

Health Professional Education in Intellectual and Developmental Disabilities

May 24 - 25, 2011

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This educational activity was jointly sponsored by the Association of University Centers on Disabilities (AUCD) and the Mountain Area Health Education Center (MAHEC). The Mountain Area Health Education Center is accredited by the North Carolina Medical Society to sponsor continuing medical education for physicians. The sponsors gratefully acknowledge the support of the US Department of Health and Human Services' Administration on Developmental Disabilities (DHHS ADD), the American Academy of Developmental Medicine and Dentistry (AADMD), the North Carolina Council on Developmental Disabilities (NCCDD), and the Wal-Mart Foundation.

May 24, 2011

Sharon Lewis, Commissioner, ADD

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

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

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

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

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

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

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

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

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

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

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

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

Moderator:

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

Panelists:

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

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

Adam Hays, Maryland Special Olympics Athlete

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

(Responses have been paraphrased)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

United Kingdom Overview

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

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

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

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

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

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

Australian Overview

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

Educational development

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

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

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

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

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

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

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

Specializing in developmental disability

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

Canadian Overview

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

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

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

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

Primary Medical Care in Canada

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

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

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

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

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

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

Netherlands Overview

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

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

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

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

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

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

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

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

Competences of the ID specialist include:

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

- Contribution to developing specialty

The Nijmegen Model at Radboud University

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

Teaching and training include:

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

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

United States Overview

Matthew Holder MD, MBA, CEO, AADMD

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

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

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

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

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

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

May 25, 2011

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

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

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

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

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

Moderator

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

National Curriculum Initiative in Developmental Medicine

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

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

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

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

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

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

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

Continuing the Call

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

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

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

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

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

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

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

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

Areas of Core Knowledge and Competence on Disability

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

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

Opportunities under the ACA

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Health disparities and ID

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

What differences are inequitable? What can be prevented?

Distinguishing among health conditions:

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

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

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

Health equity and social determinants

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

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

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

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

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

The following are its expected implications for health professional education:

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

“Medically Underserved Population” Status—A Progress Report

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

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

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

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

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

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

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

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

Promoting Curriculum Development in I/DD—Challenges and Opportunities

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

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

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

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

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

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

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

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

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

Tiered Curriculum Model

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

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

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

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

Phase 1

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

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

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

Phase 2

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

Phase 3

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

In Summary

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

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