26% are no longer in the program (eligibility terminated). For children on the SSI rolls, SSA conducts medical continuing disability reviews and children are re-evaluated at age 18. Compared with the non-CID cohort, a higher number of kids leave SSI rolls because of medical review. The data include annual earnings for those terminated from the program and continuing recipients. Most of those terminated are unemployed or with earnings below poverty level.

*Ruth Katz, Deputy to the Deputy Assistant Secretary of the Office of Disability, Aging and Long-term Care Policy*

Ms. Katz warned the audience to be mindful about the compelling packaging of data presented to policymakers and reminded everyone of the importance of finding a way to make high-level political appointees care and enact policies that will make a difference. Over the past year, the Office has looked at the feasibility and need for an ongoing disability survey to describe the experience of disability, and what families and communities need.

Ms. Katz explained that the Office has recently transitioned to three divisions: aging, long-term care, and behavioral health and intellectual disabilities policy. Their cash and counseling demonstrations have shown that consumer-directed approaches to long-term care work well for people over 65. In a Florida pilot site for people ID early results are showing that it has been successful.

Ms. Katz noted that the more advanced Medicaid data mining becomes, the more will be learned about workforce shortages and turnover. The over-65 long-term care user is different from people with ID, and the data distinction needs to be made for policymakers. The non-elderly account for about half of all long-term care spending. People with ID represent 14% of Medicaid long-term care users, and they consume 35% of long-term care dollars. The trend is towards more long-term care delivered in the community, consumer-directed Medicaid services, higher SSI supplements for community living, and higher Medicaid reimbursement for home health visits.

She stated that health reform related activities make up a large part of the Office's work. The ACA offers new opportunities for people affected by and interested in ID. Medicaid will be expanded by 2014 for traditionally disenfranchised populations—those not on SSI or Medicaid. The Office is examining the overall impact of expansion and other changes on people with disabilities.

ACA supports health homes as a way to contain the costs of unnecessary hospital admissions, re-admissions to hospitals soon after discharge, and inappropriate hospital outpatient department/emergency room use, while improving quality of care and treatment outcomes. This concept could affect people with ID by integrating primary, acute, emergency care, ongoing services and supports. An office is being established at the Centers for Medicare and Medicaid Services (CMS) for people with dual diagnoses. Ms. Katz predicted that better data will improve the ability to understand evidence-based services and in turn ensure that services and supports exist that make a difference in people's lives, health status, and their ability to meet their needs.

## **Self-Advocate Panel**

*Moderator:*

- *George Jesien, PhD, Executive Director, AUCD*

*Panelists*

- *Max Barrows, Outreach Coordinator, Green Mountain Self Advocates & Vice-President, Self-Advocates Becoming Empowered (SABE)*
- *Julie Petty, Disability Specialist, Partners for Inclusive Communities/Arkansas' University Center on Disabilities, Arkansas People First*
- *Anne Fracht, President, Massachusetts Self Advocates Standing Strong*

Dr. Jesien introduced self-advocates to share their experiences with health care systems, as well as, the reasons data on access, quality and health needs are so important both to self-advocates and to those in research, policy and service.

*Max Barrows, Outreach Coordinator, Green Mountain Self-Advocates and Vice President, SABE*

Mr. Barrows provided a list of suggestions compiled from self-advocates in preparation for the meeting—a snapshot of what health care providers should keep in mind when meeting with patients with disabilities. He noted that he talks with many self-advocates in Vermont and across the country, and these are some of the health care challenges for people with ID:

- Obesity/losing weight, affording and eating healthy foods
- Medications—generic drugs are often encouraged, even if the name brand is necessary
- Scarcity of doctors and dentists that will accept Medicaid in some states, some states only cover basic dental

- Need for more information about sexuality/safe sex that addresses the stereotypes and barriers for people with disabilities-lacking good information, people are more likely to make bad relationship decisions
- Assistance with quitting smoking
- How to self-examine body parts for health—doctors need to give better instructions
- Finding local health clubs with membership discounts
- Limits imposed by families
- Information about health conditions, blood pressure, heart health, stress, depression and relaxation
- Tracking medications/side-effects and reporting to doctors
- Need information about biofeedback

He mentioned that it is important to collect data on people with I/DD so doctors and other medical professionals can help those currently falling through cracks.

He provided the following list of tips for communicating well with patients with ID:

- Let the person tell you that they have disability. They might be reluctant at first because they don't want you to make assumptions about what they can and cannot do
- Speak directly to the person with a disability
- Be patient and wait for communication even though it might take a little longer
- Make one point at a time—do not rush through list
- Use people-first, respectful language and avoid labels

Mr. Barrows reminded the audience that people with I/DD should be involved in every data collection step. It is important to use accessible language while interviewing people with disabilities either face-to-face or through a survey. He encouraged doctors to use understandable words, be clear, avoid too many words and use an accessible font. He noted that confidentiality is a huge issue—people are sometimes afraid to speak frankly because their confidentiality might not be respected.

*Julie Petty, Disability Specialist, Partners for Inclusive Communities/Arkansas' University Center on Disabilities, Arkansas People First*

Ms. Petty discussed the importance of health information for self-advocates, including mental health information, and explained the importance of phrasing questions in a way that is understandable. She also emphasized the role transportation issues play in healthcare decisions made by people with disabilities.

(Paraphrased):

'I was born with Cerebral Palsy. At first, doctors said I would never walk or talk, but I proved them wrong. My involvement in the self-advocacy movement is with people of all ages, although most are

35 and older. Information is the key. People 35 and over tell me they need more information—people who grew up in the post-ADA generation tend to have different issues.

Treat everyone on an individual basis. People in my generation sometimes don't even know some of their body parts or how to communicate with doctors. In Arkansas, they're doing training to help people get the information they need. And it's not only difficult for people with disabilities to explain to their doctor what's going on health-wise, it's also hard to find doctors willing to be patient and listen.

I was on meds for 10 years and never went to doctors except in an emergency or when I was very ill. I did not start getting checkups or preventive care until I was around 28. Having the information about preventive care is so important, especially the mental health aspects Sue mentioned. If you don't feel like you can go to doctor or be healthy, you're not going to feel good mentally, you'll get depressed. Mental health support is just as important as physical health support. I've been there myself. Insurance doesn't pay for a therapist or meds to help people with depression.

Another important issue is the abuse of people with intellectual and developmental disabilities, who are the number one population subject to abuse. The CDC is looking at the effects of violence and abuse.

It is very important for our government to get correct data. We have to have data to know what is going on in our community. While people might be individuals, they often share similarities, too. In Arkansas, the state conducted a survey but people did not understand the language in the survey and got frustrated. It took hours to complete the survey because I had to translate all the information. We should use self-advocates and peers to help develop the surveys so they will achieve their goals. If we know what the needs are, we can improve the system. Consider attending a national self-advocacy conference to get to know self-advocates and collect data.

Transportation is a huge issue in accessing doctors and health care, which was another reason I didn't go to doctors often. I have two little boys. My first pediatrician was awesome but the second talked down to me, which was very demeaning.'

### *Anne Fracht, President Massachusetts Self-Advocates Standing Strong*

Ms. Fracht noted that individuals do not always report their problems due to privacy concerns—they worry about what will happen to the information. She stressed the importance of developing trust, being shown how to do things rather than being told and said that it is really a challenge to live and get health care. Some people with ID have a very high threshold for pain and might not report pain until it is too late.

(Paraphrased):

'I know people who have avoided mammograms because of the pain. One friend told me it hurt and the health providers teased her. Sometimes doctors talk to the person you bring with you rather than directly to you. My doctors are great and they speak in a way I can understand. They review my instructions until I understand them, and they write them down. I think that's very important—having written instructions to take home.

Cuts to Mass Health, Medicare and Medicaid are driving service downhill. People must find doctors who accept those payments, which are often those working in hospitals right out of school. The quality of care has been affected. Sometimes physical therapists, dieticians and occupational therapists tell you what to do instead of showing you. I need to be shown how to do things instead of being told. To motivate people with disabilities, use people-first language that self-advocates understand. Other challenges for people with intellectual disabilities include food stamps and work restrictions under SSDI.'

## Data Analyzers

*Moderator:*

- *Glenn Fujiura, PhD, 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*

*Panelists:*

- *Valerie Bradley, President, Human Service Research Institute*
- *Charlie Lakin, PhD, Director, Research & Training Center on Community Living, University of Minnesota*
- *Ismaila Ramon, Disability Surveillance and Epidemiologic Research Fellow, NCBDDD/CDC*

*Valerie Bradley, President, Human Service Research Institute*

Ms. Bradley described National Core Indicators (NCI) as a state effort with federal support. NCI is a multistate collaboration initiated by public managers in late 1990s to measure outcomes for people with disabilities, based on the premise that if you don't measure it, it won't happen. NCI provides a baseline, making it possible for states to compare themselves with other states and national norms. NCI has grown from a small group of state directors to include 25 states and 25 sub-state regions. Each regional center collects a 400-person sample. The recent addition of California more than doubled the database.

She noted that the core of the ongoing data collection is a consumer survey, which yields considerable information about people with disabilities, including their experience, health and safety issues, inclusion, choice and employment. The survey also defines characteristics of service recipients,

including where they live, what they do during the day, their experiences with support, context of their lives, nature of relationships, and involvement in community safety, health and wellbeing. NCI is used to influence policies, identify issues, launch strategic initiatives and improve performance. The survey measures overall health, preventive exams, immunizations, body mass index (BMI), and use of psychotropic medications, exercise and smoking.

The Consumer Quality of Life survey is a three-part survey that collects demographic and health information in a face-to-face interview. The random-sample survey is given to a minimum of 400 adults. Proxies are not used for the first two parts—only the person with the disability can answer. Sixty-five percent of respondents can answer all the questions. The third section of the survey can be answered by proxy.

Ms. Bradley reviewed a sampling of statistics from the 2009/2010 survey. In the 2009/2010 survey, almost 57% were males. The intellectual disability was mild for 32% of the sample; profound for 19%. Of the sample, 75% were white and 23% black. Seven percent identified as Hispanic. Most people live in group homes, an institutional facility or their parents' home. The most common other disabilities were a psychiatric diagnosis (35%), Cerebral Palsy (15%) and Autism (11%). Thirty-eight percent of the sample rated their overall health as excellent to very good, and 5% said their health was poor. The further away the sample population got from a structured setting, the less likely they were to get health/cancer screenings and vaccinations. In community-based settings, 64% of those in the sample were taking at least one psychotropic medication, and there was a significant relationship between taking the medication and obesity.

*Dr. Charlie Lakin, PhD, Director, Research and Training Center on Community Living, University of Minnesota*

Dr. Lakin explained that he does not organize data—he forages for it because rarely is access available to a single data set necessary to satisfy an inquiry. More often researchers must forage through many different types of data and the data are scattered in various locations. There are interventions ongoing around the country to improve the health and healthy lifestyles of people with ID but a great need exists for a single information repository.

He noted that one of the biggest challenges is the intersection of ID, developmental disabilities (DD) and related conditions for adults in non-institutional and residential settings. People with ID in some settings are often missed.

The number of children with ID in special education has decreased—there are 20% less than a decade ago. Meanwhile, the number of children with Autism has increased. Dr. Lakin posed the following question: 'Are we all of a sudden dealing with fewer people with ID or are we dealing with people too simplistically?' NHIS compares people with ID/DD with people with other disabilities. In the

comparisons, most categories for the two groups are similar, except for learning and economic self-sufficiency. If access to health care is of interest, he suggested, looking at people with functional limitation, intellectual and developmental disabilities and everyone else. The needs of this population are similar to those of people living in poverty, young adults and people who self-report in poor or fair health. Models are necessary in considering these issues whether to focus on ID or whether issues are broader than that. Dr. Lakin suggested the Institute of Medicine framework for social and physical environment, health-related characteristics and behavior, and health systems, all relating to health outcomes. His summary of the five biggest challenges is below:

- Difficulty identifying people with intellectual disabilities
- Varying methods (and results) in identifying people with ID
- Understanding the nature of case definition and limitations.
- Clarifying the intent of information gathering and use
- Assuring relevance and quality

*Ismaila Ramon, MPH, Disability Surveillance and Epidemiologic Research Fellow, NCBDDD/CDC*

Mr. Ramon urged participants to step back, look at conceptual issues and then drill down to data. Conceptual issues drive the search for solid population-based data. He encouraged the audience to think about the challenges of data and better ways to use data. It is known that people with ID have a high mortality rate, possibly thirteen times as high as that of the general population. We also know something about disparities in mortality, morbidity and quality of life. While the leading cause of death among all children is injuries, children with ID die more often from disease, secondary conditions and complications.

The prevalence of chronic conditions is much higher for people with ID than others. The rate of strokes for those without ID was 0.7% versus for 14.2% for those with ID in one recent study.

He described the disparity story as being much the same for preventive care with environmental issues playing a role. There are often difficulties accessing care and there are disparities in quality of care as well. People with ID are roughly 5% of the Medicaid population, but they account for 15.7% of the Medicaid budget.

Two US Surgeon General Reports (2002 and 2005) urged greater efforts to improve data systems, as did two earlier meetings on surveillance for people with ID. There is a need for a better data system to move forward and resolve some issues, such as transitional discordance. Data exists about people with ID when they are school-aged, but after that, they disappear. It is difficult to enact effective policies and interventions without knowing more. It would be useful to learn more about co-morbidities, measures of ID, differences among countries and where adults with ID reside, such as in nursing facilities or group homes.

While the theoretical population is a homogeneous group of people with ID, the accessible population is limited by the lack of a definition of ID, severity, multitude of living settings and cognitive ability, as well as issues surrounding consent.

Mr. Ramon noted that population-based (Behavioral Risk Factor Surveillance System, Medical Expenditure Panel Survey) and administrative data systems (Centers for Medicare and Medicaid Services) have different advantages and disadvantages. The next steps are to define ID, compile and synthesize a knowledge base, extend past analyses of existing data, pilot state or regional demonstrations and expand surveillance nationally.

## **Research Topic of Interest Presentation: Operational Definition of Intellectual Disability**

### **RTOI Presentation: Operational Definitions**

- *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, University of Massachusetts*

Ms. Bonardi stated that a team with members from the University of Massachusetts Medical School Center for Developmental Disabilities Evaluation and Research (CDDER) and the Human Services Research Institute (HSRI) has collaborated on establishing an operational definition of ID.

This collaboration is part of a one year 2010 Research Topic of Interest (RTOI) funded by NCBDDD through AUCD and has three overarching goals, to:

- Develop an operational definition of ID
- Create a compendium of sources of health data, including critical review of reliability, validity and utility
- Expand knowledge about population not included in current sampling frames

She reviewed the current Wikipedia definition for ID-both parts of which (as of May 12, 2011) encompass mental retardation and other learning conditions (such as learning disabilities). Making use of data starts with data collection and proceeds through organizing, summarizing, analyzing, synthesizing and, finally, decision making and outcomes.

Ms. Bonardi provided an overview of the activities of the project advisory group to date. The project advisory group has reviewed definitions currently in use, including administrative definitions used by Social Security and Medicaid, national household surveys, such as the National Health Interview Survey, other large surveys, such as Special Olympics, and regional-specific/population-specific

surveys (e.g., prison, Indian Health Services). The group recognizes that many people are not captured by any of those means.

