

Medicaid Reform Agenda Creating a Partnership Across Disability and Aging with The Center for Medicare and Medicaid Services

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On July 23rd, a grassroots coalition organized by the Center for Self-Determination (CSD), met with Cindy Mann, Director of the Center for Medicaid and State Operations at the Centers for Medicare and Medicaid Services (CMS). The Coalition presented CMS with a written set of issues that need to be addressed in order to begin reforming the Medicaid long term care Program. The meeting was structured to promote ongoing dialogue with CMS and together create a long-term care reform agenda.

CSD Director Tom Nerney said, "This is the first time that a cross-disability and aging alliance has presented a formal Medicaid reform agenda to the highest official in the federal Medicaid program. We were welcomed by the new Director and pleased to see so many key CMS staff in attendance."

Members of this alliance include: Mike Oxford, ADAPT and the Topeka Independent Living Center; Dan Fisher MD, PhD, **National Empowerment Center**; Susan Goodman Esq., **National Down Syndrome Congress**; **Judith Cook, PhD, Department of Psychiatry, University of Illinois at Chicago**; James Conroy, PhD **Center for Outcome Analysis**; Eli Cohen, Esq. **Erickson School of Aging Management**, University of Maryland, Former Commissioner on Aging in Pennsylvania; Ari Ne'eman, President of the **Autistic Self Advocacy Network**, Andy Imperato, **CEO of the American Association of People with Disabilities**; **Kelly Buckland from the National Independent Living Centers**; Lauren Spiro, **Director of the National Coalition of Mental Health???**. Each discussed priorities of the new partnership. To view all of the submitted issues, visit www.centerforself-determination.com.

In addition to Mann, CMS attendees included the Directors from the Disabled and Elderly Health Programs, the Division of Advocacy and Special Initiatives, the Division of Community and Institutional Services and the Division of Coverage and Integration. The Offices of External Affairs was also present. Ms Mann, who was appointed to the CMS directorship just weeks ago, most recently served as a research professor and executive director of the Center for Children and Families at Georgetown University's Health Policy Institute. The 2nd meeting was held on November 3rd. Click for details: www.centerforself-determination.com/docs/CSD.



The 2nd Annual International Conference on Self-Determination was a success!

Despite difficult economic times, there were representatives from 32 states as well as three countries; Cameroon, Pakistan and Ireland. The 300 conference attendees chose from 68 sessions including *Re-thinking Medicaid Long-Term Supports in a Fiscal Crisis, the*

Difference Between Having a Program and Having a Life and Moving From Services to Quality Of Life Outcomes.

Conference highlights included a keynote address from Olegario “Ollie” D. Cantos VII, Special Counsel to the Acting Assistant Attorney General for Civil Rights in the U.S.

Attendees also were given a “sneak peek” of a brand new documentary **[A New Kind of Listening](http://www.anewkindoflistening.com/)**. <http://www.anewkindoflistening.com/> *A New Kind of Listening* is an hour-long documentary that takes us inside the creative work of the Community Inclusive Theater Group, as director Richard Reho inspires cast members, some with disabilities, to be writers, actors and dancers in an original collaborative performance. Together they prove that a small community arts project has the power to transform lives. change beliefs about intelligence, disability and what it takes to be heard.

Some were also interviewed for an upcoming documentary filmed by the North Carolina Council on Developmental Disabilities.

Several sessions were dedicated to the accomplishments of advocates who are carving out a life for themselves using the tools of Self-Determination. One group in particular told their stories of being institutionalized; one even challenged the audience to a “Call to Action” demanding that all institutions in his home state be closed within the next three years.

Center For Self-Determination Training, Education and Consulting Projects

ALABAMA

Self-Determination Staying Power

During the past year, 100 Alabama citizens with developmental disabilities, family members and advocates attended two-day trainings held in Birmingham and Mobile. Built on the principles of Self-Determination, all sessions reviewed how each principle can be the foundation for a meaningful life. Ricky Broussard (www.imagineenterprises.com/success_story_ricky.html) from “Get a Life in Texas” and author of **The Top Ten Reasons for Self-Determination** led much of the training and will continue on as the “**Self-Determination: Staying Power**” project continues with more statewide training in 2010. (“**Self-Determination: Staying Power**” is funded by a grant from the **Alabama Disabilities Council** (www.acdd.org) and implemented by the **Center for Self-Determination** and **Imagine Enterprises** (www.imagineenterprises.com.)

