Special Olympics USA National Games

Health Symposium

Improving Health for People with Intellectual Disability - Policy, Practice and Possibility

Saturday, July 17, 2010
8:30 a.m. – 5:00 p.m.

University of Nebraska Medical Center
Durham Research Center I, Room 1002 (Auditorium)
Omaha, NE
Dear Colleague,

Thank you for attending the Special Olympics USA National Games Health Symposium. We look forward to receiving your input on the status of health care for people with intellectual disabilities and the best ways to improve the wellbeing of this often neglected segment of our population. Special Olympics has a keen interest in the health of our athletes, but we do not have all the answers. Rather, we are a catalyst for discussion through events like this one.

This conference is a heightened call to action for health providers, policy makers, educators, funders, researchers, media, and others interested in improving health and opportunities for people with intellectual disabilities. In the follow-up to comprehensive health reform, we must remain diligent so the health of people with intellectual disabilities can be advanced, both through improved access to personal health care and integrated public health systems, as well as through facilitated self advocacy and personal health promotion.

The speakers here today are among the best researchers and health providers in the area of developmental disabilities and our two-act play and other features of the event will provide a glimpse into our health care system from the perspective of a person with an intellectual disability. We are confident it will be an eye-opening experience for us all.

Special Olympics’ interest in health goes back many years. In 1995, Special Olympics held its World Games in Connecticut. For the first time, it included a health screening tent.

When the event ended, and the doctors came to me with the results, I was stunned. Here’s what we found: 85% of the athletes screened had refractive errors; 28% had astigmatism; 25% had Strabismus; 29% had untreated visual problems; 27% had not seen a doctor within three years; 68% had Gingivitis; 20% reported pain in the oral cavity; and 15% went to the emergency room from the tents because they had such acute disease in the oral cavity and such sharp pain. These were athletes who have traveled from all around the world, had access to their community’s social systems, and had strong and committed caregivers. Yet, the state of their health was abysmal.

I would like to report that significant progress has been made in the 15 years since, but we know this is not the case.

So, what can be done? The primary mechanism Special Olympics has to address these issues is our Healthy Athletes initiative. Officially launched in 1997, this program provides free health screenings in seven disciplines to our athletes and free products and services such as prescription eye glasses, sunglasses and more. As of earlier this year, the program has provided more than 1,000,000 screenings worldwide. We are extremely proud of these efforts, but we are well aware that we are just beginning and there is a long road ahead of us.

So, I encourage you – I URGE you – to join us on our journey and help bring the best health outcomes possible to our friends, neighbors, and colleagues with intellectual disabilities.

Thanks again for your participation.

Timothy P. Shriver, Ph.D.
Chairman and CEO
In the United States, 74% of people feel that children with intellectual disabilities should be educated separate from other children.
Speaker Bios

Dr. J. Michael Leibowitz, Hattie B. Munroe Professor and Director, Munroe-Meyer Institute for Genetics and Rehabilitation

J. Michael Leibowitz, Ph.D., is also Director of the federally designated Nebraska University Center of Excellence on Disabilities supported by the Administration on Developmental Disabilities. In addition, he serves as Professor of Medical Psychology and Section Chief of Rehabilitation Medicine in the Department of Pediatrics, UNMC College of Medicine.

Dr. Leibowitz received his B.A. in Psychology from New York University, received his M.A. in General Psychology and his Ph.D. in Clinical and Experimental Psychology from the University of Maryland in 1974. He joined UNMC’s Munroe-Meyer Institute in 1974. Before that he held positions at the Johns Hopkins School of Medicine for five years.

He has published numerous research articles and book chapters on intellectual disability, child behavior analysis and child development and has been principal or co-principal investigator on over thirty federal and state grants.

Dr. Joseph Evans, Professor and Director of Psychology, Munroe-Meyer Institute for Genetics and Rehabilitation

Dr. Evans graduated with his Ph.D. in Psychology from the University of Kansas in 1974. He is a Professor at MMI and in the UNMC Department of Pediatrics. Dr. Evans is an active clinician and serves as a staff psychologist for the Nebraska DHHS Children with Special Health Care Needs program. He is a member of the AAIID and was involved in the 1992 “New Definition” of intellectual disability that promulgated functional and adaptive aspects of diagnosis for persons with intellectual disabilities.