To develop a draft definition, the research team held an Expert Summit to define ID. In preparation they engaged in discussions with self-advocates, researchers, family members, service representatives, agencies and clinicians. The assumptions and guiding principles for the summit were as follows:

*Assumptions:*

- Focus on adults with ID
- Focus on health surveillance
- ID = mental retardation
- Health surveillance demands a representative population
- Consider ethical issues of labeling
- The definition is for health surveillance, not eligibility

*Guiding Principles:*

- Applicable now and in the future
- Include a functional component to inclusion criteria
- Go beyond service eligibility definitions
- To the extent possible, identify the cause (neurodevelopmental) of ID
- Refrain from putting negative value on people with ID
- Definition must be mindful of current, ongoing and any new data collection efforts

The American Association of Intellectual and Developmental Disabilities (AAIDD) domains were used at the expert summit: intellectual abilities, adaptive behavior, health, participation, context, age of onset, and support needs. The following draft definition of ID for health surveillance purposes was produced:

- IQ score roughly 70 or below
- *or* a clinician told person he/she had ID
- *or* related condition with support need

*And*

- Needs formal or informal support

*And*

- Diagnosed in developmental period

*And*

- Expected to need some help for entire life because of intellectual limitations

Or

- Person is eligible for state or federal public health program because of ID

The definition *includes* adults with lifelong intellectual limitation and long-term support needs in order to function/participate. It *excludes* cognitive disability that is short-term or first manifested after developmental period and disability due to mental or emotional conditions with no intellectual limitations. To test whether this draft definition would be useful for surveillance, it was applied across data sources to identify the population in three scenarios:

- Mining current administrative or survey data
- Tweaking current collection of information (e.g. modification of Behavioral Risk Factor Surveillance System or American Community Survey questions)
- New data collection (e.g. *de novo* survey or longitudinal study)

## **Workgroup 1: Research and Methods**

*Matthew Janicki, PhD, 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 of Chicago*

*Report Out of Key Workgroup Themes:*

- Using the definition of ID as the entry step into data systems and then having a secondary process to introduce specificity by way of more stringent criteria
- Importance of hitting specificity right
- Feasibility-How do you reliably define people into the system for whom there is no documentation trail?
- Concern about the continued use of the term “mental retardation” rather than “intellectual disability”
- Validity-difficult to make sweeping characterization of such a varied group
- Given that eligibility criteria vary across states, how could we use those definitions? Could we speak only at the state level? How would that be handled on a national level? Duplication will be an issue
- Concern that definition can lead to prioritization of public health resources
- Live data versus data locked in place
- Eligibility is not constant and maybe should not be part of definition
- As the context of disability is so specific to different cultures, it might not be possible to have single worldwide definition

- South Carolina state law allows for the merging of data from various state sources via the South Carolina Interagency Office of Disability and Health—the system started with a decision made by the state legislature in an effort to improve the ability to better inform state policymakers about services and care being provided
- Sharing data is more easily accomplished at the state level
- It is more a matter of political will than of costs—science serves the issues politicians consider important and the political agenda changes over time
- The diagnosis of Autism has been rising while that of intellectual disabilities has been declining—perhaps include the autism population in the population with intellectual disabilities

## Workgroup 2: Data to Policy

*Aaron Bishop, Executive Director, National Council on Disability*

### *Report Out of Key Workgroup Themes:*

Mr. Bishop noted that much of the workgroup debate focused on whether the necessary data exist and how to sort through it.

*What are some of the policies and priorities in which data is needed?*

- Healthy People
- Barbara Altman’s chart book, there should be a system review of existing data, such as a compendium
- Risk-adjusted spending
- Increase the number of primary care doctors to be able to take care of people with ID

*What are the priority policy areas (do we have it and is it accessible)? Who is asking the question and who are they asking? Should we be changing the broader dialogue? Should we abandon the old?*

- Data for different purposes
- Some of the most powerful data are qualitative
- Australia has had changes in the last decade and governments have signed up to monitor services and more importantly to make sure that services are provided in collaboration with disability advocacy organizations—data sets are now linkable to qualitative data
- Compared effectiveness between institutionalization and community living
- Work to ameliorate inoperability in order to identify our population in the larger data sets.
- Review existing types of data collection methods

*What questions should we be asking for the future?*

- Cloud computing for people with disabilities, government-owned and operated

- In Canada efforts are moving forward to build case management systems with data collection built in such that if people want services they must fill out a data surveillance form
- Understanding what style of data presentation works in today's political environment

*What if it takes an act of Congress to collect the data?*

- HIPPA data can be used as long as records are de-identified
- Within the federal government, there are 67 different definitions of disabilities
- On the HRSA negotiated rule-making committee-analyzing data at a clinical level would be ideal
- The key is linking the systems with the databases
- There needs to be a comprehensive data set

*What can we focus on now? What could we do to help move, influence and shape?*

- Ensure that ACA does not leave out people with disabilities
- Chronic conditions beyond the typical diabetes and COPD
- Build capacity for infrastructure links
- Encourage HHS to implement the meaningful-use concept
- Indicators/markers for health information exchanges
- Helping and supporting the conditions to help interpret data

## **May 24, 2011**

### **International Panel**

*Moderator:*

- *Eric Emerson, PhD, Co-Director, Program Improving Health & Lives: Intellectual Disabilities Observatory for England*

*Panelists:*

- *Ron Chalmers, PhD, Director General, Disability Services Commission, Australia*
- *Errol Cocks, PhD, Director Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, Curtin University of Technology, Australia*
- *Lisa Belzak, Epidemiologist, Health Surveillance and Epidemiology at Public Health Agency of Canada*
- *Helene Ouellette-Kuntz, Associate Professor in the Departments of Community Health and Epidemiology and Psychiatry (Division of Developmental Disabilities) at Queen's University, Canada*

- *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*
- *Michael Kerr, PhD, Professor of Learning Disability Psychiatry, Department of Psychological Medicine and Neurology, Cardiff University, United Kingdom*

*Ron Chalmers, PhD, Director General, Disability Services Commission, Australia*

Dr. Chalmers remarked that Australia has a very useful data system but could use it better. Western Australia is enjoying strong economic growth, and the government's interest in investing in human services provides some with unique opportunities, including a flow of additional funding into disabilities/mental health. Anyone who uses any disability service in Australia is captured in the national disability agreement sets, which are linkable.

Dr. Chalmers noted that in Australia, data are collected around policy development, with a strong research focus. He said they are starting to see rich linked database systems used for policy formulation. Policy development projects have been identified that will draw existing data systems, and some initiatives will drive policy based on new data.

*Errol Cocks, PhD, Director Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, Curtin University of Technology, Australia*

Dr. Cocks explained that the Australian Bureau of Statistics (ABS) relies on two sources of population data: the census and national statistical collection. National census collections include a question on disability in general but not about specific disabilities. Since 1991, surveys have included the following question: "Is there someone in the house who has difficulty in learning?"

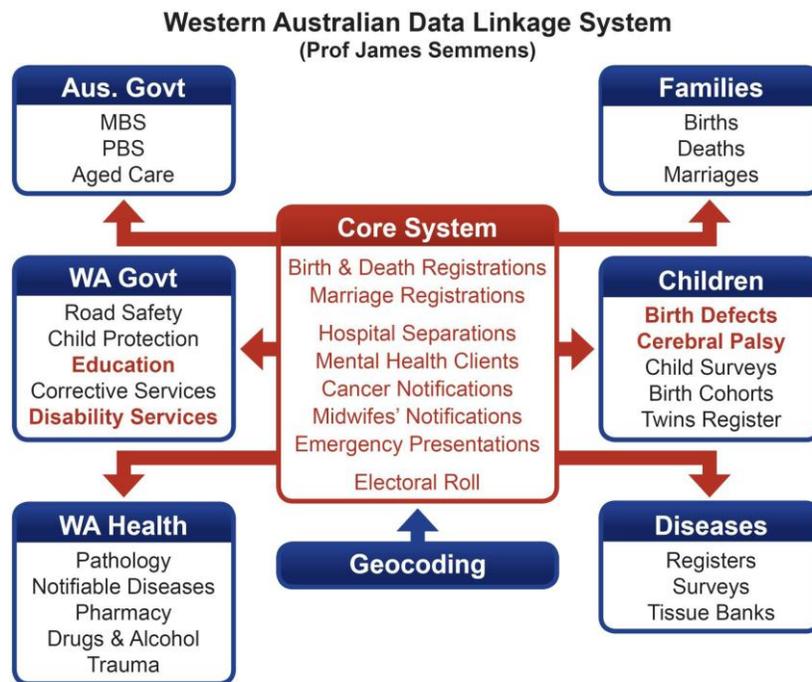
Using the ICF framework enables researchers to drill down from condition to impact on person's life for four disability groups: sensory, intellectual, psychological and physical. Intellectual and developmental disorders constituted 4.9% of disability population in the 2009 survey. Overall disability prevalence has declined from 20% in 2003 to 18.5% in 2009. ABS uses a short disability module for social surveys to investigate restrictions and the extent of limitations.

The Australian Institute of Health and Welfare (AIHW) maintains the National Minimum Data Set (NMDS), which holds data on participation in all government-funded disability services. In 2008-9, there were 279,000 service users in 11,000 provider "outlets." The government spent \$6.5 billion on services and \$16 billion on disability support pensions (DSP). Every service organization must enter data into this system.

People with intellectual disability made up more than 25% of service users (followed by psychiatric disability and physical disability). This group has the highest support need (ICF severe core activities limitation) and is the highest in non-core activities related to education and employment. Eighty-eight percent of this group received the DSP vs. 51-61% of other disability groups. Fifty-six percent of people in this group of working age did not work, which is of great concern. Regularly published reports are useful but could use more detail, especially about disparities.

The database is useful for research. The AIHW provides detailed information about service utilization. It captures a linkage key enabled researchers to follow a cohort on AIHW over two to three years, mapping shifts in employment.

Dr. Cocks pointed to Data Linkage Australia (DLA) as a good example of a data linkage program: population of 3.7 million participants over 30 years and partnerships between key players—Curtin University (Curtin Health Innovation Research Institute - CHIRI), University of Western Australia School of Population Health (UWA), Telethon Institute for Child Health Research (TICHR), Data Linkage Branch and Office of Population Health. Dr. Cocks displayed the following rendering of the Western Australian Data Linkage system:



Future planned developments will connect health data with: 1) spatial and environmental information, 2) economic measures, and 3) health outcomes of groups vulnerable through social disadvantage, illness, disability, or isolation.

The Developmental Pathways for Children and Youth Project under TICHHR and UWA explores the vulnerability of children with intellectual disabilities to adverse outcomes. The study will link de-identified, longitudinal, population-based data collected by various departments.

A proposed Vulnerable Cohort Data Repository of Vulnerable Health Groups could be used by many different entities. The project will draw on core data sets, geo-coding, commonwealth data, state data and research databases to create a master links file.

Intellectual Disability Exploring Answers (IDEA) was established in 2003 and is linked to DLA. Thirty databases are linked together, one going back to the 1950s. This is a very valuable source of data on intellectual disabilities, from birth throughout life. In 2003, the database was transferred out of government into the data linkage unit, which brought both positives and negatives. The database acquired the power of linkages but lost the guarantee of data captured around individuals. Today there is no ability within the system to capture people and track them through life.

The AIHW Data Linkage Studies include roughly 20 reports on the use of linked databases in aged and palliative care, drawing on existing databases and statistical linkage keys. AIHW holds the National Hospital Morbidity Database. Many studies analyze service utilization pathways.

There is a proposal to introduce a national disability insurance scheme, which has the potential to change the landscape of disability services across Australia. The proposal is being reviewed by the productivity commission. This is an entitlement-based insurance scheme under which everyone with a disability would be guaranteed access to a funding package. The package would include assessment, planning and referral services, personal plans and supports. There would be common eligibility criteria. As it is an insurance-based scheme, it would depend on actuarial calculations and data to predict future cost and needs.

Dr. Cocks spoke of Australia's large indigenous population and the existing data on disparities. The mortality rates are much higher for the indigenous population—their lifespan is a fraction of that of the European population. Despite all the data, health indicators for the indigenous population are still declining—which suggests good data are not enough. Governments and money have not seemed able to make a difference. Knowledge is not enough for action. He said he fears they already have sufficient data—the problem lies elsewhere. Data are important, essential even, but not enough.

*Lisa Belzak, Epidemiologist, Health Surveillance and Epidemiology at Public Health Agency of Canada*

Ms. Belzak provided an overview of the Public Health Agency of Canada's role in public health surveillance of adults and children with intellectual disabilities. The agency—which is like a smaller

version of CDC—spun off from Health Canada in 2004 in response to the SARS outbreak. It is charged with support of all public health surveillance functions: population health assessment, disease and injury prevention, health promotion, health protection, and emergency preparedness and response. The surveillance is intended to be used to forecast health events, develop health policy and plan, implement and evaluate health programs. The Agency's core surveillance areas are chronic and infectious diseases, and maternal and child health (which includes *new* developmental disorders). Federal partnerships include Pan-Canadian Public Health Network and its structures, Statistics Canada and the Canadian Institute for Health Information.

There is no national mandate for provinces and territories to report health data to the federal level; the Agency operates on a collaborative basis to collect data consistently across counties and consolidate at the national level for analysis. A new developmental disorders surveillance unit has just been started with three goals for the first year:

- Perform an environmental scan of existing initiatives nationally and internationally
- Create an advisory committee of experts to guide the development of standard case definition(s) and a national surveillance plan prioritizing autism spectrum disorders
- Build partnerships and surveillance capacity through pilot projects

During the second and third years, the unit will develop and implement sentinel surveillance centers across the country. In the fourth year and going forward from there, the unit will expand surveillance to other disorders and age groups (including ID in adults).

New joint surveys are being undertaken with Statistics Canada: the Community Health Survey (CCHS) and the Standard Disability Screening Module (under development) (Human Resource Skills and Development Canada). The CCHS is on a two-year rolling cycle, and a survey is being piloted to describe the population of residents of long-term care facilities. The Standard Disability Screening Module will assess underlying level of disability in adults (15 and older). It will replace the Participation and Activity Limitation Survey (PALS) and will be added to ongoing national surveys.

The Public Health Agency's most pressing data needs are for accurate assessments of prevalence and incidence, health status and access to services. At the Agency, the need for data has been a driver of a policy to improve surveillance. Strong advocates for I/DD demanded better surveillance systems from politicians.

*Helene Ouellette-Kuntz, Associate Professor in the Departments of Community Health and Epidemiology and Psychiatry (Division of Developmental Disabilities) at Queen's University, Canada*

Ms. Ouellette-Kuntz described several potential data sources and systems:

- Two national surveys: the Canadian Community Health Survey and Participation and Activity Limitations Survey
- Provincial surveys—Quebec
- Hospital data—Canadian Institute for Health Information
- Linked provincial administrative data—Manitoba and Ontario

In 2002, there were calls for proposals to develop initiatives to investigate health disparities, similar to the process in the United States. Queens University put together a research program across Canada to look at health equity issues for people with ID with the aim of reducing health disparities in Canada. The article “Addressing Health Disparities through Promoting Equity for Individuals with Intellectual Disability,” which was published in the March/April 2005 *Canadian Journal of Public Health*, co-authored by Ouellette-Kuntz, had to be based on research in the United States, United Kingdom and the Netherlands, because there was no population-level data in Canada.

Both the Canadian Community Health Survey (CHS) and the Participation and Activity Limitations Survey (PALS) (which is becoming part of the CHS) for 2006 appear to under-report prevalence of intellectual disabilities. The sample sizes for the age groups are small. The same is true for the data across provinces. PALS allow proxy responses for the entire survey. CHS does not allow proxy responses for disability questions, which would exclude people with severe disabilities.

Project Sante was conducted across rehabilitation centers and first-line health services. The surveys were proxy and self-completed and were compared with provincial statistics. The response and consent rates were both low, and the sample was not representative of the served population.

A Canadian Institute for Health Information survey relied on ICD coding and hospital data to look at procedures and mortality. The survey identified disparities, although identification of the population was difficult. The Manitoba Center for Health Policy Data Repository holds de-identified data files with the ability to be linked. It is a rich source of information about health, education, database support, registries, social/ recreational programs, housing and more. Users can adjust findings by age, sex, region and possibly prevalence. Dr. Rob Balogh developed his PhD thesis, “Hospitalizations for Ambulatory Care Sensitive Conditions Among Persons with an Intellectual Disability, Manitoba, 1999-2003” using MCHP data.

Ms. Ouellette-Kuntz was encouraged to see people forming partnerships for health systems improvement—asking researchers to partner with policymakers. Better data are needed to identify people with intellectual disabilities and our researchers are partnering with people with intellectual disabilities, asking them to link their data with health data. After a year, the project has reached the sign-off stage for the data-sharing agreement.

The operational definition of intellectual disability is currently being modified. The government needs to develop a profile of the population that starts off with primary care indicators to look at access to

care and quality of care indicators. The quality of care indicators are based on recently published primary care guidelines in Canada, which address continuity of care measures, whether people get regular physicals and cancer screenings, and more.

