



United States Department of Health & Human Services

Office on Disability Newsletter

Volume I
Issue I

Spring/Summer 2007

Inside This Issue of the Office on Disability Newsletter:

- FYI: Updates on policies and decisions that affect the lives of persons with disabilities
- I Can Do It, You Can Do It
- Co-Occurring Initiative
- The October Annual Event
- The 9th International Congress
- Inside the OD
- The Surgeon General's Call to Action
- Constituent Spotlight:** National Council For Independent Living

For More Information: Please Visit the Office on Disability's Website

www.hhs.gov/od
or email the OD at
ODInfo@hhs.gov

A LETTER FROM THE DIRECTOR: MARGARET GIANNINI, M.D., F.A.A.P. Greetings!

Since 2002, it has been my esteemed privilege to serve as the director of the United States Department of Health and Human Services Office on Disability. Each year, the Office continues to grow in its scope and accomplishments. This past year, the Office on Disability took on national issues, addressing challenges faced by persons with disabilities in their communities and states, as well as within the federal government. The Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities*, the Office is taking the initiative to change the national disability agenda by changing the culture of disability in everyday life. What is so unique about the *Call to Action* is that its goals can be made a part of personal and professional lives. Another unique event hosted by the Office on Disability was the 9th International Congress on Community Services for Children, Youth, and Families with Special Health Care Needs, with an emphasis on youth with disabilities. This meeting was an opportunity for teams from all over the world to come together and discuss disability in a global context while maintaining a community focus. Each team was comprised of an advocate or parent, a youth with disabilities, or other professional. The United States Agency for International Development (USAID) was a major partner in this year's Congress. The Congress was attended by 64 countries and 4 territories with each participant making a valuable contribution to the international healthcare agenda.

EMERGENCY PREPAREDNESS FOR PERSONS WITH DISABILITIES

The Office on Disability has aggressively pursued the development of an emergency preparedness plan that takes into account the unique needs of persons with disabilities and the challenges they would face in the event of an emergency. The OD has also been an integral part in revising the National Response Plan. Working in conjunction with the Office of the Assistant Secretary for Preparedness and Response (ASPR) will provide the following emergency preparedness and response supports, which will ensure that the needs of persons with a disability are addressed during an emergency:

- 1) a web-based training toolkit targeting State and local emergency response managers;
- 2) an introductory web-based training module on disability which will first be used to educate HHS public health and civil service staff to be detailed for an emergency; and
- 3) a Shelter Assessment Tool developed with the National Red Cross identifying persons with disabilities and medical conditions to ensure correct assignments to the shelter option with needed accommodations to maintain independence unless medical issues necessitate a more medical-based shelter.
- 4) The OD chairs the subcommittee on health in the Interagency Coordinating Council on Emergency Preparedness, through President Bush's executive order with the Department of Homeland Security.

OFFICE ON DISABILITY: MAJOR INITIATIVES

YOUTH WITH CO-OCCURRING DEVELOPMENTAL DISABILITIES AND EMOTIONAL/SUBSTANCE ABUSE DISORDERS

The Office on Disability, along with the Department of Education and the Center for Medicare and Medicaid Services and other federal partners, is working to address the problem of youth experiencing co-occurring developmental disabilities and emotional/substance abuse disorders. The OD believes that children in this population are best served in settings that are community-based, children centered, family driven, and take into account the diverse cultural backgrounds of the communities they serve. In addition, the care that these children receive should be individualized, comprehensive, integrated, and foster the development of meaningful relationships between the child, the care provider, and the family.

The goal of this OD initiative is to decrease existing barriers that impede the delivery of adequate and appropriate quality care to youth with co-occurring disorders. This goal includes efforts to stop the historic non-service, “ping-pong” approach to care by developing a new and sustainable administrative infrastructure that supports the system of care approach, ensuring a “no wrong door approach” for children and their families, addressing eligibility and financing problems, and increasing access for families to non-clinical support systems like in-home help and respite care.