Dr. Evans has been the recipient of over $11,000,000 in training and research grants from a variety of federal agencies including the Administration on Developmental Disabilities, Family Youth Service Bureau, Corporation for National and Community Service, Department of Justice, and HRSA Graduate Psychology Education, and Allied Health grant programs. He currently administrates an AmeriCorps program at MMI that is designed to provide service opportunities for persons with disabilities. Dr. Evans was the 2008 recipient of the Cummings American Psychological Foundation Psyche Award, presented for his work in developing a model program that integrates behavioral health into rural primary care.

Dr. Timothy P. Shriver, Chairman/CEO, Special Olympics

Timothy P. Shriver is a social leader, an educator, activist, film producer, and business entrepreneur. He is the Chairman & CEO of Special Olympics, and in that capacity he serves nearly 3 million Special Olympics athletes and their families in 180 countries. He has helped transform Special Olympics into a movement that focuses on acceptance, inclusion, and respect for individuals with intellectual disabilities in all corners of the globe.

He has worked with the leaders of China to launch a thriving program in their country and supported their efforts to bring the 2007 Special Olympics World Summer Games to Shanghai. He has begun programs in developing or war-torn countries such as Afghanistan, Bosnia Herzegovina, Iraq, Macedonia, and Serbia. Shriver has also created exciting new initiatives that enhance the quality of life for millions of people with intellectual disabilities through programs in athlete leadership, cross-cultural research, health initiatives, education, and family support. For example, Special Olympics Healthy Athletes® was designed to help

Among Special Olympics Athletes in North America, 29.0% have obvious, untreated tooth decay; 27.8% fail hearing tests; 22.0% have low bone density; and 16.0% have eye disease.
Special Olympics athletes improve their overall health and fitness. Shriver has been successful harnessing the power of Hollywood to push the movement forward. He has pursued initiatives in music, film, and television to help raise funds and awareness for the movement. In addition, he worked to get more legislative attention and government support for issues of concern, testifying in front of Congress every year since 2001.

Before joining Special Olympics, Shriver served in various roles including educator, counselor, author, and speaker bringing issues to the forefront such as substance abuse, violence, dropout rates and teen pregnancy. He worked with the New Haven Public Schools’ Social Development Project, and the Collaborative for Academic, Social, and Emotional Learning (CASEL), the leading research organization in the U.S. in the field of social and emotional learning. Shriver currently chairs CASEL. Shriver applied his educational interests to film, co-producing DreamWorks Studios’ 1997 release, “Amistad,” and Disney Studios’ 2000 release, “The Loretta Claiborne Story.” He is Executive Producer of “The Ringer” a Farrelly brothers’ film, and “Front of the Class,” a Hallmark Hall of Fame movie.

Shriver earned his undergraduate degree from Yale University, a Master’s degree in Religion and Religious Education from Catholic University, and a Doctorate in Education from the University of Connecticut. He has authored articles in many leading publications including The New York Times, The Washington Post, and Commonweal. He and his wife, Linda Potter, reside in the Washington, D.C. area with their five children.

Dr. Steve Eidelman, H. Rodney Sharp Professor of Human Resources Policy and Leadership, Department of Human Development and Family Studies, University of Delaware

In 1974 Dr. Eidelman was a graduate student in Social Work Administration at the University of Maryland in Baltimore. He accepted a yearlong field placement at the then John F. Kennedy Institute for Handicapped Children, the first university-affiliated facility. That experience changed his life. One year
turned to five, and under the watchful eye of the many excellent faculties in two-dozen professional disciplines he became “hooked” on the field of services and supports to people with developmental disabilities and their families.

Since then Dr. Eidelman has held numerous positions in the field of developmental disabilities including Executive Director at the Blick Clinic for Developmental Disabilities in Akron, Ohio; Director of Mental Retardation Services in Philadelphia’s Department of Public Health; Deputy Secretary for Mental Retardation in the Pennsylvania Department of Public Welfare; Executive Director of the Joseph P. Kennedy, Jr. Foundation; Executive Director of The Arc of the United States; and many others.