Researchers are pursuing the use of administrative data and engaging more stakeholders across provinces and territories. There has also been a focus on standardizing measures and cohort definitions across jurisdictions, using the health guidelines developed by the International Association for the Scientific Study of Intellectual Disability (IASSID).

Ms. Ouellette-Kuntz spoke of the difference between surveillance and research. Surveillance must be ongoing, while researchers work in three-to-five year grant cycles. Surveillance is the responsibility of the government. Researchers can validate measures and data used to develop systems, but decisions are ultimately made by policymakers. She noted that while waiting for better data systems, we must rely on work done elsewhere, convincing decision-makers in their own countries that the science very likely applies here. The Canadian Institute of Health Research is being innovative in improving health systems, funding projects that would be international in scope and looking for people in other systems to partner with.

*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*

Ms. Carmichael described the United States and United Kingdom (UK) as having very different systems. Disasters are hugely important in driving English health policy. Rather than starting with good data, powerful anecdotes are used—such as about people not receiving treatment for their cancer or starving in hospital wards. The attention the anecdote triggers provides the context for demanding better data. She encouraged the audience to attract attention to make changes, and good stories make a convincing case for change, first to the press, then to the ministers. Ms. Carmichael noted that Dr. Emerson and his colleagues wrote a story in 1999 furnishing evidence of a National Health Service (NHS) provision that was not working and was not good for people. The story triggered a huge shift in public opinion, which led to generous funding and redirected policy. In the absence of data one must forge ahead and deliver what people need for their health, then sort it out retrospectively.

*Michael Kerr, PhD, Professor of Learning Disability Psychiatry, Department of Psychological Medicine and Neurology, Cardiff University, United Kingdom*

Dr. Kerr reminded the audience that information is key; the aims are to reduce disparities, improve care and answer the right questions. The solutions only occur when you have leaders, drivers, solutions, and focus. He described a project in Wales monitoring the public health impact of Health

Checks for adults with a learning disability. This study involves a collaboration with the Welsh Public Health Service to analyze the outcome and uptake of Health Checks for adults with a learning disability in Wales. The study has supported the development of an electronic tool, “Audit Plus” to extract Health Check data from primary care electronic sources and in its next phase analyze this process. It provides anonymous, aggregated extraction of data on health status of people with intellectual disabilities and health processes, including data from the Health Checks. A snapshot of data downloaded in June 2010 was compared with the Welsh Health Survey (self-reported) of the general population in Wales. The comparison shows wide disparities in BMI and extensive usage of anti-psychotic prescriptions—more than 20% of people with intellectual disabilities are receiving anti-psychotic medications.

In the future, there will be a data template for all general practitioner computer systems. In the UK, Confidential Inquiry looks at every death of each person with intellectual disability. A comparable group is looking at nondisabled death to investigate disparities. It is a three-year effort, and the first year ended in March 2011.

## **Gloria Krahn: Summary and Next Steps**

*Gloria Krahn, PhD, Director of the Division on Human Development and Disability, NCBDDD/CDC*

Dr. Krahn proposed a few rhetorical questions for the audience to reflect upon: What is the purpose of these efforts—why should we do it? What will happen if we don't?

She advised making the case for more attention to this population in a way that compels action and draws a line in the sand. Then the goal will be tracking changes and improvements, documenting clinical practices for chronic conditions with a focus on intellectual disability-specific concerns.

This population has much higher rates of chronic conditions and we need to know whether they receive similar treatment for similar conditions. What lessons can be learned from efforts to reduce disparities on account of race/ethnicity? Dr. Krahn provided the following list:

- Prepare a definition of ID to use in responding to ACS questions or for other opportunities
- Anticipate opportunities to be ready
- Synthesize knowledge and ensure it is held in an accessible repository of information
- Ensure the inclusion of international experiences and practices

The SSA research is a solid example of extending analysis and what can be accomplished by developing/enhancing public and private partnerships. It is important to make data more widely available and make confidentiality agreements easier and more broadly applicable.

Dr. Krahn left the audience with the following blueprint for a path forward:

- Share ownership
- Communicate data and what we know
- Links and networks
- Get ready for opportunities

She encouraged clarity around the questions that need to be answered and specific action to move the issue forward, such as running a special issue in AAHD's *Journal of Disability and Health* in addition to pilot state or regional projects, obtaining funding, and improving packaging to make a strong case.

# Health Professional Education in Intellectual and Developmental Disabilities

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May 24 - 25, 2011

Sponsors: AUCD (Association of University Centers on Disabilities) and MAHEC (Mountain Area Health Education Center). Supporters: Physical Health SIRG of IASSID, AADMD (American Academy of Developmental Medicine and Dentistry), Wal-Mart Foundation, and the North Carolina Council on Developmental Disabilities (NCCDD).

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## May 24, 2011

*Sharon Lewis, Commissioner, ADD*

Commissioner Lewis noted that until and unless it is acknowledged that all of our systems need to focus on collaborative practice and we ensure that generalists understand the perspective of people with intellectual disabilities, we cannot move forward and will not be able to successfully address disparities.

Commissioner Lewis shared with the audience her own family experience with ID (paraphrased):

'I have a daughter with an intellectual disability. She's 14 years old and very healthy and happy. But it didn't start out that way. She was born prematurely with multiple medical conditions, one of which was an enlarged head. We rushed her in for a cat scan and for a follow-up at four months. We saw geneticists. We were overwhelmed by the number of physicians we saw. We had a good relationship with our pediatrician. A follow-up MRI said that increased prominence in ventricles should be monitored, but was generally in the range of normal and recommended another follow-up in 60 days. Over next year, my daughter's head grew another 20 centimeters. Meanwhile our PCP, with whom we had a great relationship, was afraid or unable or whatever to work with anyone else. So we didn't see the specialist until my daughter's first birthday. At that visit, the specialist arranged for MRI post haste and then our daughter was quickly scheduled to be shunted. The system failed us, despite the

fact that pediatrics represents the best of our health care system. I had everything going for me, but our pediatrician did not work in partnership. I've heard similar stories from many people.'

Commissioner Lewis reminded the audience that it is well known we need better data on co-occurring conditions, oral health, nutrition, vision and hearing pyramids, mental health and dual diagnosis. Definitional issues account for some part of what is holding us back. This is a transitioning population. About one in five households include one child with a chronic medical condition or disability. The incidence of chronic conditions is increasing as more children survive their conditions but continue having health problems.

The system of care for children with disabilities is much stronger than the system for adults with disabilities. For a variety of reasons, children have access to special clinics and personnel trained in an interdisciplinary approach with a broad range of disabilities. The system has developmental behavioral pediatricians, federal programs, Title 5, and other funding dedicated to training and research for kids, the concept of the medical home. Children are more often able to access health benefits through families/support structures. When they become adults, they age out of many of these programs and out of their pediatric specialists.

Commissioner Lewis noted that families often experience several cliffs in transition: education, employment, and residential living and health issues. Some young adults stay with their pediatricians because there is nowhere else to go. Some find adult-oriented specialists, which are few and far between. There is not a comparable system for adults. Medical schools churn out specialists, and there is little advice and support for general practitioners in treating this population. There are individuals across the country struggling to access primary care, and their needs will not be met by establishing more specialties. General practitioners receive scant medical education for treating this population, although all physicians will have patients with I/DD. It is important to begin to address this issue.

Commissioner Lewis cited several barriers to health care. Communication and transportation were mentioned as the major barriers. If the doctor talks to the patient's mom rather than the patient with ID, what happens to communication when mom isn't there? How can we help primary care providers and other physicians understand people with ID? If you can't get to the doctor, how do you access health care?

Disability is a critical disparity issue, and data is necessary to substantiate that. As DHHS rolls out their definitions under the ACA, lacking good data on disparities is problematic. Disparities have many sources: transportation, complexity of medical issues, and lack of provider training. Many physicians do not know how to get the information they need from their patients with developmental disabilities, and many are uncomfortable trying to do so. There is no incentive to participate. Reimbursement rates are often insufficient given the time it takes to care for people with ID. Finding physicians who accept Medicaid is also a problem. DHHS is rolling out incentives to improve opportunities for Medicaid users to find physicians.

Focusing on patient-centered care is a critical component. Medical education programs must provide opportunities for health professionals to meet people with ID. Health is a critical component to achieving quality of life; it is a basic human civil right. Data must be collected to underpin efforts to ensure that people with intellectual disabilities have access to basic health and wellness information presented in a way they can understand. People with intellectual disabilities have the same right to quality health care as everyone else, but disparities persist.

Commissioner Lewis noted that the most important task might be figuring out how to infuse in health professionals a basic understanding that people with intellectual disabilities have the same rights as everyone else: to live a healthy life. Individuals with intellectual disabilities can be healthy, enjoy a quality life and contribute—be valued members of our society and important parts of our communities. That assumption should be fundamental to important changes are considered for people who provide health care at all levels.

## **Self-Advocates Panel—Hearing Our “Call to Action”**

*Moderator:*

*Jeffrey Okamoto, MD, Joseph P. Kennedy Jr. Public Policy Fellow, Committee on Health, Education, Labor and Pensions, Office of Senator Barbara A. Mikulski*

*Panelists:*

*Caroline “Carrie” Ambrose, North Carolina Council on Developmental Disabilities self-advocate member*

*Robert “Rusty” Bradstock, North Carolina Council on Developmental Disabilities self-advocate member*

*Adam Hays, Maryland Special Olympics Athlete*

*Tell us about an experience you had when a health professional did something right?*

*(Responses have been paraphrased)*

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Mr. Bradstock: Around a year and a half or two years ago, I had surgery on my shoulder and the doctor actually listened to me and fixed my shoulder.

Ms. Ambrose: Doctors basically leave me alone and I call them when I need help or assistance.

Mr. Hays: I have had many ER visits with possible shunt failure where the CT scan appeared normal. My neurosurgeon trusts me when I say I don't feel good. He will continue to examine me and, in most cases, I needed shunt revisions.

*What are some important things health professionals need to know to help with your health?*

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Ms. Ambrose: Delegation. My primary care provider knows nothing about cerebral palsy so she sends me to the right specialists. Doctors should think of appointments with us as first dates. Ask one or two questions and don't bombard patients with information.

Mr. Bradstock: Doctors need to talk to each other and shouldn't just assume. If you're a specialist, talk to my family doctor. Don't just go off and give someone a prescription that could screw them up. My prescribing doctor kept increasing my medicine, and it screwed up my balance. It's been 6 years since I've been diagnosed with that. People with developmental disabilities might not understand a lot, but the doctors need to talk at our level. In the emergency room, you guys need to get to know patients. Don't see them only as a person with disabilities.

Mr. Hays: Understanding that the answer you receive might not always be the right answer. Individuals with disabilities sometimes are not good communicators. Sometimes it takes more than a one-word answer to understand how we feel and what we're experiencing. Help us expand on our answers so we can explain ourselves better. Take your time explaining in steps what you are going to do, because I have found breaking things into steps makes it easier to understand what's going to happen. I feel more comfortable that way.

[What would you want to make sure that doctors and other professionals know about disabilities?](#)

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Mr. Hays: Make eye contact. When you're speaking with me, look at me, not at a chart or computer. I'm there; I want to know what's going on. Don't talk about me to my mom or another person. I'm there; I want to know as much as my mother wants to know. I feel like it's easier when someone gives me that chance. Give us time to explain what is wrong with us, explain step by step what might be happening. Be patient.

Mr. Bradstock: ER doctors are just ignorant. I told them what to do, but they ignored me. The ER doctor didn't listen to me. Listen to your patients. They're people. I'm the expert on my life. You're the expert on medicine, but I'm the expert on my life.

Ms. Ambrose: Have a really good bedside manner. Listen to your patients, whether they're 5 or 99. Leave time for questions. An advocate should be ready with great questions all the time. Not asking questions is silly.

[When did you decide that you wanted your doctors to talk to you, not your mom?](#)

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Mr. Hays: When I was around 15-16. My mother always encouraged me to talk to my doctors and tell them what may be wrong.

Mr. Bradstock: I agree with Adam. I take my mother to some doctor appointments but not others. I bring her with me to the kidney doctor for an extra set of ears and to calm me down.

Ms. Ambrose: I don't take my mom anywhere. The doctors always have me fill out a paper saying whether there's someone who can reschedule my appointments, pick up medicine, or call if I don't understand something. So my mother always has permission to call. At around age 12 I started seeing the doctors at my parents' practice. I had a rude awakening as a teenager going into adult medicine.

*Have any of you been involved in helping health professionals or social workers?*

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Ms. Ambrose: My 9-5 job is working for an agency under MAHEC. We developed three curriculums to help families. My agency in which I was lead wrote a youth guide about transitioning from pediatric health care providers.

Mr. Hays: I would love to be involved in something like that. I sort of do that in my own way. I work for Special Olympics in Maryland doing clerical work and create videos showing my messages of how people with intellectual disabilities are able to share with others what we can do.

*Do any of you find that nurses treat you as adults or do they speak down to you?*

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Mr. Bradstock: Nurses who don't know me speak down to me.

Mr. Hays: I've had over 30 surgeries, and when I go into the hospital, I see tons of nurses on main floor. They talk to me; they're always trying to find ways to make me feel comfortable. In the middle of the night, when they do their 6-hour checkups, they're as quiet as they can be, always trying not to wake us up. Nurses have always been there for me. In a major surgery in 2002, I had one nurse I loved. It was my birthday, and she got me some ice cream. Just like docs, nurses are really important. They can help you heal faster and get out of the hospital. I love nurses.

*Carol Heaton: Do you e-mail with your docs? Do you ever write up symptoms and send them to them?*

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Ms. Ambrose: I recently had my first visit to a general practitioner in two years, and she asked me for my e-mail address. I use the Internet all the time.

Mr. Bradstock: I haven't done that and don't know if I would like to. I have a learning disability and have trouble reading, so I would rather talk to the doctor or nurse on the phone.

Mr. Hays: I guess it depends on who it is, but for me, it would be neat to have e-mail with my doctors. I'm on the computer a lot so it would be neat. For the first time, my doctor back at home is starting to use a computer. I thought it was cool how she typed all my information, and instead of giving me a slip to take to CVS, she pressed enter and my prescription went to CVS. If someone sent it to me and explained in easier terms, it would be neat to be able to communicate back and forth with my doctor; it just gives us another way of communication.

## United Kingdom Overview

*Michael Kerr, PhD, Professor of Learning Disability Psychiatry, Department of Psychological Medicine and Neurology, Cardiff University, United Kingdom*

Dr. Kerr reflected upon his experiences in taking on the challenge of educating health professionals. He noted that while the components of education are fairly clear—importance of communication and knowledge—a knowledge transfer problem exists. Lots of facts about people with ID seem impossible to imprint in the minds of our health professionals, even very simple facts, such as people with Down syndrome being prone to hypothyroidism. Less than 50% of people with Down syndrome are screened for hypothyroidism. Dr. Kerr concluded that either different models of education or possibly a bigger stick is necessary. Education and other things that lead to change in care and practice are primarily postgraduate issues. Undergraduates in the United Kingdom (UK) must work with people with disabilities to get into medical school.

He noted that knowledge and research are necessary to underpin improvements and trigger public concern. The Disability Rights Commission in the UK produced a detailed report showing problems with the delivery of primary and secondary health care delivery to people with ID (“Injustice: Death by Indifference”). “Healthcare for All,” by Sir Jonathan Michael revealed the state of access to health care services for people with learning disabilities.

There is a drive to make changes to education and to the triad of adult care: primary care, secondary care, and specialist psychiatric care. What matters is that people with learning disabilities are included as equal citizens. In the UK system, he explained, there is a need to educate primary care teams on transition to adulthood issues. Primary care is central to the delivery of adult health care.

Health Checks in Primary Care uses a quality-outcome framework to reduce the disparity in health experienced by adults with a learning disability. Health checks identify illness, treat illness, and provide access to health promotions and to more specialist support. To improve provider education, a Step-by-Step Guide for General Practitioner (GP) Practices: Annual Health Checks for People with a Learning Disability was published by Dr. Matt Houghton and the Royal College for General Practitioners (RCGP) Learning Disabilities Group.