The ultimate goal is to provide a seamless set of services which are accessible and available to all children and youth with co-occurring developmental disabilities and emotional/substance abuse disorders.

I CAN DO IT, YOU CAN DO IT

The Office on Disability has initiated the nationwide program *I Can Do It, You Can Do It*. It is a mentoring program to increase physical fitness among youth with disabilities. The program pairs an adult mentor interested in physical fitness and health and a child with a disability. The pair work together in an initial six week program of planned increased physical activity and education about good nutritional choices.

Physical activity can mean any activity that consumes energy, i.e. activities around the house, dancing, etc. Good nutritional behaviors will be taught so the child adheres to a health-smart diet of choices from the five food groups and avoids unhealthy choices, such as high fat snack foods and overeating. The weekly plan for the increased physical activity and good nutritional behaviors is determined by the mentor and the sponsoring organization in collaboration with the child, the family, and the primary health provider. Therefore, the combination of good diet and increased physical activity will result in increased physical fitness!

Organizations dedicated to better services and quality of life for people with disabilities can volunteer to become a sponsor. Currently, there are 108 organizations and agencies interested in implementing the Initiative. These organizations include Spina Bifida Association of America, Council for Exceptional Children, American Physical Therapy Association, National Association of Directors of Special Education; Brain Injury Association of America, Disabled Sports USA, and the American Association on Health and Disability. The Presidential Challenge program for Physical Fitness is the partner for the award system for each mentee. The awards include a Presidential Patch and then move up to a bronze, silver, or gold medal.

OFFICE ON DISABILITY: MAJOR INITIATIVES

9TH INTERNATIONAL CONGRESS ON COMMUNITY SERVICES FOR CHILDREN, YOUTH, AND FAMILIES WITH SPECIAL HEALTHCARE NEEDS

The *International Congress on Community Services for Children, Youth, and Families with Special Health Care Needs* is a United States initiative that began in 1992. Every two years, the Department of Health and Human Services/Office on Disability hosts the Congress in the United States or a selected host country. This year, the OD was proud to hold the Congress in Washington, DC. Almost 450 youth, families, and individuals representing agencies and organizations from 64 different countries and four territories all met to discuss the future of community integrated health care services.

The theme for the 9th Congress was “Community Access and Resources for Everyone” (CARE). The meeting included general sessions for all to attend, as well as smaller workshop sessions. Speakers addressed the important roles of families and communities in supporting children and young adults with special health care needs, and described ways to build programs that combine health, education, recreation, and social services and use professionals from different disciplines to help children participate in everyday community activities, with emphasis on youth with disabilities

The roster of nations and number of people participating in the Congress has grown, and progress has occurred. For example, progress can be seen with the growth and improvement in adaptive and computer technology to help reach children and youth with special needs worldwide. The underlying precepts and goals of the Congress have remained constant. They include all children, particularly those with special needs, in all activities in their communities, the primary importance of families and their vital partnerships with professionals, and the importance of an approach that brings together professionals from different disciplines to create and maintain supports and services at local levels with a particular emphasis on youth with disabilities, families, and advocates. During the Congress, an awards ceremony for national and international awardees was held in recognition for their work surrounding children, youth, and families with special health care needs. The awardees are noted below. In their honor, the National Spinal Cord Injury Association hosted a gala at the French Embassy, which was attended by many notable figures.

Alfred E. Mann, Chairman / Co-Chief Executive Officer, Advanced Bionics Corporation, USA

Eunice Kennedy Shriver, Founder, Special Olympics, USA

Emmanuel Ofofu Yeboah, Disability Activist, Ghana

Lex Frieden, LL.D., Director, ILRU Program, The Institute for Rehabilitation and Research, USA.