Steve is the immediate past President of the American Association on Intellectual and Developmental Disabilities (AAIDD) and was recently appointed Senior Advisor to the Chairman and CEO of Special Olympics International. He is also on the Board of The Open Society Institute’s Mental Health Initiative, focusing on deinstitutionalization and community supports for people with intellectual disabilities in Central Europe and the Former Soviet Union.

Dr. Jack Dillenberg, Dean of the Arizona School of Dentistry & Oral Health, A.T. Still University of Health Sciences

Dr. Dillenberg is the inaugural Dean of the Arizona School of Dentistry & Oral Health. This is Arizona’s first dental school which incorporates innovative processes, strategies and curriculum becoming the nation’s first truly public health dental school. The selection of students with significant community service experience, numerous community-based and leadership experiences, extensive clinical experience, and a certificate in public health all are integral components of the ASDOH education. ASDOH has an onsite 85-operatory clinic, a 5-operatory clinic in Glendale, AZ, and fourth year community-based clinical training in educating the next generation of community minded general dentists.

Mrs. Fenner received her bachelor of science degree with an emphasis in accounting from Oklahoma City University in 1993. She was a governmental auditor and a financial administrator for a metropolitan area school district, where she completed a 3-year certification program for school administrators through Oklahoma State University and obtained her license as a certified public accountant. She also attended law school in Oklahoma and worked for the Nebraska Attorney General’s Office.

Jodi Fenner has prior experience as an auditor/accountant, a school administrator, and an attorney. Mrs. Fenner came to the Nebraska Department of Health and Human Services as their Chief Legal Counsel in 2007. Her experience in negotiating and leading the implementation of the 2008 settlement agreement with the U.S. Department of Justice with regard to the Beatrice State Developmental Center led to her appointment as Director in August 2009. She is currently leading the Division in recertification of its ICF/MR and significant reorganization of its community-based services. The Division has already amended its Medicaid waivers to enhance community employment opportunities for people, and it is in the process of a complete overhaul of its comprehensive waiver to allow for more flexibility and self-directed services for people living in integrated community settings. Mrs. Fenner is also in the process of reorganizing the medical and clinical services of the State’s ICF/MR to allow for better communication, education, and support to individuals in community-based services.

Mrs. Fenner, Director of the Division of Developmental Disabilities, Nebraska Department of Health and Human Services

More than 80% of U.S. medical school students report not getting any clinical training to treat people with intellectual disabilities.
Approximately thirty percent of ASDOH graduates that go into practice go to community health settings.

Before returning to Arizona, where Dr. Dillenberg served as the Director of the Arizona Department of Health Services for four years; he also served as the Associate Director for Public Health Programs for the California Department of Health Services. He directed the development of statewide oral health policy and evaluated the operation and effectiveness of California’s oral health programs. He also served as the Area Health Officer for the Los Angeles County Department of Health Services.

Dr. Dillenberg is recognized at the local, state, national and international levels as an expert in the area of public health leadership, health program development, social marketing and oral health issues.

Chuck Cooper, President/CEO, 2010 Special Olympics US Games

During the last seven years Mr. Cooper has led Special Olympics Nebraska as its CEO and successfully bid and won the 2010 Games at which time he assumed the position of President/CEO of the 2010 Games. Prior to joining Special Olympics, he was CEO of Big Brothers Big Sisters in Nebraska for 10 years. Mr. Cooper was born in Hartington, NE and attended Wayne State College before embarking on a successful 20-year business career leading to his decision to join the non-profit world in 1994.

Mr. Cooper has a long history of involvement in the Nebraska community, including as a volunteer and parent for Boys Scouts of America; Men's and Women's Varsity XC Coach, Skutt Catholic High School; Board Member of the Omaha Running Club for 10 years, 4 years as the Chairman; Race Director for running events in Nebraska that raised over $250,000 for charity including the Gun Amnesty Program in Omaha; and member of the US Leadership Committee for Special Olympics. He has also been featured in Runners World Magazine with the Golden Shoe Award for Community Volunteerism; joined the Nebraska Running Hall of Fame for Coaching, Volunteerism and Community leadership; was named American Marketing Association Marketing Person of the Year; and was a Founding Member the Non-Profit Association of Nebraska.