Research to monitor Health Checks is currently underway, seeking the views of people with disabilities and measuring inequality in uptake. General practitioners are paid extra for doing Health Checks. As for secondary care, Sir Michael reports finding negative attitudinal issues, quality issues, difficulties with access. Lack of listening is at the root of many problems. Liaison nurses have been introduced in hospitals, often funded by disability services, to identify people with disabilities and make sure they receive the care they need and to educate staff and talk about access. Specialist psychiatric care teams educate primary care teams as a mental health service. At issue is whether it should also be a physical health service, given the relationship and interactions between mental health and physical health.

## **Australian Overview**

*Robert Davis, PhD, Director of Centre for Developmental Disability Health, Monash University – Victoria Australia*

### ***Educational development***

Dr. Davis explained that the government played a vital role in setting up the Centre for Developmental Disability Health following deinstitutionalization in the mid-1980s. Money that had formerly gone to institutions funded by disability services was quarantined to provide training for doctors in communities to support people with disabilities. The center advertised for doctors who were interested in ID and started with two units. Currently they have 500-600 medical students. The other aim is to influence post-graduate training, which has been done in a number of ways. Funding from the federal government in Australia is provided for this purpose. Integrating content on I/DD into the curriculum involved the following:

- Placing units within university departments
- Training in delivery of higher education
- Active participation in education planning committees
- Integrating educational plan with curriculum
- Prepared for opportunities with curriculum development
- Advocacy directed at Australian Medical Council

The center had access to planning committees and could infiltrate DD into both curricula such that they had the ability to develop programs that integrated well into both universities. Groups lobbied councils about including DD in the medical curriculum. Several challenges were encountered in accomplishing these education goals:

- Maintaining permanent academic teaching position
- Maintaining educational objectives
- Competition for space in curriculum
  - Need to have presence on relevant planning & review committees
  - Importance of documenting students response

There is always competition for space on the curriculum. It helps when students value the programs. Modern health practitioners must be able to deal with chronic conditions; particularly as modern medical care is more about dealing with chronic health issues. The coursework must be interesting and relevant, and the delivery imaginative. Some curriculum is delivered in remote sites in Australia and there is some focus on other health professionals, such as occupational therapists and social workers.

Dr. Davis noted that they have developed a range of educational material that includes DVDs, to allow remote students to share in the experience of lives of people with disabilities. Some web-based modules enable GPs to access training and get continuing education points. As far as impact on

attitudes and knowledge, he said the best teachers are people with intellectual disabilities themselves.

### *Specializing in developmental disability*

The center is looking at the place of a developmental disability specialist in the health care system and to develop a training program. The government must provide the first recognition of responsibility. Some patients require a specialist approach. The center provides a central referral service and generally does not have problems getting patients.

## **Canadian Overview**

*Ian Casson, MD, Family Practice Residency Training, Queens University, Kingston, Ontario, Canada*

Dr. Casson noted that Canada is a big country but much less densely populated than the United States. Most of the population lies along the American border. He was impressed to see that the National Portrait Gallery featured Eunice Shriver and Special Olympics participants in an exhibition called Struggle for Justice. The other paintings were about civil rights and women's rights. Health care for people with intellectual disabilities is a struggle for justice.

*William F. Sullivan, MD, CCFP, PhD, University of Toronto*

Dr. Sullivan described the initial efforts in Canada to create specialized health/medical professional training in I/DD which centered on two educational programs: the Developmental Disabilities Primary Care Initiative (DDPCI) and the Family Medicine Developmental Disabilities Program of the College of Family Physicians of Canada. The programs were co-sponsored by two ministries responsible for the care of people with DD/ID: the Ministry of Community and Social Services and the Ministry of Health. The DDPCI works to increase the capacity of primary care providers to treat adults with DD. The other program supports the development of education and certification in these different areas. DD and ID were recently granted program status within the College of Family Physicians Canada (CPFC).

### *Primary Medical Care in Canada*

Half of all physicians in Canada are family physicians. Canadians must have a GP to access the Canadian health care system. Medical education is based in universities, with two years of post-graduate education and the possibility of a third year. The CPFC encompasses the activities of the AAFP (American Academy of Family Physicians), ABFM (American Board of Family Medicine), Society of Teachers of Family Medicine (STFM) and Accreditation Council for Graduate Medical Education (ACGME). It promotes a broad-based, comprehensive, continuing care model for family practice and also has an academic pathway for family physicians with special interests and focused practices (to encourage family practitioners with interests in a special area, such as ID).

Part of the context of care in Canada of people with ID is de-institutionalization. One foundational report, “Primary Care of Adults with Developmental Disabilities, Canadian Consensus Guidelines,” was the key document and triggered the relationships with the two ministries. Out of that came the proposal to use that document to train people. Extensive training was provided to family physicians doing this work. Out of that effort tools were developed to respond to their common issues. He noted that as people became more familiar with each other they were able to establish clinical support networks for family doctors. This key document led to the Developmental Disability Primary Care Initiative involving:

- Continuing medical education
- Practice tools
- Clinical support networks
- Curriculum

This, in turn, led to the Family Medicine Developmental Disability Program of the College of Family Physicians of Canada. The program teaches basic standards of care with recommendations on physical, behavioral and mental health issues. It is distributed to all Canadian Family Practice doctors. The tools are available online and encourage good primary care of people with developmental disabilities.

Government support for the Developmental Disability Primary Care Initiative came from the Ministries of Social Services and of Health. The medical education efforts were supported by the Ministry of Education and the College of Family Physicians of Canada (member fees). Patient services are supported by the Ministry of Health. There has been a big shift to family health teams to encourage more interdisciplinary care.

It is too early to evaluate acceptance and impact. This is the fifth year of the five-year program to improve the capacity of primary care providers to care for this population. The next step is changing the medical curriculum. There have been evaluations and a subgroup involved in data linkage. The initiative is now looking at a baseline of primary care indicators to evaluate the care people are receiving.

## **Netherlands Overview**

*Professor Henny MJ van Schrojenstein Lantman-de Valk, MD, PhD, and Marijke Meijer, MD, Department of General Practice and Governor Kremers Centre, Maastricht University, Maastricht, Netherlands*

Dr. van Schrojenstein Lantman-de Valk informed the audience that The Netherlands is the only country in the world with ID specialists. It is a very small country, 16.6 million people, and life expectancy is around 80. The health care system was reformed in 2006 with a single, compulsory health insurance system with private health insurers and expensive premiums (\$1,700/year). The

government controls prices, access and quality. In the Netherlands, 9% of gross domestic product is spent on health care.

She explained that the general practitioner is the gatekeeper to health care and hospital entry, and most people are registered with a general practitioner (GP). Electronic databases use International Classification of Primary Care (ICPC) codes. The system is uniform throughout the Netherlands. Continuity of care is important—people have one GP for 30 or more years. Dentists, midwives and physiotherapists are directly accessible.

There are 155,000 persons with disabilities using care in the Netherlands (.9%). Of this group, 90% have ID, 50,000 use daycare for people with ID, and 69,000 use residential care in small group homes, institutions and sheltered living. Eleven (11%) of the health care budget is devoted to health care for people with ID.

Practice shifted from the medical model of the 1960s to a development model and then in the 1990s to a citizen paradigm. Until 2000, about 45% of people with ID lived in institutions and were cared for by physicians who worked in the institutions. The other 55% lived with family or in group homes and received health care from regular GPs. There was no official government policy to close institutions. Currently most people with ID live in small-scale residential settings with mixed populations on the campus grounds and flexible care arrangements. People with ID obtain primary health care from their GP. Physicians for people with ID provide disability-specific and complex medical care.

In 1981, a professional organization of physicians working in ID-care (NVAZ, Dutch Society of Physicians for People with Intellectual Disability) was established to acknowledge a new specialty of ID. NVAZ allows for the exchange of experiences, and provides guidelines as well as postgraduate course in 1985. In 1993, the Royal Dutch College of Physicians established requirements for the new specialty. NVAZ went to work to establish final attainment levels and received a “State of Science” grant to continue its work. Documents were submitted to the Ministry of Health in 1997 and training programs started in 2000 and began graduating officially registered ID physicians. In 2006, a competence profile for ID physicians was formulated.

There are now 181 registered physicians for people with ID. The requirements include a three-year postgraduate training program, a two-year internship in ID care, and a one-year residency in genetics, psychiatry, rehab, epilepsy, primary care, etc. ID physicians get one day a week of university training, are registered and certified, and are specialists in disability-related health problems.

Competences of the ID specialist include:

- Communication with ID persons, families and caregivers
- Specialized knowledge about: psychiatry, genetics, co-morbidities, epilepsy, vision and hearing, neurology and motor functioning
- Integrating specialized knowledge
- Multidisciplinary network, collaboration with broad spectrum of other professionals

- Contribution to developing specialty

### *The Nijmegen Model at Radboud University*

Training is provided for all physicians under a consortium involving the university medical center and three service providers. The mission is to improve health care provision and thus quality of life for people with intellectual disabilities by conducting research, providing teaching and training, and practice. The consortium funds research provides access to clients and establishes internships for students.

Teaching and training include:

- Bachelor programs integrated in primary care, genetics, nervous system, psychiatry and electives
- Master programs integrated in primary care, child health, traineeships (4 to 12 weeks), research trainees
- Postgraduate programs with GP and nursing home physician training, and conferences for ID physicians

Master programs are now integrated in primary care, child health, genetics, nervous system and psychiatry. Dr. Meijer described the main challenge as delivering care to all people with ID (outpatient services). People with ID and GPs are often unaware of special programs, and a better job needs to be done of integrating information about people with ID in primary care. The program should be expanded to other universities. Another threat is the growth in care expenses due to population aging—health care costs are expected to be 15% of GDP in 2018.

### **United States Overview**

*Matthew Holder MD, MBA, CEO, AADMD*

Dr. Holder explained that pediatric training is far more developed than training for the adult population in the United States, and most medical student exposure to people with DD occurs in pediatric programs.

Two subspecialties associated with pediatrics have been established: neurodevelopmental pediatrics, and developmental and behavioral pediatrics. Board certification for neurodevelopmental pediatrics started in 1999. The Section on Developmental and Behavioral Pediatrics started in 1960 but did not receive board certification for 42 years. There are now 570 certified developmental behavioral pediatricians in the United States. The field covers neurodevelopmental theory, motor disabilities, communication disorders, neurobehavioral disorders, visual and auditory impairments, neurodevelopmental disorders associated with major medical conditions, rehabilitation, counseling, advocacy, ethics—including research ethics—and more.

The Curriculum Survey of Needs Project assessed the state of medical education on the adult side:

- 81% of medical students will graduate without having had any clinical training in the care of adults with neurodevelopmental/ID
- 90% of primary care residency programs offer no formal training in adults with neurodevelopmental/ID

Dr. Holder provided a list of several training programs available to students in the United States. These programs are scattered around the United States with little standardization and little communication. The lack of communication partly reflects different circumstances, goals and funding. A national curriculum is necessary with standards at all levels, recognition of intellectual disabilities as an underserved population, a better financial structure, and consensus that we can promote around the country, telling states what they need to be doing.

Recognition of people with ID as an underserved population would open up funding streams, making a curriculum financially feasible. Professionals in medical education and physicians tend to be fairly isolated. Recognition from people outside the medical community is pushing things forward.

## **May 25, 2011**

*Rick Rader, MD, Vice President of Policy and Advocacy, AADMD*

Dr. Rader emphasized that it has been a long time since the American medical community has been influenced by curriculum building. In the 18th century, medical education consisted of an apprenticeship and a few classes. Students would not pay tuition and instead bought tickets to each lecture.

The system negates the value of people with ID. Writing in a British medical journal, Sir Robert Platt said: “The first staggering fact about medical education is that after two and a half years of being taught on the assumption that everyone is the same, the student has to find out for himself that everyone is different.”

That is the core value of teaching students about DD: Everyone is different. As Lord Walter Brain said in the Canadian Medical Association Journal, “... as each specialty came of age it demanded a front door key to medical education and a roof of its own in the curriculum and examination hall...The curriculum should not be that of a honeycomb in which individual bees add cell to cell, but rather that of the cerebral Cortex in which all the cells are functionally inter-related.”

## **International Participants Panel—“Curriculum-Building 101”—Lessons Learned**

*Moderator*

- *David Wood, MD, MPH, Professor, University of Florida College of Medicine- Jacksonville, Director, Jacksonville Health and Transition Services (JaxHATS) Panelists*

- *Robert Davis, PhD, Director of Centre for Developmental Disability Health, Monash University – Victoria Australia*
- *William F. Sullivan, MD, CCFP, PhD, University of Toronto*
- *Ian Casson, MD, Family Practice Residency Training, Queens University, Kingston, Ontario*
- *Henny MJ van Schrojenstein Lantman-de Valk, MD, PhD, Department of General Practice and Governor Kremers Centre, Maastricht University, Maastricht, Netherlands*
- *Marijke Meijer, MD, Department of General Practice and Governor Kremers Centre, Maastricht University, Maastricht, Netherlands*

Dr. Wood described the goal of this panel-to dive more deeply into the nuts and bolts of curriculum development in an effort to gain a better understanding of how it is done. He posed several questions regarding curriculum development: How do those who have done it implement, disseminate, assess and evaluate? How do they demonstrate value to their schools and communities? What are the critical elements of the curriculums being taught internationally?

*Ian Casson, MD, Family Practice Residency Training, Queens University, Kingston, Ontario*

Dr. Casson noted that the competencies in Canada are similar to American ones. The CanMEDs framework is a guide to the essential abilities physicians need for optimal patient outcomes. The framework defines competencies needed for medical education and practice, which are organized around seven key physician roles:

- |                  |                   |
|------------------|-------------------|
| ▪ Medical expert | ▪ Health advocate |
| ▪ Communicator   | ▪ Scholar         |
| ▪ Collaborator   | ▪ Professional    |
| ▪ Manager        |                   |

There are important learning objectives in developmental disability medicine at all levels which fit very well with the competencies, especially those difficult to teach, such as communicator, manager, collaborator and professional.

The Canadian university experience generally involves real people, volunteers and patients. An important resource is partnering with community agencies. Poverty is discussed in the universities as a determinant of health for people with ID but no other social factors.

He described a Canadian study linking Ontario health utilization data with a social services database and identifying people with DD. The study compared graduates of the training course to a sample of physicians who did not receive the training. The study looked at how often patients with developmental disabilities received annual physicals from one physician group versus the other. The results will be published in the next few years.

Guidelines are evidence-based, providing a robust center on which to build curriculum. If everyone has bought into the guidelines, building a related curriculum should be an easy task of marrying competencies to guidelines. That has been the experience in Ontario. Nurse-facilitators help people access education on DD.

*William F. Sullivan, MD, CCFP, PhD, University of Toronto*

Dr. Sullivan advised the audience to build curriculum and make sure it is implemented. He described his work with a group of experts in preparing problem-based learning modules. They investigated where the gaps were and then focused problem-based learning on those gaps. The format was usually cases and vignettes based on real patient stories. These are meant to grab people and to relate to experiences they have had themselves—a way of stimulating students to think about difficulties they have struggled with. The DD module takes about two hours. There are key learning points, an action plan and follow-up. Before coming up with curriculum, the group had to reach consensus about key goals.

Dr. Sullivan acknowledged that research on this topic is currently lacking. There was a case control study involving a cohort of practicing physicians, with pre- and post-training evaluations. It was a quick, web-based survey but there was also a control group. The training was 25 hours of intense education, and then physicians had some period of time to make changes to their practice. The initial results were surprising—the majority of doctors did not feel comfortable treating patients with DD and did not feel confident about assessing the patients' capacity to give informed consent. The control group was given resources but peer learning is very important.

AAIDD has a group working on guidelines. Consensus around guidelines can serve as the core of what should be taught. When teaching within a basic framework, you know you are teaching what people consider important.

Colleagues play an important role. He noted that his university agreed to provide a roof for this community and support to grow and suggested using a long-term strategy to build a community of faculty who can train their colleagues. The message is not restricted to just a few formal teaching centers—they become part of the culture. It is the same with ethics—seeing practitioners practicing within an ethical framework.