THE NEW OD WEBSITE IS HERE

The Office on Disability (OD) is pleased to announce the launch of a completely redesigned website. The new website provides comprehensive yet easy-to-access information supporting the seven life domains: housing, education, information technology, transportation, health, employment, and community integration; identified by the President’s New Freedom Initiative. It also includes information on advocacy and entitlements for persons with disabilities. The restructured OD website also adheres to Section 508 guidelines. The OD website redesign process received significant support and contribution from the Johns Hopkins University Capstone program, HHS Webmaster, and several HHS employees with disabilities to ensure increased usability and accessibility. **Please visit the new site at www.hhs.gov/od.**

OFFICE ON DISABILITY: MAJOR INITIATIVES

THE SURGEON GENERAL'S CALL TO ACTION TO IMPROVE THE HEALTH AND WELLNESS OF PERSONS WITH DISABILITIES

In 2005, the U.S. Surgeon General released a *Call to Action (CTA) to Improve the Health and Wellness of Persons with Disabilities* to address the access challenges to health and wellness faced by individuals with disabilities of all kinds. Developed by the OD in collaboration with the Surgeon General, it emphasizes the need to overcome impediments that limit access to all health and wellness services by persons with disabilities. They include issues related to public awareness, professional knowledge, and consumer access to integrated health care and wellness-promotion services. It articulates both an overarching principle and four goals that, together, can surmount those impediments and help the nearly 54 million Americans of all ages who have been born with or who have acquired disabilities during their lifetimes experience full, rewarding, and, above all, healthy lives across their lifespan and in their communities.

The Office on Disability continues to promote the Surgeon General's *Call to Action (CTA) to Improve the Health and Wellness of Persons with Disabilities*. The four goals of the CTA each focus on a different domain of health and wellness among persons with disabilities. The Office on Disability has begun to increase attention to disabilities in media and entertainment industries. Through the implementation of Goal One, the OD has created an environment of increased understanding for persons with disabilities. The four goals are:

- Goal One: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.
- Goal Two: Health care providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity.
- Goal Three: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
- Goal Four: Accessible health care and support services promote independence for persons with disabilities.

The Call to Action is being used across the United States by a significant number of health care professionals, policy and decision makers, and a wide variety of other individuals interested in the health care field and bringing services to persons with disabilities. The Office on Disability believes in the CTA and the changes it strives to realize for persons with disabilities across the nation. As a result, the OD is committed to the continued implementation of each goal and is currently working on innovative and creative ways to bring the four goals and the attitudes associated with them to life .

A People's Piece was also published in addition to the Call to Action. The People's Piece helps spread the goals of the Call to Action across the nation. It has recently been published in the *Exceptional Parent Magazine*.

To learn more about the *Call to Action* or for more information on how to incorporate the CTA into your organization and/or community, please contact the Office on Disability.

OFFICE ON DISABILITY: MAJOR INITIATIVES

ANNUAL OCTOBER CELEBRATION FOR PERSONS WITH DISABILITIES: HONOREES

On October 25, 2006, the Office on Disability hosted its fourth annual Celebrating Persons with Disabilities event. Each year, the Office on Disability celebrates the abilities of persons with disabilities and those making a difference in the lives of persons of all ages with disabilities nationwide by honoring them with the Secretary's Highest Recognition Award. This year's honorees were:

Julie Beckett: For relentless advocacy leading to the establishment of the Katie Beckett Medicaid waiver that allows families to care for their children in their homes and communities rather than in hospitals or institutions.

Peter Galpin, M.D.: For professional achievements, including becoming the first surgeon in the United States to have started and completed medical and surgical training from a wheelchair, community service, outreach to the medically needy in less developed parts of the world, and a physically active lifestyle.

Andrew Imparato: For his commanding leadership of the American Association of People with Disabilities and politically and economically empowering all people with disabilities through public policy advocacy and programs.

Ronan Tynan, M.D.: For overcoming difficult challenges, undertaking new endeavors and attaining tremendous success as a gold medal winning Paralympian, a physician, an inventor, an eminent opera singer, and a celebrated speaker and motivator.