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DELAWARE

From Programs to People: Empowerment Through Self-Determination Across Recovery, Aging and Disability

The Delaware Division of Services for Aging and Adults with Physical Disabilities a workshop on Self-determination July 30th 2009 at the Delaware's 38th Annual Summer Institute - Systems transformation from traditional support models to Self-Determination based support models was the main topic. Sixty-five people attended, primarily leaders of the non-profit, advocacy & academic organizations, serving the older adults and adults with disabilities, living in Delaware Center trainer, Elaine Taverna, discussed changes to federal policy for grants funded by the Administration on Aging and Medicaid and how they will impact publicly funded programs. Break-out sessions allowed small groups to work on issues facing their region and develop ideas on how to move these initiatives forward. The feedback was positive and encouraging! Delaware's commitment to providing community based supports to the people it serves is strong.

NEW YORK

A Life in the Community

The New York Association of Psychiatric Rehabilitation Services (www.nyaprs.org) held their 5th Annual Executive Seminar on Systems Transformation late last Spring, in Albany, New York. This groundbreaking seminar focused on promoting "*A Life in the Community.*" Sessions were held in three tracks: Service Transformation, Integrated Care, and Community Integration. Tom Nerney was one of the opening keynotes on Self-Determination and Mental Health.

GEORGIA

Person Directed Services at Home

Information about how to incorporate Self-Determination based models of support within Atlanta's current system of care, along with best practices nationally, was the training topic of the day September 17th, 2009.

Center trainer, Elaine Taverna, presented Atlanta's current system of Community Based Services, funded through the Administration on Aging and Medicaid, the changes to public policy that support self-determination and person centered practices. Outcome and cost data comparing Self-Determination to traditional supports was shared. Over 80 conference participants representing the non-profit system supporting older adults and adults with disabilities who reside within the Atlanta region attended. Feedback about training information was very good. The Atlanta region is committed to supporting people in their homes and communities.

ILLINOIS

The Urgency of Now: Mental Health and Self-Determination

The University of Illinois at Chicago Department of Psychiatry Conference titled: **Self-Determination: The Fierce Urgency of Now, an Invitational State of the Science Summit.** Tom Nerney was just one of the presenters on Self-Determination and Mental Health at this groundbreaking meeting. Click here for details including all PowerPoints and live presentations as well www.cmhsrp.uic.edu/nrtc/summit2009/summit-products.asp. The National Research and Training Center on Psychiatric Disability (NRTC) promotes access to effective consumer-driven and community-based services for adults with serious mental illness. The Center is located at the University of Illinois at Chicago in the Department of Psychiatry.

TENNESSEE

Inventing the Future: Implementing Self-Determination Across Disability & Aging

The September 21st and 22nd conference was phenomenal! Conference participants attended from 18 states as well as from Ottawa and Windsor Canada. Conference participants were primarily professionals from organizations supporting people with disabilities, seniors, self-advocates, family members and advocacy groups. Conference materials offered practical tools needed to transform a traditional system of supports to one that is based on the principles of Self-Determination. Participants learned from each other as they shared information about the systems they worked in or were served by, as well as gathered information about the best practice approaches used nationally from the conference training materials. Personal stories about living in an institution and then moving into the community and living a self-determined life were shared by people receiving supports from Community Living Services of Kentucky. The feedback was positive, noting that the speakers were very inspiring and helped people truly understand the negative impact institutional care can have on a person's life and how these same people can thrive and achieve remarkable outcomes living lives in the community receiving self-determination based supports.

*Efforts are underway to plan the next **Inventing the Future** conference in 2010, visit the center's website @ www.centerforself-determination.com for more information.*

TEXAS

Got Determination?