He noted that they work with interdisciplinary teams and that many family practices are becoming more interdisciplinary. The University of Toronto is committed to medical education involving interdisciplinary education. One way to infiltrate content is via that format – inter-professional education involving people with different disabilities. The University is working on curriculum development for the coming year and looking externally for examples

*Henny MJ van Schrojenstein Lantman-de Valk MD, PhD, Department of General Practice and Governor Kremers Centre, Maastricht University, Maastricht, Netherlands*

Dr. van Schroyen Lantman-de Valk said that in The Netherlands, the process is similar to Canada. The competency model developed in Canada was used, which is organized around seven domains (the United States has six instead of seven). An outside scientific committee reviewed them, and the competencies were finalized within a year or two. Dutch universities make competencies available via one day training. The day starts with exchanging experiences (two hours). This is very important to increasing knowledge. The training addresses complications and medical expertise.

The most important competency is to communicate with the person with intellectual disabilities—communicate with the patient. In The Netherlands, the module for GP residents was started by a family physician with two boys with disabilities. In the universities there is cross-disciplinary teamwork which encourages cooperation, communication and knowledge of different disabilities.

*Robert Davis, PhD, Director of Centre for Developmental Disability Health, Monash University – Victoria Australia*

In the case of Australia, Dr. Davis explained, the curriculum has been redone three times. It is a problem-based learning effort, and the quality of the case studies enables us to reach into other areas, such as obstetrics, pediatrics, general practice, and psychiatry. There are six modules of web-based training. All general practitioners have access and get points for completing the training. Within modules, case studies are used to teach and to engage GPs and registrars. At the undergraduate level, the material appears in exams, which makes the students a lot more attentive.

Giving students opportunities to see patients with DD has played a central role. A package of DVDs is available but the students like contact with patients. The DVDs are very useful for tutorials for rural practitioners. Evaluation of Australian curricula has focused mostly on content. Measurement is a difficult thing to do.

As a private practitioner at a general practice he explained that there was already a relationship with the local university and some degree of influence established. This influence was useful when the college was writing its curriculum. Australian universities are looking at ways to develop interdisciplinary teaching—ID is great for teaching interdisciplinary care. There are some models. A clinic in Melbourne interacts with a community health service, and we are trying to use that as a way in to a new medical school. Australia also has a large immigrant population and looks for ways to incorporate aboriginal funding/resources around indigenous issues.

## **National Curriculum Initiative in Developmental Medicine**

*Matt Holder, MD, MBA, CEO, American Academy of Developmental Medicine & Dentistry*

Dr. Holder provided an overview of the National Curriculum Initiative in Developmental Medicine (NCIDM) and distributed a draft. The project was initially started by two groups working independently. The MAHEC had been working on physician education and then joined with AADMD and the Family Medicine Education Consortium. The target audience is graduating primary care

residents. The focus is on adults with I/DD. A tiered approach has been taken—this curriculum is meant to be a toolbox of goals and objectives, given there may not be sufficient curriculum time for all residents to cover all goals and objectives. Goals include core knowledge, intermediate and advanced level.

Planning for the curriculum started in May 2010. A group of stakeholders formed and divided into two tracks: programmatic and curriculum development.

At an initial October meeting in Hershey, 20 people assembled from around the country to work on the project. Weekly conference calls were held to reach intermediary goals. The group was eventually divided into three groups, each covering two related core competencies. The entire group reviewed a draft in March. The NCIDM is now looking for recommendations for dissemination and adoption.

Dr. Holder reviewed the six curricular themes and solicited feedback:

- Patient respect and patient-centered care
- Patient autonomy and independence
- Interdisciplinary collaboration and fluency
- Specific medical and pharmaceutical knowledge
- Improving practice quality and viability
- Patient care: demonstrate the ability to provide care that is compassionate, appropriate and effective for the treatment of health problems and the promotion of health

## Continuing the Call

*Rosalyn Correa-de-Araujo, MD, MSci, PhD, Deputy Director, Office on Disability, US Department of Health and Human Services*

Dr. Correa-de-Araujo noted that the Office is continuing the work laid out in the Surgeon General's 2002 report, "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation." As Dr. Satcher said:

*"Reports don't have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action... I ask everyone reading this report to do your part to achieve our noble objective of improving the health of all persons with mental retardation."*

In 2005, the Surgeon General issued another Call to Action relating to people with disabilities. This call to action encourages health care providers to see and treat the whole person, not just the disability; educators to teach about disability; a public to see an individual's abilities, not just his or her disability; and a community to ensure accessible health care and wellness services for persons with disabilities.

She noted that no one report summarizes what has been accomplished to date but there are many activities happening. There is a range of I/DD research supported by the National Institute of Child

Health and Human Development (NICHD) and several activities supported by various other agencies. Although this research is very important, the way it is used and properly translating findings into clinical practice is critical. Providers must understand the findings and how to apply them, and they must be translated into language that people with disabilities and caregivers can understand and policymakers can use. The OD is acutely aware of the challenges faced because data are not available or not easy to manage or use. There remains much to be done to overcome challenges, including being able to identify people with ID as they age. The system loses track of these individuals and how they are evolving, what types of services they're using or what they need. An expansion of the surveillance system must occur to bring in additional information. Researchers and policy experts must be careful to interpret this new information correctly and to use it in a meaningful way to influence practice.

She provided a list of reasons DHHS has an interest in assisting with the development of curricula in this area:

- 54 million with some form of disability
- Tools and knowledge to promote wellness
- Secondary conditions prevented or treated successfully to improve outcomes
- Integrated, culturally sensitive and respectful health care services – whole person
- Advances in technology, diagnostics and treatment - longer infant survival, survival into adulthood and old age
- Multiple co-morbidities, particularly in older adults will likely increase disability rates worldwide
- Military-related disabilities

#### *Areas of Core Knowledge and Competence on Disability*

Last April, the Office joined MAHEC and AADMD in their effort to draft a medical curriculum to ensure better training for medical residents. Their focus on adults is essential. Longevity is increasing for everyone, leading to a higher incidence of disability. Dr. Correa-de-Araujo suggested that efforts and skills need to be more than doubled to better care for this growing population. One particularly important aspect is transition/care coordination—continuity of safe and high-quality care. She applauded the NCIDM for doing an outstanding job of responding to the Surgeon Generals' calls to action.

She recommended developing a pilot implementation project, publishing results, replicating the model, and then partnering with other professional organizations, such as associations and colleges of medicine, to spread the model as quickly as possible.

#### *Opportunities under the ACA*

Section 4302 of the ACA addresses data collection, analysis and quality related to understanding health disparities. Its provisions affect data collection, analysis and reporting in HHS and also

specifically the Current Population Survey (Bureau of Labor Statistics in Department of Labor) and the American Community Survey (Bureau of Census in the Department of Commerce). The provisions apply to any federally conducted or supported health care. Within two years, data must be collected and reported for “applicants, recipients, or participants” on five demographic variables (to the extent practicable) to detect and monitor trends. Those five variables are:

- Race
- Ethnicity
- Sex
- Primary language
- Disability status

This change may parallel expected changes in disability data such as:

- Initial decrease in estimated prevalence of disability in many surveys
- Increase in the routine reporting of health outcomes, behaviors, etc. by disability status
- Inclusion of disability status in multivariate analyses as an independent variable
- Routine inclusion of disability in public health programs
- Improved data collection will allow us the opportunity to better identify gaps
- Data gaps will support the development of quality improvement interventions to meet the needs of this population
- Data on health outcomes, social participation and quality of life are critical to monitor progress
- Data may also serve to determine best practices, pending careful interpretation of findings
- We must overcome some of the current methodological challenges and ensure we include adults with intellectual and developmental disabilities
- We must expand surveillance on an ongoing basis around the country
- We must take advantage of existent surveys to expand and improve them

## **Preparing Health Professionals to Support Health and Well Being for People with Intellectual and Developmental Disabilities: An Interdisciplinary Perspective**

*Stephen Corbin, DDS, MPH, Senior Vice President, Special Olympics*

Dr. Corbin noted that Special Olympics is a sports organization. It involves 32 Olympic-type sports. There are almost 50,000 competitions, programs in 170 countries, 3.7 million athletes, 275,000 coaches and 847,000 volunteers.

He presented findings from the past four Special Olympics World Games. Twenty percent of athletes needed emergency, imminent or urgent care. The numbers have not changed significantly from the time of the 2001 hearing in Alaska, when Senator Ted Stevens made a commitment to change.

In 1997, the Healthy Athletes program was created with initial funding from CDC. It now has hundreds of partners around world. Its goals are to improve access; make referrals; cultivate systems

of care at the local level; train health professionals; advocate for improved health policies; and collect, analyze and disseminate data. Although the data are a convenience sample, it is a massive and geographically diverse sample.

Recently the Special Olympics Athlete Personal Health Record Program, a secure, comprehensive life-long electronic health record maintained in online and portable offline versions was piloted. Dr. Corbin noted that in the United States, on average, a person with ID must contact 50 doctors before finding one with specific training and experience in treating people with ID.

Special Olympics has a web-based database of healthcare providers willing to be contacted by SO athletes, and getting people to sign up has been difficult (as has been keeping it current). There are currently 1,732 members (an average of approximately five per Healthy-Athletes discipline per state), and the goal is to have 20,000.

Key players include physicians, specialists, advocacy organizations, people with ID and family members. The challenge lays in figuring out how to get all those people on the same page at around the same time with the same agenda.

## **The State of the State in Disparities and Intellectual Disabilities: Beyond Disparities**

*Gloria Krahn, PhD, MPH, Director, Division of Human Development and Disability, NCBDDD/CDC*

People with ID have poorer health and experience more adverse health conditions. Health disparities have come under broad discussion only recently. The cascade of contributors begin with higher rates of adverse health conditions, then to disparities in attention to health care needs, to disparities in preventive care and health promotion practices, and finally disparities in equitable access to health care—all ending with poor health outcomes.

Dr. Krahn reviewed some of the general statistics in the area. If you have an ID, you have a 30% chance of also having a communication limitation, a 30% chance of a physical disability, and a 30% chance of a behavioral/psychiatric condition disorder (according to research by Ouellette-Kuntz et al.). People with ID are also at much higher risk of sensory limitations, epilepsy and neurological disorders, dermatologic conditions, fractures/lacerations, gastrointestinal and cardiovascular conditions (Ouellette-Kuntz et al. and Krahn et al.).

Chronic conditions also disproportionately affect people with ID, including arthritis, diabetes, asthma, high blood pressure and high cholesterol (MEPs 2006). With the exception of flu shots, preventive care—such as mammograms and dental checks—is less frequent for people with ID.

*Health disparities and ID*

What are health disparities in the context of disability? They are *differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations that are not explained by selection bias or underlying condition.*

What differences are inequitable? What can be prevented?

Distinguishing among health conditions:

- Associated health conditions led to or are part of a syndrome that led to the impairment in functioning
- Co-morbid conditions are unrelated disease processes that have an adverse effect on health
- Secondary conditions are preventable conditions that a person with a disability experiences at a higher rate than the general population
- Iatrogenic conditions are adverse health outcomes related to treatment for a condition

She provided the following chart to depict the cases in which a health difference is a disparity:

Condition	Disparity?
Associated condition (part of the condition)	No
Comorbid condition rates (e.g. later diagnosis of cancer)	Yes, even by conservative standard
Secondary condition (e.g., depression, obesity, pressure sores)	Likely, if not related to treatments
Iatrogenic condition	Perhaps, are there other treatment options?

### *Health equity and social determinants*

She described a shift occurring between a stronger sense of health equity and social determinants. A health equity perspective is positive and looks at social justice, ableism and disablism. These concepts play out in everyday conversations. The underlying expectation is for a good life for people with ID.

The concept of social determinants of health is popular in Europe and was part of the framework for the Pomona Project and Healthy People 2020. It is a blueprint for public health to think a decade forward. It will influence thinking about how to move forward over the next decade.

Three views of disability in public health are traditional (prevention), contemporary (minority) and emerging (social determinants). Traditional public health focused on prevention of disease/injury/disability among the general population. The minority model focuses on health-related quality of life for people with disabilities. The emerging model is driven by social

determinants. The health equity and social determinants approach regards people with disabilities as part of the general population rather than as “other.” It:

- Focuses on health, well-being and participation
- Disability is considered one of multiple variables that influence health
- Alters analysis methods to consider
  - Multiple simultaneous effects and interactions
  - Disability as more than dichotomous
- Promotes an expectation of inclusion

The following are its expected implications for health professional education:

- People with ID experience unnecessarily poor health as a result of multiple reasons
- People with ID have more adverse health conditions to identify and manage
- Poor health occurs in a context of other influences
- Early improvement and maintenance of good health is important across the life course

### **“Medically Underserved Population” Status—A Progress Report**

*Barbara Kornblau, JD, OTR/L, Dean, School of Health Professions and Studies, University of Michigan, Member, HRSA’s Negotiated Rulemaking Committee on MUA/P and HPSA*

Ms. Kornblau described HRSA’s Negotiated Rulemaking Committee on MUA/P and HPSA. There are 28 committee members representing federal qualified health centers (FQHCs), primary care doctors, homeless, migrant and seasonal farm workers, public housing residents, Asian and Pacific Islanders, limited English proficiency, rural health clinics, American Indians, lesbian/gay/bisexual and transgendered community, DD, people with disabilities, HIV/AIDS, nurse practitioners, physician assistants and many varieties of data people all with lots of data documenting disparities.

She reminded the audience that this designation is a first step, not a panacea. Depending on the designation, it could provide eligibility:

- To apply for a FQHC
- To be a rural health clinic (group practice)
- Increased reimbursement through Medicare
- A bump-up on reimbursement or an encounter rate or cost-based reimbursement
- National Health Service Corps
- State loan repayment and others

This is the first step toward being considered MUA/P. For people with ID, it could mean more primary care providers being trained to work with people with disabilities and people with ID in particular through the National Health Service Corps.

There has been some progress and tentative agreement. The charge of the committee has been extended to October 2011. There are four criteria for being considered a MUA/P:

- Factors indicative of health status of population group
- Ability of population to pay for health services
- Access to health services (barriers)
- Availability of health services to residents of a population group

There are (currently) three groups: streamlined, simplified and regular. Streamlined are those assumed to meet all four criteria. The simplified group, which would include those with ID, includes groups established by DHHS legislation; groups assumed to meet three criteria.

## **Promoting Curriculum Development in I/DD—Challenges and Opportunities**

*Lois Nora, MD, JD, MBA, President Emeritus and Dean of Medicine Emeritus, Northeastern Ohio Universities College of Medicine, Member, Council of Academic Medicine*

Dr. Nora spoke on promoting curriculum development. She posed the following question: How do you make an impact on the Liaison Committee on Medical Education (LCME)? The subject is more human rights than curriculum development. The important part is framing the issue so the person at the other end of a conversation becomes passionate about it too. This subject is competing with many themes that people are trying to get traction on.

She likened the experience of moving a curriculum to moving a graveyard. You never know how many friends the deceased had until you try to move his grave. She encouraged the audience to be act as change leaders in their area of change and follow Kotter's 8-step change model. This model involves identifying a vision of the preferred world and then getting other people to care about this preferred world by forming a powerful guiding coalition and empowering others to act on the vision.

Another option is curriculum by stealth. Medical students want to be competent. In this era of political correctness, it can be helpful to encourage them to explore and overcome their discomfort in working with people with disabilities. Energizing students is an enormous step.

She also encouraged publishing in education and asking students to bring the issue to the attention of the American Medical Association and their school's chapter of the Association of American Medical Colleges (AAMC) as well as the Multimedia Educational Resource for Learning and Online Teaching (MERLOT.org).

## Enhancing Training in Family Medicine—Where do we go from here?

*Caryl J. Heaton, DO, FAAFP, Associate Professor and Vice Chair, New Jersey Medical School, Department of Family Medicine, Past President Society of Teachers of Family Medicine, Past President NJ Academy of Family Physicians*

Dr. Heaton noted that in the United States, primary care physicians take care of people with disabilities. There are shortages of health professionals around the country, especially specialists. The major organizations that control the curriculum of Family Medicine include the American Academy of Family Physicians, Family Medicine Educational Consortium, Association of Family Medicine Residency Directors, North American Primary Care Research Group, and Society of Teachers of Family Medicine (STFM). Put together, they number roughly 98,000 people. Other important groups are the American Board of Family Medicine, Family Medicine Education Consortium, residencies, medical departments, primary care associations and independent practices.