SECTION 508: ENSURING ACCESS OF TECHNOLOGY TO ALL

The Office on Disability has taken on the role of ensuring compliance with Section 508. Service to the public can take many forms at HHS, including disaster assistance; bioterrorism preparedness, response, and recovery; Electronic Health record standardization, Ticket to work, or many of our other services to the community of persons with disabilities in the nation and beyond. Whenever these services are provided by technology, or when our employees use technology in their daily activities, Section 508 ensures the accessibility of that technology to all persons, regardless of disability.

To ensure all HHS agencies are equipped to meet these goals, the Office on Disability is commencing the third Phase of the Section 508 training cycle. Phase I was a basic online awareness training regarding how technology accessibility is important to persons with disabilities and the mandate for our employees and members of the public with disabilities. Phase II consisted of intensive live Webcast sessions with over 2000 managers and others with IT acquisition responsibilities.

Consistent with the Office on Disabilities' role in ensuring Department wide compliance with this NFI-supporting mandate, the Phase III in person training objective is to provide hands-on specific input, practice and guidance on complying with Section 508. The Phase III training will support acquisition managers and other HHS staff in understanding and performing all Section 508 tasks related to major EIT acquisitions, including documentation, RFP language, 508 review, and exception approval. All acquisition forms and vendor documentation will be examined, using real-world examples. Two "test sessions" will be held this month to obtain input from agencies across HHS, which will be used to finalize the Phase III training to be provided starting in the Spring of 2007. Please Contact Eileen Elias with questions.

THE OFFICE ON DISABILITY: STAFF

Dr. Margaret Giannini, *Director*

Eileen Elias, *Deputy Director*

Lauren Solkowski, *Sr. Program Analyst*

Dr. Michael Marge

Marta Campbell

Marilyn Brundage, *Office Assistant*

Brian Bergmark, *John Gardner Fellowship*

HONORS:

THE AMERICAN MEDICAL ASSOCIATION HONORS MARGARET GIANNINI, M.D., F.A.A.P

In February 2007, The American Medical Association (AMA) honored Dr. Margaret Giannini with the Dr. Nathan Davis Award for Outstanding Government Service, the organization's highest award for a presidential appointee in the executive branch for public service and public health. "Dr. Giannini is truly deserving of this recognition, she has contributed greatly to the well being of individuals with disabilities through her long and remarkable career," said William G. Plested, AMA President.. Dr. Giannini was nominated for the award by Errol R. Alden, M.D., Executive Director of the American Academy of Pediatrics, a member of the AMA Federation.

DR. GIANNINI HONORED IN FRANCE

On March 16th 2007, Dr. Giannini received the *Trophée of Honor* from the Federation of Disabled Youth and Adults, which represents over 600 organizations in France. The award ceremony, held under the patronage of the President of the Republic of France, UNESCO, the Regional Counsel of the Ile de France and the City Council of Paris, was held at the Palais des Congres in Paris, France. Dr. Giannini received the award for the outstanding contributions she has made nationally and internationally for persons with disabilities for more than five decades. Each year the Federation selects a country for its exemplary policies on behalf of persons with disabilities and selects an outstanding person from that country.

THE OFFICE ON DISABILITY: INTERN EXPERIENCE

Each year, the Office on Disability hosts fellows and interns from local and national colleges and universities. Internships at the OD provide an opportunity for students to gain insight into policies, programs, and initiatives that help shape the national agenda on disability, as well as interact with experts in the field, policy and decision makers, as well as constituents. An internship at the OD provides students from diverse backgrounds, who have diverse interests with a well-rounded and comprehensive learning and working environment.