Dr. Rubens Pamies, Vice Chancellor for Academic Affairs and Dean for Graduate Studies, University of Nebraska Medical School

Ruben J. Pamies, M.D., has served in his current position as well as Professor of Internal Medicine at the University of Nebraska Medical Center (UNMC) since September 2003. Prior to that, Dr. Pamies was Chairman of the Department of Internal Medicine and The Edward S. Harkness Professor of Medicine at Meharry Medical College School of Medicine. He also was Chief of Service in the Department of Internal Medicine at the Metropolitan Nashville General Hospital. While in Nashville, he was a Professor of Medicine in the School of Medicine at Vanderbilt University Medical Center.

Born in Haiti, Dr. Pamies’ family moved to New York when he was six. Dr. Pamies received his baccalaureate degree in 1981 from St. John’s University and his medical degree in 1986 from the State University of New York at Buffalo. He completed his residency training at Cornell-North Shore University Hospital in the internal medicine primary care track.

Recognized widely for his expertise on health disparities, Dr. Pamies was recently selected as a new member and Chair of the Advisory Committee on Minority Health for the U.S. Department of Health and Human Services’ Office of Minority Health.

75% of U.S. medical school students express interest in treating people with intellectual disabilities as part of their careers if given the opportunity.
Dr. Richard Besser, Senior Health and Medical Editor, ABC News

Since his arrival at ABC News in 2009, Dr. Besser has been at the forefront of news coverage for every major medical story. Most recently, he broke news on the health problems facing then-hospitalized, former President Clinton in an ABC News special report with Diane Sawyer. Also, he reported from the ravaged country of Haiti in the immediate aftermath of a devastating earthquake in January 2010. Additionally, he has established two weekly medical series consisting of Your Family’s Health on “Good Morning America” and Changing Your Life on “World News with Diane Sawyer.”

Dr. Besser came to ABC News from the Centers for Disease Control and Prevention (CDC), where he served as Director of the Coordinating Office for Terrorism Preparedness and Emergency Response. In that role, he was responsible for all of the CDC’s public health emergency preparedness and emergency response activities. He also served as Acting Director for the CDC and Acting Administrator for the Agency for Toxic Substances and Disease Registry from January to June 2009, during which time he led the CDC’s response to the H1N1 influenza outbreak.

He has authored and co-authored hundreds of presentations, abstracts, chapters, editorials, and publications. He has received many awards for his work in public health and volunteer service including the Surgeon General’s Medallion for his leadership during the H1N1 response.

Dr. Besser received his bachelor of arts degree in economics from Williams College and his medical degree from the University of Pennsylvania. He completed a residency and chief residency in pediatrics at Johns Hopkins University Hospital in Baltimore, Maryland.

Dr. Rick Rader, Editor-in-Chief, Exceptional Parent magazine

Dr. Rick Rader is the Director of the Morton J. Kent Habilitation Center at Orange Grove (Chattanooga, TN) where he serves as a medical futurist in the predictive modeling of future medical problems of individuals with intellectual and developmental disabilities as they age. He is cross trained in internal medicine and medical anthropology.

He has served as a consultant to four former Surgeon Generals, as well as to the Director of the Office of Disability (HHS) in the area of health and disabilities. He was the first appointed Special Liaison for Family Healthcare Concerns at the President’s Committee for People with Intellectual and Developmental Disabilities (PCPID). He also serves on the board or in an advisory capacity for a number of organizations including the Institute for Environmental Health at the American Association on Intellectual and Developmental Disabilities, the American Association on Health and Disability, the World Congress on Disabilities, and many others.

In addition to being editor-in-chief of Exceptional Parent magazine, Dr. Rader has published over 150 articles in the field of developmental disabilities, and serves on the editorial advisory board of the Journal of Health and Disability and the International Journal of Nursing in Intellectual and Developmental Disabilities.

Dr. Joseph Acierno, Dep. Chief Medical Officer, Div. of Public Health, NEHSS

Dr. Acierno is a three time graduate of Creighton University. He received the following degrees: bachelor of science, doctor of medicine and juris doctor.

