

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

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**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?"

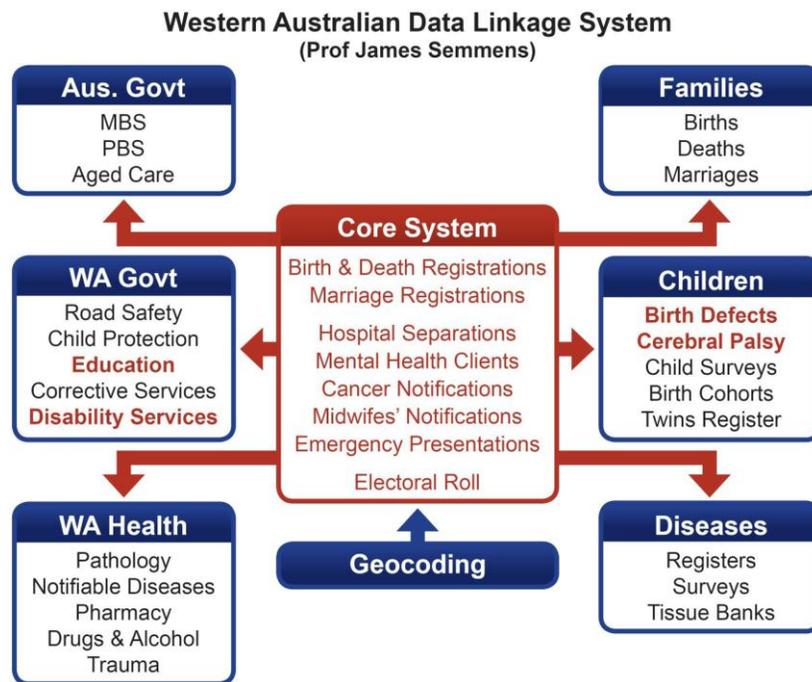
Using the ICF framework enables researchers to drill down from condition to impact on person's life for four disability groups: sensory, intellectual, psychological and physical. Intellectual and developmental disorders constituted 4.9% of disability population in the 2009 survey. Overall disability 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 TICHR 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.