Brian Bergmark (John Gardner Fellow) graduated from Stanford in 2006 and will be with the Office on Disability under a John Gardner Fellowship in Public Service until July 2007. The Office is giving Brian a unique chance to understand and shape disability policy at the national and international levels, while also granting him the opportunity to observe a singularly talented, accomplished, and committed staff effect major change for people with disabilities. Brian will be attending Harvard medical school beginning this fall, and will put his experiences in the Office to use in the future as a clinician, researcher, and advocate.

OFFICE ON DISABILITY: INTERNS

Katie Bleekrode (spring intern) is a junior at The Catholic University of America, where she is studying political science. Katie was introduced to the Office on Disability after taking a class on Global Disability Policies. Through her internship at the OD, Katie has had the opportunity to learn more about different programs and initiatives set forth by the federal government for people with disabilities. She has also learned about the different issues persons with disabilities face on a community level through her work with OD constituents. Katie will be leaving the OD in May 2007.

Kassie Fields (spring intern) is a senior at Model Secondary School for the Deaf (MSSD). She has been deaf since she was 8 months old. Her deafness was caused by a high fever. She communicates with her family by sign language, and she has been raised in deaf schools. MSSD provides internship for seniors to work off campus to expose them to working in the real world after graduating at MSSD. She thinks it's a great experience to work at the Office of Disability and that communicating with her co-workers through writing on paper or email has been a very beneficial experience. Kassie was working on monthly events, 100 foundations for disability, and working on transferring old forms to new forms, which she found challenging. She was used to using the computer for PowerPoint, internet, emails, and AIM. Now she has had the opportunity to learn to do more work related programs on the computer! She has enjoyed the internship here; she is looking forward to continuing her relationship with the Office of Disability after graduating at MSSD. Kassie would like to thank you for all she has learned and the wonderful opportunity.

Anna Freeman (summer intern) is a graduate student from the College of Family and Consumer Sciences at the University of Georgia. Anna is excited about working in the Office on Disability this summer to further her knowledge and experience in the field of disability. She looks forward to gaining insight into different programs that are available for people with disabilities as well as how these programs and initiatives are developed and handled through the OD and other agencies in HHS. Some of the areas Anna is working on in the Office are: the Surgeon General's Call to Action, Universal Design, the I Can Do It/ You Can Do It program, and Healthy People 2010.

Samuel Irving (summer intern) is a junior at Concordia University in Portland Oregon where he majors in Psychology. He plans to complete his undergraduate degree in May of 2009 and plans to earn his masters in Counseling. While participating in this internship he is responsible for the inclusion of various State disability websites to the HHS website and IT support of the "One Stop Shop" website. He hopes to learn about public policy surrounding disability, various regulations and to forge new Governmental relationships.

Joe King (summer intern) is a graduate student in the Masters of Arts program at Columbia University's Teachers College. He is studying clinical psychology and will graduate in December. He will be involved in several areas of the Office on Disability. Joe will be working on services for persons with Traumatic Brain Injuries, the constituent database, and healthcare disparities. Joe hopes to gain a better understanding of how the federal government coordinates policies for persons with disabilities and how these policies are adapted to changing times to better meet the needs of those with disabilities.

Ngan Le (spring intern) is a graduating senior at the University of Maryland, College Park, where she is studying Community and Public Health. Through her internship at the Office, Ngan has had the opportunity to learn about different aspects of Emergency Preparedness, and what goes into developing a solid plan. The OD has also provided Ngan with insights into future career paths and skills.

OFFICE ON DISABILITY: INTERNS

Anna Maria Lenhart (2006-2007 academic year intern) joined the Office in Fall 2006. She is a 2005 graduate of Loyola University New Orleans and will receive her MPH from George Washington University in May 2007. The Office has provided Anna with insight into the promotion and protection of health and wellness extending beyond clinical care settings, as well as a deeper understanding of health policy. Anna has learned a great deal from this tremendous opportunity, and the members of the OD have been invaluable examples of commitment, excellence, and passion in the field of disability.