A highly successful conference in Houston on September 15th-18th 2009 presented outcomes from **Self-Determination for Texas** (www.imagineenterprises.com/self_determination.html) a project of Imagine Enterprises funded by the Texas Council for DD. In the past five years, Imagine has partnered with Community MHMR Centers, Independent Living Centers, private providers, advocacy organizations and individuals to organize local trainings to share information about the values and basic practices that result in Self-Determination for people with developmental disabilities. The **Got Determination** conference featured Center Resource Guides Pat Carver, Jan Lampman, Kathy Harris and Tom Nerney, presenting on several related subjects. Kathy Harris, Esq., discussed guardianship and its alternatives. She focused on utilizing the tools of person-centered planning to enhance decision-making and building the supports needed for people with disabilities to live self-determined lives. Additionally, an esteemed Center member, Virginia Eernisse, was honored with a "Keeper of the Vision" recognition award. "It is always good to keep an unpaid, values-based, trained on the front-line, unstoppable advocate by your side as a touchstone in reality and to remind you of the vision for the future". Virginia Eernisse is just that kind of person, to Imagine and all the people who call on her for her support."



WISCONSIN

In-Control

At the second statewide Wisconsin Self-Determination conference, CSD Executive Director, Tom Nerney received the "Distinguished Leadership Award" that honored and thanked Tom for his "leadership, dedication and perseverance to the principles and practices of Self-Determination. You have made and are making a positive difference in the lives of people with disabilities in Wisconsin and across the country." In his introductory remarks on October 14, conference organizer Dennis Harkins thanked Tom for spreading self-determination "across the entire planet." Nerney then spoke of new leadership and the need to form close, cross-disability alliances with a shared agenda. He called for, "infusions of thousands (of people) with a keen sense of social justice into human services. We need people who are impatient and angry about current social injustice," said Nerney.

For more information about this successful conference visit: http://www.wi-bpdd.org/whoweare/2009_Events/selfdetermination.cfm

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WISCONSIN

In-Control

The Center for Self-Determination is an active partner in the advancement of Self-Determination throughout Wisconsin. In addition to various consultations and training sessions, the Center was very pleased to be part of the training series, **Stories of Self-Determination – Next Steps in Wisconsin** in November 2008. Along with resource guides from the Center, a panel of powerful speakers with disabilities spoke in Milwaukee, Racine, Rothschild, Wisconsin Dells and Madison about their lives and the successes they've experienced while directing individual budgets and receiving supports based on the principles of Self-Determination. The audiences included people who receive support and services, Managed Care administrators and teams, access and provider staff, advocates and Independent Living Centers. Attendees noted that the speakers were very inspiring and helped people truly understand how self-determination works.

The Center works closely with Wisconsin on training issues associated with the rollout of the new IRIS Waiver. Annette Downing from the Center heads up this important training effort.

People living a self-determined life and supported by CLS of Oakland County (Michigan) addressed the gathering. David DeWitt Taylor, Kim Rosario, John Toppi, David Taylor and Daniel Perry talked about the day-to-day implementations of directing services and the successes that follow when personal empowerment is encouraged and control over supports is shifted. **Freedom, Support and Everyday Life** was sponsored by the **Wisconsin Board for People with Developmental Disabilities (www.wi-bpdd.org/whoweare/2009)**

THE CENTER FOR SELF-DETERMINATION PRODUCTS AND SERVICES

Training, Education and Consulting Services: Our trainers and consultants were at the forefront of the design, development and implementation of the person-centered planning and of the Self-Determination movement in the 1990's and have the experience, knowledge and expertise in teaching all aspects of Self-Determination from the principles and foundations to system development and transformation. We can custom design training sessions that will meet the unique needs of the region or system that you work or live in. Trainers and consultants travel nationally and internationally. Contact the Center for more information.

Information and Resource Contact Center: The Center staff are available to answer questions and provide insight and information to help you. If we can't answer your questions, we will connect you with someone who can. For more information visit: <http://www.centerforself-determination.com/contact.us.html>.

AVAILABLE SOON.....

Membership: The Center will offer annual memberships with rates you can afford. Membership packages will include discounts and access to resources and materials.

Resource and Training Information: The Center has a series of audio and video courses with pre-written courseware that can be adapted for your personal use.

Online Training Courses: The Center is developing a Virtual Training Center on its website. Plans are underway to offer online training courses, webinar meetings and conference sessions

For more information, contact the **Center for Self-Determination @ (734) 722-7092** or check out our website: www.centerforself-determination.com.