He practiced emergency medicine in Omaha, while attending law school. He relocated to Los Angeles where he practiced medical-legal law. He defended various entities including hospitals, physicians, nurses and home health care professionals.
healthcare providers. He was a member of the firm's maternal-fetal injury team. The team's primary focus was obstetrical negligence. He returned to Omaha after five years of California practice. In Omaha, he was a shareholder of a private law firm. In September 2006, Dr. Acierno accepted a position with the legal division of the Nebraska Health and Human Services System. He was counsel to the various public health programs and professional boards in the Department of Regulation and Licensure. Dr. Acierno has given various presentations on medical-legal matters.

In May 2007, Dr. Acierno was appointed the Deputy Chief Medical Officer in the Division of Public Health. He is responsible for the regulatory portion of the division specifically the Licensure, Investigations and Environmental Health Units. He also is Chairperson of the state's Child Death Review Team.

Dr. Stan Shepherd, Chairman, Health One Global

Dr Stan Shepherd gained his first degree in Aeronautical Engineering and flew as an RAF pilot for 6 years before qualifying in Medicine in England. In 1984 Dr Shepherd introduced electronic health records into his medical practice. Today he is a Family Physician in a deprived, high demand, multi-ethnic, multi-lingual, inner-city practice in the East End of London with 12,500 patients from all around the world. His medical practice is fully computerized and paperless.

Health One Global is an international healthcare software company with users in UK, Ireland, Belgium, France, Switzerland, USA, South Africa and Australia. Since 2003 Health One Global has been the exclusive Special Olympics Healthy Athletes Global Partner for electronic health records. As Global Partner, Health One Global provides and manages the Healthy Athletes Software (HAS) in use by Special Olympics Programs worldwide to record Healthy Athletes screenings in a single global database. This has created for Special Olympics the world's largest, richest and most comprehensive database on the health parameters of people with intellectual disability.

Dr Shepherd combines understanding of both medicine and technology. As a physician he understands the business of healthcare intimately, as an engineer and IT specialist he understands how to harness the power of technology to improve healthcare outcomes significantly. Throughout his career the focus of Dr Shepherd and of his company has been the use of electronic health records to deliver both the most clinically-effective care and the most cost-effective care for the benefit of the patient, the provider and the healthcare system.

Dr. Wayne Stuberg, Professor and Associate Director for Education and Director of Physical Therapy and Motion Lab Analysis Lab, Munroe-Meyer Institute

Dr. Stuberg is board certified in pediatrics by the American Board of Physical Therapy Specialties, a past President of the Nebraska Physical Therapy Association and past Chair of Board of Physical Therapy for the Department of Health and Human Services Division of Licensure and Credentialing. He has served as a consultant for the state of Nebraska on the Governor's Early Childhood Interagency Coordinating Council and also as a member of the Department of Education's Special Education Advisory Council.

Dr. Stuberg has presented at numerous state, national and international conferences on the topic of management of individuals with developmental disabilities. He has continuing involvement as a faculty member in the entry-level doctorate of physical therapy curriculum at the University of Nebraska Medical Center and he coordinates the Pediatric Physical Therapy Residency program being
developed at MMI. He has been recognized as an Outstanding Teacher of the Year at UNMC. Dr. Stuberg’s research interests are in the areas of gait analysis and outcomes of physical therapy treatment. He has been recognized as a Distinguished Researcher by the Section on Pediatrics of the American Physical Therapy Association.

Dr. Cynthia Ellis, Director Developmental Pediatrics and Director LEND Program, Munroe-Meyer Institute

Dr. Ellis is board certified in Pediatrics, Developmental/Behavioral Pediatrics and Neurodevelopmental Disabilities and has been practicing in the field of Developmental/Behavioral Pediatrics for over 20 years. She received her doctor of medicine degree and bachelors of science from the University of Nebraska in 1985 and 1981, respectively. She completed her residency in pediatrics at the Children’s Medical Center, Medical College of Virginia and was a fellow in the Division of Child and Adolescent Psychiatry at the Virginia Treatment Center, Medical College of Virginia, in Richmond, VA.