Jaime Lok (January –August 2007 intern) is a graduate student from the University of Maryland who joined the Office in January 2007. In February, she was selected by the American Public Health Association Student Assembly Board to serve as a co-chair on the Student Assembly Development Committee. The APHA Student Assembly (APHA-SA) is the nation's largest student-led organization dedicated to furthering the development of students, the next generation of professionals in public health and health-related disciplines. Congratulations Jamie!

William Manderscheid (summer intern) is a rising junior at the University of Virginia in Charlottesville, VA and loves it. He was recently accepted into the McIntire School of Commerce and is pursuing an undergraduate degree in Finance and Accounting. He comes into the Office on Disability relatively unfamiliar with many issues surrounding the population of people with disabilities, yet Will wants to learn as much as possible about some of the things he can do to educate himself and others to help people with disabilities lead full and happy lives. He is currently working on the Call to Action to achieve some of these goals.

Lindsay Mulcahy (summer intern) recently graduated from Boston University with a B.A. in Hispanic Language and Literatures and a minor in public health. While interning at the Office on Disability, Lindsey plans to gain first hand experience in a health-related office, learn more about disabilities and persons with disabilities and also, meet new and interesting people. Lindsey will be interning until August with a possibility of staying into the fall. She looks forward to her experience with the Office on Disability and the challenges the Office has to offer.

Denae Phillips (spring intern) is a senior at the University of Massachusetts Amherst where she is studying Public Health and Epidemiology. She came to the Office via the Washington Center for Internships and Seminars. Denae has had an amazing experience working and meeting people through her internship, and she is excited for the upcoming weeks. Denae credits her time at the OD with teaching her about the different aspects of the U.S. Public Health system, and providing her an incredible experience through her projects and assignments.

Elena Quattrone (summer intern) is originally from Marlton, New Jersey. Elena is a senior at Boston University, and she is majoring in Health Science and Public Health. Elena joins the Office on Disability with an interest in health policy and advocacy. This summer, Elena will be working on initiatives predominantly concerning The Surgeon General's Call to Action, Traumatic Brain Injury, and Universal Design. Elena is excited for the opportunity to work in the Office on Disability and anticipates a challenging yet rewarding summer.

Heather Sturgill (spring intern) comes to us as a senior in the Urban Studies program at the University of Cincinnati in Ohio. This enterprising non-traditional student is acting as bridge between issues of housing, transportation and emergency management/mitigation and individuals with disabilities. Upon her return she will graduate and intends to start working on her Masters of Community Planning degree in the fall. She also anticipates continuing as a community activist in her inner city neighborhood promoting social justice and equity through education, and community development.

Visit Our Website:
www.hhs.gov/OD

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The Office on Disability, created in October 2002, oversees the implementation and coordination of disability programs and policies for America's 54 million persons with disabilities.

The Office on Disability leads the United States Department of Health and Human Services toward accomplishing the goals outlined by President Bush's New Freedom Initiative, and ensures persons with disabilities across the lifespan have a voice within the Department of Health and Human Services.

Constituent Spotlight: National Council on Independent Living

By: Elizabeth Leaf, Healthcare Policy Analyst

(Elizabeth is a former intern of the Office on Disability and now works at the National Council for

As a membership organization, the National Council on Independent Living (NCIL) advances independent living and the rights of people with disabilities through consumer-driven advocacy under the leadership of John Lancaster, Executive Director. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

NCIL is the oldest cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL's members are comprised of over 700 organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities. The CILs NCIL serves provide services in all but five US Congressional districts.

Our CIL and SILC members work tirelessly throughout the country to provide essential services to people with disabilities, enabling them to live independently and productively in their own homes and communities. Meanwhile, we provide our members with the tools they need to operate more effectively and serve more consumers. NCIL membership benefits include meticulous legislative monitoring and advocacy; training and technical assistance on CIL & SILC management, consumer services, disability law and much more; group insurance programs; and our myriad collection of advocacy bulletins, action alerts, training manuals, newsletters, and other publications.