She noted that the Primary Care plate is full: electronic health records, patient-centered medical home, health care reform and teaching—all while serving more patients and receiving less reimbursement. Those interested in expanding medical curriculum can network, join listservs, and connect on websites. STFM has 48 special interest groups (including one on disabilities). There is no appetite now for adding another fellowship (already added fellowships for sports medicine, geriatrics, and adolescent medicine). Dr. Heaton suggested a tiered curriculum model outlined below:

### *Tiered Curriculum Model*

- Core Tier
  - Should be basic and so straightforward that any reasonable residency director would say—of course we should do that
  - More likely they will say “of course we already do that”—but wonder if they really do?
- Advanced Tier
  - Should be an expected goal for each residency and residency graduate
- Exemplary Tier
  - Should be a level that suggests a graduate could be prepared to take responsibility for a large number of complicated patients
  - Should be recognized as a center of excellence

She noted the immediate goal would be for every residency to teach and support core competencies.

### *Family Medicine Education in the Care of Patients with Intellectual Disabilities in the U.S.*

Dr. Heaton also outlined a three phase approach to enhancing training in Family Medicine:

#### **Phase 1**

Recognize the excellent work that has been done internationally and incorporate it to:

- Create an excellent curriculum document
  - Create tools, methodology and evaluation to support the curriculum—match to objectives

- Must have face validity
- Should have curriculum “tiers”
- Create a repository of all curricular materials
  - Don’t reinvent the curriculum wheel
- Residency faculty as the unit of intervention

## Phase 2

- Create a support network—
  - Family Medicine Education Consortium
  - National network “partners” —NC, FL and CA
  - Connect with university department champions
- Recognize “Advanced” and “Exemplary” residencies
- Recognize residency faculty champions
  - Connect residency faculty in some meaningful way
- Move the curriculum through organized family medicine

## Phase 3

- Create advocacy support for residency and residency faculty champions network
  - Link patient self-advocates to network and individual residencies
- Develop policy and funding initiatives
  - HRSA priority for patients with ID/DD
  - Search out other funding partners
- Accountable Care Organizations—Virtual ACO

## In Summary

*David O’Hara, PhD, COO, Westchester Institute for Human Health & Development*

Dr. O’Hara reminded the audience that future efforts are contingent upon sustained partnership between health professionals, researchers, and the university community. Communicating the need for training and keeping the issue visible is essential. He noted the analogy that moving a curriculum is like moving a graveyard is particularly apt to the experience of infusing disability related curricula into health professional education. It will be important to create an excellent curriculum document as a basis for rallying support around policy and funding initiatives that promote partnerships to champion the issue.

# State of Science Conference on Lifespan Health and Function of Adults with Intellectual and Developmental Disabilities: Translating Research into Practice

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*May 26, 2011*

*Sponsors: Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, National Institute on Disability and Rehabilitation Research (NIDRR)*

## **Laying the Foundation for Research and Practice: Outcomes of the Meetings on Health Surveillance and Health Professional Education**

*Gloria Krahn, PhD, Director of the Division on Human Development and Disability, NCBDDD/CDC*

Dr. Krahn reviewed the events of the past three days. Multiple major issues in intellectual disabilities (ID) had arisen. On surveillance: The purpose of good data is to drive practice and policy. In the long run, it is to improve health outcomes of people with ID. Population-level health data about ID do not exist, despite a great need for it. Going forward it will be important to:

- Plan for and link electronic health records to build a strong data base
- Collect data about social and life circumstances to learn more about the larger context in which people with ID live including all factors that drive health outcomes
- Design quality health promotion activities

*David O'Hara, PhD, COO, Westchester Institute for Human Health & Development*

Dr. O'Hara noted that in the United States, two groups have been looking at the medical curriculum—Mountain Area Health Education Center (MAHEC) and American Academy of Developmental Medicine and Dentistry (AADMD)—and have created a framework for physicians. Work is in progress to establish people with ID as a medically underserved population (MUA/P). The presenting self-advocates have reminded the audience that professionals are not the experts in their lives—they are the experts. It took a long time to incorporate an interdisciplinary approach into the medical care of children. The same is possible for adults with ID: champions are needed who can move these major themes forward, create opportunities and open up new possibilities.

## **Emerging Research Findings on Lifespan Health and Function**

*Tamar Heller, PhD, 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)*

Dr. Heller explained life course research is about looking at transitions and other times of predictable stress, such as the transition from teenager to adult, when people with ID age out of the pediatric health system, become ineligible for certain services and often contemplate moving out of the family home and assuming adult responsibilities.

Disability across the life course is organized by age phases but focuses on four aspects: health, families, self-determination, and policies/legislation. Key trends in research include more emphasis on evidence-based approaches and systematic reviews, which are currently scarce for ID. Some efforts do exist to translate NIH research to practice, such as by Translational Research Centers, and conducting studies of ways to roll out best practices.

She noted that the *Journal of Intellectual Disabilities Research* published a systematic review of a group in Holland describing the environmental factors affecting community participation of people with ID consisting of nine studies over several years. The studies found important variables, many relating to self-determination, autonomy, choice, decision-making, family involvement and social support.

Research trends also include recognition of a disability studies-social model approach to understanding the experience of people with disabilities. Qualitative studies of lived experience are important. Dr. Heller encouraged the involvement of people with ID in research at all levels and the use of innovative methods to better understand their perspective. Longevity is increasing, and there are more older Americans, meaning caretakers that are aging, too. Roughly 25% of caregivers are age 60 or older, and 35% are 41 to 59. These demographic shifts are affecting the research.

Siblings are taking on bigger roles in caring for people with ID. The Sibling Leadership Network is a national movement with chapters all over the country, and interest from Japan, Canada, and Australia. According to the data, fourteen percent of personal support workers are siblings.

Policy trends are not favorable. There is a push for integrated health and long-term care in Illinois provided by insurance companies such as Aetna, which should be evaluated. A disability advisory group with self-advocates is involved in ongoing evaluations, along with a health economist. There is some bridging of aging and disability interest in long-term care, and a move towards collaboration between the aging and disability networks under the ACA.

## Health Disparities

### Longitudinal Health and Intellectual Study on Obesity and Health Risk Behaviors

*James Rimmer, PhD, Professor Department of Disability and Human Development,  
Director of National Center on Physical Activity and Disability*

Dr. Rimmer described a longitudinal study examining the health behaviors and health outcomes in adults with ID, including changes across time in the prevalence of six health behaviors: physical activity, diet and weight control, oral health, smoking, alcohol consumption, and social participation. The study also examines the impact of health behavior changes across time on psychosocial well-being and community participation. Participants included more than 1,600 adults with ID recruited in 2010. A rich amount of information was acquired about changes in health across the lifespan and this effort will continue in 2012 and 2013.

The mean participant age was 39.86, and about half of participants had ID only. Almost 10% of participants had autism. Slightly more than half reported having mild to moderate level of ID and 26% did not report level of ID. The top five health conditions reported by participants were (in order of prevalence): obesity (39%), seizure disorder (19.8%), anxiety disorder (18.6%), depression (17.6%) and high blood pressure (15%). Almost 30% had other chronic health conditions, such as high blood pressure or high cholesterol.

Obesity was higher at all ages and was much higher among females, and morbid obesity was significantly higher for women with ID. Those taking medications for depression and living in less restrictive settings had higher rates of obesity. Nine of eleven chronic health conditions were significantly more common among adults with ID who also reported being obese.

There were not dramatic differences in health risk behaviors except for insufficient activity. Health risk varied by living arrangement, and there were significantly higher rates of health risks, such as eating fewer fruits and vegetables, smoking and drinking, for people living on their own. Looked at by Special Olympics participation, nonparticipants had more inactivity, higher rates of watching TV, and slightly higher smoking rates.

He described his recommendations based on this study:

- Customized health promotion interventions by living arrangement and health risk behavior(s)
- Greater focus on obesity reduction and prevention, particularly in less restrictive settings
- Technologically enhanced self-management strategies including use of electronic personal health promotion records for greater self-monitoring of high risk behaviors
- Greater community inclusion

Targeting key populations should provide a level of customization that could prove equally useful for the general population. A greater focus on obesity prevention is necessary, particularly for those

living with their families or on their own, to promote greater self-monitoring of high-risk behaviors and establish more connectivity to large national databases.

### **Self-Reported Health-Related Quality of Life by Persons with ID**

*Glenn Fujiura, PhD, Associate Dean for Academic Affairs, Associate Professor and Director of Graduate Studies, College of Applied Health Sciences, Department of Disability and Human Development, University of Illinois at Chicago*

Dr. Fujiura described the aim of this research study is to develop a function-free, health-related quality of life instrument that would not penalize people with disabilities automatically. He explained that there are ideological and utility reasons for pursuing self-report. Those who cannot respond or are not reliable must be screened out. Methodologists advise against self-reports unless certain criteria are met yet you see wholesale use of this method. The purpose and research objectives of the project are as follows:

- Phase I: SF-12 adaptation and preliminary field testing
- Phase II: psychometric evaluations
- Phase III: final field testing, psychometric evaluation and validation

Fundamental issues have emerged. In Phase I, item adaption and cognitive testing and conversational analysis (a think-out-loud strategy) was used. Participants did not view their participation as contributing to the project—they felt like they were taking a test, despite efforts to keep surveys informal.

While it is easy to presume that people understand concepts, that assumption should be questioned. A second presumption—that people tell you the truth—must also be challenged. There have been very sophisticated and detailed conversational analyses. The intent of this project was simpler: to identify points of miscommunication.

Many participants were confused about (the difference between) nervous and sad. This question was revised as follows: Do you ever feel nervous? When you feel shaky and nervous, is it hard to do things? What kinds of things are hard to do?

It is important for researchers to directly challenge the veracity of what is often assumed to be objective data. Under the current approach, methodologists have very precise guidelines for how to revise questions and give response options. The thrust is to exclude most people from the self-report process. In this field what people think and feel is often reported as data. Participants tend to have a lot to say and it is a challenge to figure out the best ways to ask them the right questions so our understandings are often superficial.

*Philip Davidson, PhD, Professor Emeritus of Pediatrics and Psychiatry, Strong Center for Developmental Disabilities, University of Rochester, Rehabilitation Research and Training Center*

### *Neurodevelopmental conditions and lifespan health outcome*

Dr. Davidson explained that according to the data, as people with ID age, they require more health care and morbidity is higher than we would expect in the normal aging process. State governments are reducing support for community services due to waning budgets. Improving health for people with ID as they age has been difficult, which is of great concern.

Since RRTC's inception, the Rochester project has been plotting trajectories for health status among older people with ID using mostly large-scale data sets. For the first five years, the focus was on collecting secondary data on people older than 40 in New York, Israel or Taiwan. There is data on nearly 5,000 people. For the next five-year cycle the focus was shifted to neuro-developmental conditions that occur or co-occur with ID, including Down Syndrome, Fragile X, Autism Spectrum Disorder, Cerebral Palsy, Spina Bifida and Prader-Willi Syndrome.

Large-scale data is collected on the general population, mostly in the United States but also in countries like Italy and Romania, among others.. Comparisons are then made between the older data and the newer data. The second approach is to identify locations where people with specific neuro-developmental conditions are cared for and collect data on them. Roughly 1,000 people have been identified in the new phase and the target is to enroll another 2,000 people by the end of the fifth year.

The data collection instrument is the Rochester Health Status Survey (RHSS). The survey collected data on people with ID being served by New York during a certain period of time. The instrument was used to collect enough data to determine service needs and determine the modifications required for the New York system.

The instrument has undergone three revisions. It is a labor-intensive survey that includes 58 validated questions and must be filled out by health care professionals. The survey tracks organ system morbidity, incidence/prevalence of health conditions, with lifetime prevalence going back to the earliest point in the group survey (age 16 for Spina Bifida). It also summarizes cardiac and neurological health, identifies clusters of disorders and tracks health services utilization.

He noted that work is either in progress or completed on three neuro-developmental conditions. Adults ages 33-79 in New York with and without cerebral palsy were compared to look for higher morbidity. Data was adjusted to reflect the severity of functional impairment index and this index was used to adjust for age-related trends in people with and without Cerebral Palsy. There was a significant difference in functional impairment, but Cerebral Palsy did not predict organ system disparities—everything else was predicted by the functional impairment.

Risk factors for chronic disease and weight-related chronic disease in adults with Down syndrome were assessed. Interventions prescribed could include medication, diet, and exercise. Exercise is one of the biggest prevention tools.

The study compares disorders over the lifetime, and many of these people carry health compromises throughout their entire lives. The implications of these disorders include, in a year, three or more acute PCP visits for 82% and one or two emergency room visits for 44%.

## **Health Promotion Practices and Intervention**

### **Sustainable Health Initiative Programs: Translating Knowledge through Interactive Distance Learning (iShip)**

*Beth Marks, PhD, Research Assistant Professor, Department of Disability and Human Development, Associate Director of Research, RRTCADD, UIC*

Dr. Marks explained this project's goal: to assess the effectiveness of the *Health Matters* program using an interactive distance learning (IDL) training model for staff working in multiple community-based organizations (CBOs) serving adults with ID. As paid caregivers, direct support professionals (DSPs) are key in promoting sound health practices for people with ID.

The project had a multi-level design with data collection points. DSPs were randomly assigned to intervention and control groups. IDL intervention participants were compared to the control group of participants at three, six and 12 months measuring CBO capacity, staff participation and achievement of client goals.

The hypotheses tested were whether:

- CBOs increased organizational commitment for health promotion activities at one year compared to baseline
- DSPs increased cognitive learning gains and perceived self-efficacy, reduced barriers, met health promotion outcome expectations and improved health advocacy skills among intervention group after the training and six months later compared with control group
- Clients achieved health and wellness goals after the IDL intervention

She described the two phase process during which the intervention occurred. Phase 1 was to develop and implement an online CBO assessment. Cornell University's Survey Research Institute converted the RRTCADD's *Health Matters* Organization Assessments (HMOAs) to an online format. The data were collected at baseline and 12 months. Phase 2 involved a randomized control study of IDL with the intervention and control groups.

The non-interactive web-based *Train-the-Trainer Program* was converted to IDL intervention (online instructor moderated, distance learning 12-week course). CBO staff dedicated 30-40 minutes per week for total of 6-8 hours helping one to three adults with ID develop tailored health and wellness goals and action plans.

Moving out into the community, people were doing a better job because they were more familiar with the people and their routines. While this model worked, it was not sustainable. Most of the organizations felt that health was not part of their mission. The project received an NIH grant for capacity building.

In a comparison of health status, knowledge and skills, fitness status improved between groups and pre- and post-test for people with ID, including social/environmental supports for exercise, social/environmental supports for nutrition, cholesterol, glucose, self-efficacy to exercise and more.

In pilot testing the distance learning course, user challenges arose, including learning insecurities and diverse online proficiencies. There were platform issues with Moodle, Blackboard and the interactive self-paced narrated website. Many of the DSP's do not view themselves as health professionals or health as their job.

When reading a website, people typically follow an F pattern, scanning horizontally across the top part, then horizontally a little lower, and finishing by scrolling vertically down the left side. But this does not hold true for people with low literacy (who are more likely to focus in the center of the screen and less likely to scroll). Dr. Marks recommended that development of online materials should reflect the way intended users will use them.

For people with ID, improving outcomes of health and wellness programs in CBOs can be supported by using the RE-AIM (reach, adoption, implementation and maintenance) framework to foster sustainable adoption and implementation of effective, generalizable and evidence-based research findings/interventions, service learning and training, along with knowledge translation opportunities to move what was learned into real-life applications for people with ID.

People who went through the Train-the-Trainer program were passive recipients, but the staff that went through the intervention experienced significant improvements in nutrition. Results showed that they ate more fruit and vegetables, however fewer changes in exercise behavior were observed.

### **Identification of Falls Risk in Adults with ID**

*Kelly Hsieh, PhD, Research Assistant Professor, Department of Disability and Human Development, Associate Director of Evaluation and Statistics, RRTCADD,UIC*

Dr. Hsieh noted that falls are a leading cause of injury and death among people older than 65. According to AHRQ, there are 2 million fall-related emergency room admissions annually. People with ID are at much higher risk of falls than the general population. More than 60% of people age 65 and older with DD experienced falls in the last year, with women more likely to fall than men. The studies of falls in the DD population are limited, but we need good population-level data to support policy going forward.