Dr. Cynthia Ellis’s research interests include psychopharmacology of developmental disabilities, autism, ADHD, and interdisciplinary training. She has held a number of positions at UNMC, including Developmental/Behavioral Pediatrician, Associate Professor of Pediatrics and Psychiatry, Section Chief of Developmental Medicine in the Department of Pediatrics, and Director of the Munroe-Meyer Institute’s MCH-funded LEND (Leadership Education in Neurodevelopmental and Related Disabilities) and ALA (Autism Leadership Academy) Interdisciplinary Training Programs. She has held other leadership and teaching positions and has served on numerous committees, board of directors, and task forces.

Dr. Ellis has published extensively in the field of developmental disabilities, including dozens of book chapters and papers, and has given many national presentations.

Katy Bednar, Student, Boston University Goldman School of Dental Medicine

Katy Bednar graduated Cum Laude from Providence College in 2005 with a degree in Biology and is currently a third year DMD student at Boston University Goldman School of Dental Medicine.

At Boston University, Ms. Bednar is both an active American Student Dental Association Community Outreach Committee Member, as well as a member of the Hispanic Student Dental Association. Through the Applied Professional Experience program at BU, she has been most fortunate to have had the opportunity to work with Dr. Steven Perlman in private practice and hospital settings and be mentored by him in both dental and special needs fields. It is through her association with Dr. Perlman and recent involvement in the Massachusetts Special Olympics Special Smiles Program that Ms. Bednar has been afforded the opportunity to work with patients with special needs at the dental office and realize the courage and extensive determination displayed by these patients.

Dr. Wendy Gray, Fellow, Boston University Primary Care Academic Fellowship Program

Dr. Gray is currently a student in Boston University’s School of Public Health and a Fellow in the Boston University Primary Care Academic Fellowship Program. She received her medical degree from Brown Medical School (Brown-Dartmouth Program) and completed her residency at Cambridge Hospital, Harvard Medical School, Internal Medicine Residency Program. Her primary interests include health care for adults with developmental disabilities and health care policy.

She is also active in numerous organizations including the Society of General Internal Medicine, American College of Physicians, Physicians for a National Health Program, and others. She also serves on the Special Olympics Massachusetts Medical Advisory Panel.

Special Olympics has provided more than 1,000,000 free health screenings to its athletes.
The USA National Games in Lincoln, NE will unite the country through sport and serve as a living legacy of founder Eunice Kennedy Shriver. These Games will provide an opportunity to showcase and celebrate the Special Olympics movement and athletes, while illustrating the power of sports to educate and inform about the true abilities and achievements of people with intellectual disabilities. While providing opportunities for all to get involved, the USA National Games will present a nationwide platform to engage youth as “agents of change” to foster and promote unity, inclusion, acceptance, respect, dignity and advocacy for people with intellectual disabilities.

The Games includes:

- 3,000 athletes
- 1,000 coaches
- 8,000 volunteers
- 15,000 family and friends
- More than 30,000 fans
- $40 million dollars in economic impact
- More than $5 million dollars in estimated tax revenue to Nebraska
Healthy Athletes® is a Special Olympics program that provides free health screenings to Special Olympics athletes in seven different health areas (vision, hearing, oral health, healthy lifestyles, general fitness, podiatry, and sports physicals). Offered in a fun, welcoming environment, Healthy Athletes screenings remove the anxiety and trepidation people with intellectual disabilities often experience when faced with a visit to a doctor or dentist. In addition to screenings, Healthy Athletes also provides eyeglasses, sunglasses, hearing aids, mouthguards and other free items to athletes who attend. With Healthy Athletes, Special Olympics has become the largest public health organization specifically for people with intellectual disabilities and maintains the largest database of health data for people with intellectual disabilities in existence.

Since its official launch in 1997, Healthy Athletes has provided more than 1,000,000 health screenings to Special Olympics athletes in more than 100 countries, trained more than 75,000 health care professionals on the specific health concerns faced by people with intellectual disabilities, and given more than 70,000 pairs of eyeglasses to those that need them free of charge.

Healthy Athletes is made possible thanks to its corporate sponsors – Lions Clubs International, Essilor International, and the Safilo Group. The Athlete Personal Electronic Lifetime Health Record is being made possible thanks to support from partners HealthOne Global, Shanghai Sunray Technology Co. Ltd, and Fudan Microelectronics.

All Special Olympics health initiatives are supported in part by a cooperative agreement with the U.S. Centers for Disease Control and Prevention (#U59 DD000240).