

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

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## **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).