Risk factors among those with I/DD include being ambulatory, having seizures, taking anti-seizure medications and having impaired mobility. Among the general population, risks include a history of

falls, reduced lower muscle strength and a fear of falls. Risk factors common across both groups include being older, poly-pharmacy (taking four or more medications daily), urinary incontinence, poor vision, and abnormal gait or balance. Forty percent of Special Olympics athletes have abnormal gait and many people need to improve their balance.

This project was supported by four research questions:

- What is prevalence of falls among adults with ID living in community settings?
- Do adults with ID who fell in last month differ in characteristics, physical function, health conditions and medication use compared with non-fallers?
- How reliable are strength and balance instruments in adults with ID?
- How do strength and balance measures of participants with ID compare to general population?

Dr. Hsieh explained that the sit-to-stand test was used to measure lower extremity strength. The timed-stand test measures time to complete five full stands from a sitting position. Balance was assessed by the four-test balance scale, which involves rising from a chair, walking 10 ft. and returning to the chair. Only 24% of participants could stand on one leg for 10 seconds. The overall prevalence of falls was 42.6% for those age 65+, while 41.7 percent of all ages had one fall within the last year. Almost 25% of participants reported four or more falls.

Fallers were more likely to be female, obese and have Cerebral Palsy and less likely to participate in Special Olympics, live with their families and be employed. They were more likely to use walking aids, have functional limitations, and experience seizures, urinary incontinence, foot pain and/or visual impairment. They were more likely to use anti-seizure medications, psychotropics and take four or more medications a day. Risk factors for falls include using walking aids, experiencing foot pain, poly-pharmacy and not using a wheelchair.

Next steps for this project include the following actions:

- Continue to recruit participants including more minorities for the control randomized fall intervention trial.
- Test the efficacy of strength and balance training to reduce falls.
- Examine the relationship between occurrence of falls and all the strength and balance measures (predictive validity).
- Investigate the relationship between musculoskeletal markers (e.g., bone density, osteoporosis) and occurrence of falls.

## **Response to Longitudinal Health and Intellectual Disability Study on Obesity and Health Risk Behaviors**

*I-Min Lee, MD, ScD, Professor of Epidemiology, Harvard University*

Dr. Lee used the prospective cohort study as a good example of a strong study design noting that it allows for examination of trends in health behaviors in the same population over time, to compare, for example, obesity trends in the ID population compared with trends in the general U.S. population. It also offers an example of correct temporal sequence, risk factor-outcome relations, inferring causality.

The study starts people with ID who are not obese and divides them into two groups: those who meet guidelines and those who do not. The study tracks the rate of development of obesity in the 2 groups over the ensuing five years of study and asks whether following the physical activity guidelines reduce the risk of obesity for this population.

The study invited 2,800 adults to participate and 1,600 responded, for a 57% response rate. A lower response rate might limit the generalizability of findings, but does not, by itself, invalidate findings. A larger initial response is generally more representative than the response rate achieved. Response rates in other national surveys vary from 50% to 90%. In the Framingham study, the response rate is 67%-69%.

#### *Data reporting*

Dr. Lee reminded the audience that self-report is easier than measurement, because some data cannot be measured. For the National Health Interview Survey, survey-takers go into homes and ask participants about their height and weight. The BRFSS is conducted by phone surveyors and relies on self-reported data. People may be less willing to report accurate data on certain subjects. For example, women tend to be fairly truthful about their height but much less so about their weight. For men, the reverse is true.

Furthermore, in a BMI survey, BMI was lowest in phone self-reports, higher when face-to-face interviews were used, and highest when someone measured participants' weight and height.

Dr. Lee listed some of the challenges ahead for this study:

- Follow-up of cohort
- Low follow-up rates threaten validity of findings (bias—less healthy are usually less willing to participate)
- What's next: How to change health behaviors in people with ID?

## **Discussion of the Presentations on Health Disparities**

*Meindert Haveman, PhD, Professor of Special Education and Rehabilitation, University of Dortmund*

Dr. Haveman noted that research finds marked differences in health between people with ID and the general population. The poorer health status of persons with ID reflects a combination of factors below:

- Genetic predispositions to certain health conditions
- Less favorable social circumstances typically experienced by people with ID
- Reluctance or inability to utilize generic and special health services
- Being left out of public health awareness campaigns
- Residential circumstances that foster inactivity and poor lifestyle choices

Dr. Haveman said that quality of care in all countries should be measured by people with intellectual disabilities. This group is expensive and vulnerable to the first cuts in budget. Dr. Haveman described his experience in the Netherlands providing training on later-life planning for adults with disabilities. Many of those attending were not knowledgeable about the basic functions of their bodies. School had not become compulsory until they were already adults. There is a need for more involvement by people with disabilities in designing care and services. In most countries, it is still a fact that people with disabilities remain largely excluded from decision-making. Efforts to reduce obesity must be conducted in a participatory framework in an interactive, engaging manner, rather than being top-down.

The Pomona (2002-2008) survey of people with disabilities was undertaken in 14 countries. It found the proportion of smokers was relatively low among people with ID in EU countries. Smoking was more common among people 65 years and older than among younger people. Only 7% of teens smoked more than 20 cigarettes, and the use of alcohol was also quite modest among people with disabilities. Older people were more likely to drink often, but younger people were more likely to be heavy drinkers. Lack of regular physical activity and unhealthy eating habits were prevalent among people with disabilities. In Pomona, it was found that the most sedentary were the oldest. Only 2% of those ages 18-34 participated in intense physical activity more than once a week. This could be accounted for by lack of stamina.

He noted that obesity rates among people with disabilities are lower in Europe than in the United States. In European studies, the largest differences in BMI between the ID and general populations were found not with regard to obesity, but in the underweight category.

### **Translating Research into Practice**

*Thomas Prohaska, PhD, Professor, Community Health Sciences, Co-director of Center for Research on Health and Aging, Institute for Health Research and Policy, UIC*

Dr. Prohaska stated that evidence-based wellness and health promotion programs are comprehensive, multifaceted interventions that are based on an understanding of the mutable determinants of the health and well-being of older adults.

- All include a therapeutic element (treatment) and a well-developed strategy for implementing the treatment (program delivery).
- May be oriented toward healthy older adults as well as those with moderate to significant health conditions
- Documented impact on meaningful health outcomes and related demographic, psycho-social and environmental correlates that influence the behaviors
- Evidence of a systematic review and deemed an “evidence-based program”

The translational research questions pursued by researchers in the audience all relate to health promotion—incidence/relevance of risk factors, associations between risk factors and subsequent risk—and all ask the question: Can we intervene on these risk factors and make a difference?

Common characteristics of evidence-based programs for successful translation:

- Randomized Control Trial and similar non-randomized trials with established efficacy and effectiveness
- Essential elements clearly defined (and documented “implementation manuals”) and opportunities for reinvention, program tailoring
- Incorporation of the priorities and realities of community practitioners and agency directors
- Documented cost and cost effectiveness
- Sensitive to realities at the community and organizational level (demonstrated flexibility; settings where program delivered, level of expertise required and mode of program delivery).
- Evidence of a systematic review and deemed an “evidence-based program”

He recommended using the RE-AIM framework for evaluating overall public health impact of evidence-based programs:

- Reach (number and percentage of people recruited and representativeness of targeted population)
- Effectiveness (how well do the outcomes compare with the original; quality of life)
- Adoption (number and range of settings where program is implemented)
- Implementation (consistency and the fidelity of adherence to program essential elements and cost and resources to do so)
- Maintenance (extent to which participants continue program’s therapeutic elements and extent agencies/organizations continue program (beyond initial funding)

Dr. Prohaska noted that the Train-the-Trainer program is a sustainable health promotion program, is web-based and addresses multiple domains of RE-AIM. It also examines agency-level and practitioner-level factors and identifies key barriers. The pilot testing was impressive and the final product will be more sensitive to the realities of the delivery environment. In the Identification of Falls Risk in Adults with ID, the early phases of translation research have been established-the study considers broad ecological factors associated with falls, and the final product documented need.

## Advocate Panel Response (Responses have been paraphrased)

Self-advocates were asked to react to the studies presented thus far.

*Sarah Ailey, PhD, Assistant Professor, College of Nursing, Rush University, Mother of a 35-year son with intellectual disabilities*

“Much of what drives me as a professional is my son’s experiences; along with people we've met over the years, like in Special Olympics. I appreciate the supports outcome model of aging well. Glen’s work is so important—hearing the voices of people like my son. When I was working on my dissertation, I joined a theater group in which everyone had some connection to disability. I think it’s important to get at “how people talk”—a social problem-solving manual. Beth’s work is great, too. Lots of people with ID do not want to live with their parents. How do we get health promotion out to where people are living and to the people supporting them?”

*Essie Pederson, Executive Director, Capabilities Unlimited*

“I’m from Cincinnati, a Research and Training Center. From the beginning, I’ve been blessed with the privilege of watching research training dissemination activities evolve. We've asked Marvin a couple questions to stimulate his thinking.

Marvin understood Beth's research paper. As to Kelly and Jim's work, Marvin has started working on an exercise program at the YMCA. Marvin wanted a free exercise program so he took Beth's work on exercising to the YMCA so they could look at it. The YMCA agreed and Marvin has had a blast with his program for four years. There is a volunteer instructor with no funding, 25 people per 1½-hour session. The program is not only about exercise; it’s also about what to eat. Education and exercises, and that works. Most recent addition is direct support staff has to take program, too.

The discussion about life stories is very important. Lots of research is being done that can be shared. I had an older brother with Down syndrome who passed away. We wanted him to eat a healthy breakfast, so we put a photo of him walking on his Wheaties box. He would see it and then do his walking, about five times a day. He even joined a walking club. Joan included a lot about Jim in her book. I want to commend all the researchers for their work—it’s making a significant difference. It makes a difference when everyone buys in, and people are more actively buying in. Like Glen, what you've been doing with your questions is so valuable, as people do not have to know exactly what every word means to participate. Having the flexibility to meet people where they’re at is so important. Researchers challenge families with their questions. Beth's three-pronged approach—looking at the person with the disability, the service provider and the organization—is a way to make it happen.”

### *Marvin Moss, Self-Advocate*

“I have concerns about getting older. As we age, we go to doctors more and work less. We want to keep going. I am diabetic and have high blood pressure. Our problem is that we don't want to take our medicine. We need help. Not enough staff people are trained to give us medicines. What food should we eat at the airport? I had to learn about my health care and diabetes, so I felt comfortable about taking medicine, insulin, testing sugar level, what to do when number goes up or down—turn the needle, push button in and get insulin. I had to learn that. Going to the grocery store by myself, figuring out what kind of meals to eat, making the right food choices. I do it now. Beth's research sounds good. The staff don't know how to do a lot of stuff. Beth's research was good because she's talking about people who support you at home—like to see more of that all over country. Beth's approach is good. Only about half the staff know how to use a computer. We want the staff to know more so they can make sure we what we're supposed to, but not tell you what to do. We need support/help, not orders. “

### **Embracing Family and Community Supports**

*Tamar Heller, PhD, 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)*

Dr. Heller explained that most adults with I/DD in United States live with families and there has been some growth of funding for those living at home or independently. There is a growing movement of consumer-directed supports. Data from the he National Core Indicators shows that more than 45% of family caregivers make less than \$25,000. Fifty-three percent of them are ages 55-74 and 10% are over 75. Most states allow families to be paid, including parents.

Self-directed support (family support) in Illinois decreased institutional placements over eight years. When this was funded, legislators wanted to realize cost savings. The data showed that this move:

- Increased community participation and employment for people with I/DD
- Decreased institutional placements
- Decreased the prevalence of unmet needs, out-of-pocket expenses for disability services, and stress and burden for families
- Improved caregiver mental health and self-determination of people with I/DD among lower-income families

The aim of this project was to examine differential experiences and outcomes for adults with ID and their caregivers who receive services based on type of personal support worker (PSW) hired. A few thousand families were surveyed on family experience with personal assistance service. The survey population consisted of families receiving Home-Based Support Services. Interviews with adults with I/DD were also completed. The survey was similar to the consumer survey but we added items about

personal support workers and more outcome data and combined it with family data. Dr. Heller reviewed the survey results.

Characteristics of the survey participants:

- Mean age 31, from 18-69
- 58% males, 42% females
- 72% white, 27% minority
- Level of ID: mild (14%), moderate (33%), severe (22%), profound (12%), don't know (14%)

Demographics of caregivers:

- Mean age: 58, range from 21-84
- 82% female
- 60% married
- 58% employed
- Relationship to person with I/DD: Parent (91%), sibling (8%), other family member (3%)

Study participants included 522 families (27% response rate) in the Illinois Adult Home-Based Support Services Program. The analysis includes 369 families who hired PSWs. The measures included:

- Workforce characteristics
- Caregiver self-efficacy in managing PSWs
- Satisfaction with PSW
- Caregiving appraisal (satisfaction, burden, self-efficacy)
- Mental health and physical health
- Community participation of adult with I/DD
- Daily choice making of adults with I/DD

As the age of the person with I/DD rose, they became more likely to hire a sibling. Those who hired a parent as a caregiver were more likely to be married. On average, PSWs worked 27 hours a week. The mean number of PSWs who stopped working in the past year was two, and the mean number who stopped working was three. Siblings worked the most hours, and the arrangements with parents/siblings were more stable than those with friends, for which turnover was highest.

The highest satisfaction rates were with siblings, although parents were close. The least satisfaction was with agency staff. On the measure of self-efficacy in managing the PSW, siblings score highest. On measures of caregiver mental health, siblings scored highest. As an aside from another study, when siblings were caregivers, the mother's well-being was higher. The physical health of the person with ID was best with the parent. On daily choice-making, the highest scores were agency staff and the lowest with friends. Future research is needed on training interventions to help persons with I/DD and families better direct their supports.

## **By Caring for Myself, I Can Care Better for my Family: a Pilot Health Education Intervention**

*Sandy Magaña, PhD, Associate Professor, Social Work, Waisman Center, University of Wisconsin, Madison, RRTCADD*

Dr. Magaña described this intervention using a community health worker model. Latina mothers often identify their caregiving role as their primary responsibility. There is a strong need for an intervention to help Latina mothers focus on their own needs and the goal of this program name was selected specifically because it does not appear to be about the mothers, as most of these women would feel selfish making efforts on their own behalf.

Under self-efficacy theory, health education can help participants feel more confident in carrying out behavioral change leading to changes in health behaviors. These include performance accomplishment, vicarious experience, verbal persuasion and emotional states.

Dr. Magaña described the Promotora de Salud (community health workers) model as a model widely used in the Southwest and proven effective for diabetes. These community health advisors are not professionally trained but come from the community. They speak Spanish, and understand culture and community.

The pilot study was in Wisconsin. The study involved 27 Spanish-speaking mothers who were at least 40 years old or had a child 8 years or older. They had low education levels and were fairly low-income. The Promotoras, as emerging community leaders, tended to be slightly better off and better educated. The training procedures involved 10 Promotoras, a group format, and 14 hours over three 3 half days. The Promotoras played a dual role: Promotora and participant. Promotoras received a stipend for the training and for each completed individual case. The participants received a certificate at the end of the program.

Self-advocacy for participants related to health behaviors improved between pre- and post-tests. Participants increased their level of exercise, improved their nutritional habits and experienced a significant reduction in depressive symptoms. Drop-out rates were low. Next steps are a randomized trial in Chicago and working with the community agency El Valor. There are 50 enrolled in treatment and 50 on the waiting list. A group model is being tested with Community Support Services in Chicago. Compensating the Promotoras through the university system was too slow, so arrangements were made for El Valor to compensate them. There are plans to adapt the program for the African American community.

## **Examining Environmental Barriers and Supports to Home and Community Participation with People with I/DD**

*Joy Hammel, PhD, Associate Professor, Occupational Therapy and Disability Studies, UIC, RRTCADD*

Dr. Hammel reminded the audience that it is well known the environment influences participation. This study asked participants about facing barriers and where they exist in their environments. Families were asked and oftentimes made assumptions (sometimes they themselves were the barrier). The third phase of this study was to go out into the community with people with ID—into homes for a comprehensive audit. A peer mentor and an access specialist joined the study team on these trips. The teams were trained by Great Lakes Americans with Disabilities Center to look at accessibility, safety, and meaningful participation in activities of choice.

Participants were given up to two choices of activities outside the home, either something they had enjoyed that later became difficult, or something they had always wanted to do. They were followed from home to the activity locale and did the activity, performing full-blown accessibility audits of transportation, community sites (shops, etc.) along the way. At same time, people with ID were trained to take digital photos along the way to tell us about the barriers/supports they encountered.

Each audit covered the following:

- Barriers and supports checklist of issues most influencing participation
- PhotoVoice pictures and stories of what worked/didn't work
- Rating of whether they met goal or not, what helped them do so, and action plan to continue doing the activity in the future

The most common barriers were in and around home/community. There is now an extensive photo-voice library showing exactly what went wrong for participants, such as poor signage or stairs, as well as supports, all from the perspective of how it looked to participants. More than 500 community and home audits were completed. There were three times as many barriers in the community. Trend analysis explains which had the most effect.

There were three categories of environmental factors. Accessibility involves physical access and safety, cognitive access, sensory issues, weather and transportation accessibility. Social environmental issues include the social support of family and close friends, caregivers and the public. Systems-level factors include transportation policy, economic/financial control, information access, segregation and integration.

Radar plots of home and outside of plots, there are 12 environmental factors. Physical access and safety were issues but social barriers had a much bigger effect (professional staff and caregivers, family and friends). Families often became overprotective, and then participants stopped choosing things.

Transportation systems and policy have an enormous effect on accessibility. Many participants simply had no choices for getting around. Around the community, being shunted into segregated activities became more common as people with ID aged. For example, they might go to a museum but all together as a group, which played out as a segregated activity.

While change and action were often feasible and achievable in the community, the system-level barriers—like transportation—were very difficult. The peer mentoring/access specialist team approach worked in problem-solving community barriers. The intervention is now being tested in three states.

*Eric Emerson, PhD, Co-Director, Program Improving Health & Lives: Intellectual Disabilities Observatory for England*

(International reaction to presented studies)

Dr. Emerson remarked that the presentations were of remarkably diverse papers on evidence-based practices and provided the following reactions:

- Evidence of what? Impact—the difference being made in the lives of people with ID.
  - This difference must be quantified
  - In making the pitch to policy makers the risk either needs to be halved or the chances doubled
  - Need to make sure to emphasize the magnitude of the before-and-after difference
  - Forge partnerships with health economists
  
- Aims are interventions.
  - Internationally, health policy has more than one goal, and health equity—reducing disparities—has become an increasingly important goal.
  - Figure out how to make program benefits fairer and ensure equity of benefit among vulnerable populations.

*Gail Hunt, President and CEO, National Alliance for Caregiving*

Ms. Hunt reviewed a number of statistics around caregiving—of 65.7 million family caregivers, 8% are caring for someone with an ID, learning disability or Autism. Caregivers' responsibilities have tremendous impacts on their lives. Seventy percent have had to make a workplace accommodation, and 12% have taken early retirement or quit their job. The financial effects are considerable: an average of \$5,534 per year. Lower-income people spend up to 10% of their income caregiving. There are lost wages, missing pensions and no Social Security coverage. A study is slated to be released in June documenting these financial losses.

The effects on caregivers' health are somewhat worse. Higher stress levels take a toll on health, and caregivers are more likely to report having fair or poor health and being less likely to get preventive and other health care. An interesting question has arisen: Whose responsibility is it to reach the person with ID? A similar question could be asked about caregivers. Phone applications for family caregivers could reach a vast community. Comparative effectiveness research is necessary not just

across interventions and treatment, but across health service delivery. She noted that patients and family members should be in that research from the beginning. Once data are out there comparisons of treatment alternatives are available a need will exist for communication between provider and patient, which is not being addressed right now. A new caregiver program under the Veterans Omnibus Health Care Act is currently being reviewed by several groups, which allows veterans to identify a caregiver and then pay him or her as a home health aide in that geographic area. The caregiving community believes this will be a wonderful model for the rest of the country.

### **Advocate Panel Response**

Advocates were asked to react to the studies presented thus far.

*Ann Cameron Caldwell, PhD, Chief of Research and Innovation Office, the Arc of USA*

- The relocation of the disabling condition outside the person is great—the person is normalized in the social world of disability, and the environmental barrier—rather than the condition—is the problem
- Honoring the family while also honoring cultural paths and social behavior of the ethnic group is important as evidenced by the Promotora de Salud model
- Importance of continuing to build and engage and support siblings and maintain the essence of community engagement with one-on-one conversations for support

*Nora Handler, Family Advocate*

*(Response has been paraphrased)*

'I am the sibling of three adult men with ID, as well as the sibling of a sister who is the major caregiver. My brothers have not been able to select their own caregivers. Only one brother is Medicaid-eligible. They have lived with mom, with siblings and in group homes. Only one is happy in his own apartment. When they lived with my sister, all my brothers had community jobs. I salute Tamar for including siblings in her research. When we took over from my mom, we didn't understand the system (maybe we still do not). We had never heard of person-centered planning. But we have learned how to include them and let them be at the center of their own planning. I would love to see some help for siblings. So many siblings take over at a time of crisis and grief, knowing nothing, and they should have been included earlier on.

My brothers would have loved to have been taking those photos of barriers. Transportation barriers loom huge for them, affecting their ability to do anything in the community. And services are getting worse. I love that study, becoming more self-advocate and family friendly.'

*Tia Nelis, Self-Advocacy Specialist, Institute on Disability and Human Development, UIC, RRTCADD*

*(Response has been paraphrased)*

'It was so great to see Joy including self-advocates in the study. Looking at barriers is so important in every way, including social life. More people with disabilities are working at many different jobs, and we need to understand the differences between less protected/more protected environments, and how to make transitions between them smoother. It's been great to see people's pictures. Sandy's study of the Latina mothers is so valuable. We often see materials that aren't accessible to people who speak different languages or are from different cultures. I love your trainers going out there and doing some of the training, and including mothers in trainings, so they can teach other people. Peer-to-peer is the best way to learn.

Tamar's self-directed supports, choice-making, is such a huge issue. The information about self-directed supports could be very helpful. We just received money from the DD council to hire a consultant to write in a waiver for self-directed supports for adults with disabilities. We will use information presented here to make our case in Illinois. It's exciting to see many people working on same thing. Thanks for all of your research and for letting me speak.'

## **Bridging the Aging and Developmental Disabilities Networks**

*Alan Factor, PhD, Research Assistant Professor, Institute on Disability and Human Development, UIC, Associate Director for Training and Dissemination, RRTCADD*

Dr. Factor noted that in the late 1970s, service providers started noticing that they were serving more older adults—whose needs were different—and life expectancies were increasing. Aging-in-place programs began as de-institutionalizing efforts in early 1970s. Many of these people were middle-aged and older and initiatives to address those issues came about in the mid-1980s-mid-1990s.

He described key initiatives to forge collaborations across networks. In 1986, University of Maryland's Center on Aging met with all state I/DD agencies and their counterparts from state aging agencies to discuss common issues, service delivery, potential collaborations and addressing the needs of older adults with developmental disabilities and their families. That experience taught us that efforts involving state directors tend to be short-lived because of high turnover of agency directors.

Some of their recommendations became part of the Older Americans Act of 1987. Collaborations were forged across networks, and DD councils were required to comment on state aging plans. Older people with disabilities were designated as a service priority, using the same definition of DD in the DD Act. Revisions to active treatment regulations from CMS made it easier for the DD system to address the needs of older people. Before that, continuing treatment plans had to emphasize skill development. Older people with disabilities have different needs and less stamina. These efforts opened the doors to broader planning.

A formal agreement between the Administration on Aging and ADD strongly encourages state agencies to work together. The *Olmstead* decision was another catalyst. Dr. Factor listed several major programs that could potentially support collaboration:

- Aging and Disability Resource Centers
- Lifespan Respite Care Act
- Affordable Care Act
- National Alzheimer’s Project Act

## **Community Supports for Adults with I/DD affected by Dementia**

*Matthew Janicki, PhD, Research Associate Professor Institute on Disability and Human Development, UIC, Associate Director for Technical Assistance, RRTCADD*

Dr. Janicki described dementia as an age-associated condition that affects more than 5 million Americans and up to 20,000 adults with I/DD; a progressive behavioral dysfunction resulting from brain disease or trauma. Adults with some syndromes of ID—such as Down syndrome—are at high risk of Alzheimer’s dementia. Community agencies and families face greater challenges in providing residential and general living supports for adults affected by dementia. Many agencies cannot really confront the challenge of their populations aging.

The link between Down syndrome and dementia was recognized in the 1940s. A 1990 meeting in Boston gathered researchers from around the world to look at how dementia was affecting people with ID, which led to a 1994 working group in Minneapolis, in conjunction with the 4th International Congress on Alzheimer’s. Researchers focused on epidemiology, program practices and diagnoses, instruments/mechanisms for measurement, as people with ID are measured differently. In 2001, a meeting was held in Scotland to derive community support principles applicable to adults with ID affected by dementia, the results of which were disseminated worldwide by Alzheimer’s Disease International—the “Edinburgh Principles.”

The field has grown considerably as the issue has become more prominent and affects more families. National policies are desperately needed to help people have healthier and more dignified lives as they live with these diseases. The RRTC collaborative model features collaboration among 1) academic institutions; 2) national advocacy organizations/parent associations; 3) NGOs, charitable organizations, providers and the business community; and 4) government agencies and departments.

The National Task Group on Intellectual Disabilities and Dementia Practices is supported by AAIDD and AADMD, with over 90 members from various organizations and agencies. This is a collaborative effort to define a strategic plan for providing more effective services to adults with disabilities affected by dementia. The goals of the National Task Group on ID and Dementia Practices are to define best practices in technological and clinical practices that can be used by agencies in delivering supports and services to adults with ID affected by dementia, update existing AAIDD practice guidelines on care management of dementia among people with ID, and identify dysfunction indicators that can be incorporated into a first-instance screening instrument. A report is expected by late fall 2011/early winter 2012.

## Federal and National Organizations Panel

*Sharon Lewis, Commissioner of the Administration on Developmental Disabilities*

Commissioner Lewis pointed out that ADD is looking at aging issues to identify opportunities and intersections with existing aging policy. ADD has engaged with the Administration on Aging, CMS, and the Substance Abuse and Mental Health Services Administration about a little-known provision in ACA, 4202-A. It requires HHS to issue regulations to ensure that home and community-based state services allocate resources in a responsive manner, maximize independence, promote individualized community-supported lives, and design services more uniformly across programs and services. There are opportunities here to create consistency across systems and value-based approaches and then bring programs in line with these values.

Home and community-based services should reflect the values of self-direction, independence and opportunity for all. Person-centered planning and participant direction are important.

The system is far more home and community based than the systems for people with physical disabilities and aging populations. How do we help each other and learn from each other? Not necessarily knocking down silos, but beginning to knock some holes, letting some daylight in. The aging community has things to teach, and only 17% of families with a member with ID currently get any level of family support.

Both the Administration on Aging and ADD initiated a number of grants to bridge the aging and DD networks. The University Centers in Developmental Disabilities could choose to address aging issues and identify universities and centers with grants from both agencies. Follow-up surveys could be deployed to find out 1) Do bridges they created still exist? If not, why? 2) best practices, 3) obstacles. For summaries of aging issues that were presented as part of stakeholder testimony in 2010, ADD held five sessions around the country to elicit information about lifespan issues: children, adults, 60 to end of life and family support. It is important to investigate the feasibility of using some of these federal programs to foster ongoing collaboration between aging/ADD stakeholders.

*Bob Hornyak, Acting Director, Center for Policy, Planning and Evaluation, Administration on Aging*

Dr. Hornyak observed the many common themes between aging networks and networks for people with ID: independence, choice, control, dignity, honor, dissemination, evidence-based program, models, partnerships and issues of change. When making changes it is important to bridge silos in partnerships that are desirable but challenging, to overcome limitations imposed by law, regulation or lack of precedent. The National Center for Participant-Directed Services is establishing core competencies for the aging network, infusing participant-directed options throughout entire organizations, from senior management to the person who answers the phone.

The state DD agency in Massachusetts has a grant for lifespan respite—much broader than the traditional aging network—and the outcomes will be interesting. In working with an injured soldier with traumatic brain injury, he said he had two choices in Virginia: a nursing facility or a home health aide coming to his house. These options need to be expanded. Lifespan respite care could help with that. Efforts are in place to get away from silos and integrate services for all individuals served by an ADRC. Grants to a small number of states will be disability capable, dementia capable and fully integrated, such as offering meals programs, special diets and chronic disease management programs.

*Joe Caldwell, PhD, National Council on Aging*

Dr. Caldwell explained the coalition of national aging and disability organizations he leads and their Friday morning collaborative between: AUCD, the ARC, ANCOR, the VA, the Alzheimer's National Senior Citizens Law Center and AARP. The coalition was formed to urge health reform and is one of the first times the aging and disability communities came together. This group working together to get long-term services and supports into health reform, and as a group has already worked together to improve provisions for Medicaid in the ACA. He mentioned that they have fascinating discussions about terminology and assumptions about seniors and what older people want and encouraged similar coalescing on a state level. Joint funding initiatives might be the best approach in an environment where discretionary funding is hard to come by.

A caregiver support program would be a great focus as well as the reauthorizations of the Older Americans Act, DD Act and the Rehabilitation Act. These might present opportunities to promote collaboration in the legislation for healthy aging and evidence-based health promotion. On the disability side, state disability and health grants within CDC enable small initiatives to come together and accomplish something much bigger. The ACA includes public health trust fund with dedicated funding, some of that money should be directed to aging/disability populations.

*Sue Ellen Galbraith, Senior Policy Advisor, American Network of Community Options and Resources (ANCOR)*

Ms. Galbraith suggested that time-limited demonstrations and projects are not enough and that structural changes enacted through legislation and by other means are necessary. She noted that the lines between aging and disability supports are very blurry. One of the barriers between the groups is language. When will a person with a disability be considered “elderly” under Medicaid? In the current system once an individual is considered disabled; they are always disabled and never become elderly.

Section 4202-A of the ACA pertains to home and community-based services—Money Follows the Person—and potentially relates to both housing and workforce. Technologies must be brought up to date. Ms. Galbraith expressed her hope that ADD comments on the new CMS regulations on home and community-based services as to not lose expertise in the DD field or any slots and noted that savings must be directed to those on waiting lists for services.

*Sue Swenson, Acting Director of the National Institute on Disability and Rehabilitation Research (NIDRR)*

Ms. Swenson explained that NIDRR works hard on knowledge translation. She hypothesized that as Baby Boomers become the aging generation the cultural shifts will be mind-boggling.

Baby Boomers get a lot of bad press because they seem to have an inborn expectation that the culture will always shift to meet their needs. These unintended outcomes as well as those we're aiming for need to be explored in this context. How our system affects those who get nothing from it should be measured. There is also a need for understanding of segmentation. For example, in talking about the health of people with disabilities, who are the comparison group? People with ID and DD who have 24/7 support and live in the community are one population. What about those living at home? Who will tell mom when she's slipping? Ms. Swenson told the story of her son who lost 30 pounds when he moved away from her and her cooking. He lived at home until he was 26, and she spent 26 years working on her cooking skills. Compensations are often strengths. Asking how we maximize program use is the wrong question. There are parts of the United States where 20% of the kids have IEPs.

At NIDRR, big changes in the grant process are underway. Within two to three years, they will accept grant proposals from anyone with any idea in any field with any design. And the proposal has to stand against other all proposals. This will change the entire process, establishing a new competitive flow in scientific investigation. The agency considers this social impact investing, meaning not funding projects based on how good the idea looks or how it is evaluated, but its impact.

The concept of marketing is determining niche, segment, funding the right things for the right person at the right time. It is important to invest in investigations that will help explain what people want and can afford. She posed one challenge to the group: she asked the audience not to try to figure out how to solve problems under the current rock—it is always the wrong rock.

Ms. Swenson summarized effective collaboration as based on 1) communication, 2) coordination (share leadership), 3) cooperation (share mission and know your limitations—obtain best possible support for all Americans across lifespan at lowest possible cost), and 4) collaboration (share the work).