

In This Issue

Feature Stories

Cutting Edge in a City with an Edge: May 2008

Nerney challenges CMS audience

In the Ownership Society

Self-Determination Amendments of 2007

Statement of Solidarity

The Assault on Ashley

Center Member on Social Security Advisory Board

Self-Determination in Massachusetts

The integration of individuals, families, communities and services

Imagine Enterprise Holds Steady in Texas

Peter Leidy has new website and Human Serviceland CD

Closing Quote

Cutting Edge in a City with an Edge: May 2008



The Center for Self Determination is planning to present the **International Conference on Self-Determination** May 27 to 29, 2008 in Detroit, Michigan. International perspectives on progressive notions of recovery, family supports, community membership, ending forced impoverishment and system change requirements will be part of the focus of the conference. The meetings will feature leaders from across disability and aging and relate the efforts being made across the world to make freedom a reality for individuals with disabilities. As the contract with the Detroit Renaissance Marriot is finalized, registration and room information will be posted on [The Center's website](#) and the Michigan Association of [Community Health Boards](#).

Nerney challenges CMS audience

The 7th Centers for Medicaid and Medicare Services New Freedom Initiative Conference "**Choice and Independence**" held in Baltimore featured Center Executive Director, Tom Nerney. The conference focused on the policies, programs, and tools - including opportunities authorized by the Deficit Reduction Act. Nerney's plenary "**The Challenge to Change: From Better to Great: The Meaning of Freedom in Everyday Life**" addressed the important historical forces that created and continue to challenge the current system of long-term care. A DVD of Tom Nerney's poignant speech combined with his unconventional PowerPoint presentation developed by Pat Carver is under development at the Center and will be available soon. Contact [Billie Nagi](#) to reserve your copy.

In the Ownership Society

Each month, the **EQUITY** e-newsletter of the [World Institute on Disability](#) challenges readers to narrow the divide between the disability and asset building communities. Equity April 2007 issue "**Including People with Developmental Disabilities in the Ownership Society**" featured Kern Regional Center (CA) Individual Development Account Program (IDA). The Center for Self-Determination and Kern Regional Center have been collaborating for several years. Participants with developmental disabilities in Kern County can begin an IDA to buy a home, advance their post-secondary education, or start/expand their micro-enterprise. To subscribe email [EQUITY](#).

Self-Determination Amendments of 2007

The Center for Self-Determination has now developed a legislative model for changing

Principles of Self-Determination

Freedom
to live a meaningful life in the community

Authority
over dollars needed for support

Support
to organize resources in ways that are life enhancing and meaningful

Responsibility
for the wise use of public dollars

Confirmation
of the important leadership that self-advocates must hold in a newly designed system

Editors

Pat Carver
Community Drive, Inc.

Tom Nerney

Debbie Crowley
Subscription Manager

Center for Self-Determination

the federal Social Security and Medicaid Acts in order to:

- Create more flexibility in Medicaid especially around housing and work;
- Create incentives to work that include higher income disregards under Social Security, and
- Allow for targeted savings accounts that do not penalize individuals for saving earned and unearned income in special “freedom” accounts.

This proposed legislation would direct the appropriate federal agencies to accept streamlined applications for a single simplified dual Medicaid and Social Security plan and/or Medicaid waiver. See both the proposal, background paper and a summary of cost and quality data on the [Center’s website](#): Contact [Tom Nerney](#)

Statement of Solidarity

Disability activists from 15 countries and every state in the U.S. continue to denounce the “therapy” administered to a young girl from Seattle, Washington, known as “Ashley X”. In addition to the [Center for Self-Determination](#), more than 550 individuals and 80 organizations signed an online [statement of solidarity](#) against medical procedures that strip people with disabilities of their human dignity. Susan Fitzmaurice, a Michigan disability advocate, created the Ashley Solidarity Statement web site in concert with the [Michigan Partners for Freedom](#). The Partners for Freedom, created at the Center’s 2004 Atlanta Immersion Learning event, actively work throughout the state of Michigan to enhance the demand for self-determination.

The Assault on Ashley

Written at the request of the Arc of Connecticut, this article by Tom Nerney outlines two issues in “[The Assault on Ashley](#)”. Failure to develop an ethical grounding that would confront the utilitarian ethics of this assault and the extent human services contribute to a view of individuals with intellectual and or cognitive disabilities that allows some to so freely disparage them and render them less than equal under the law. For complete article [CENTER PUBLICATION](#)

Center Member on Social Security Advisory Board

Late last year Marsha Katz of Missoula, Montana was appointed to the Social Security Advisory Board ([SSAB](#)). This Advisory Board is an independent, bipartisan board created by Congress to advise the President, the Congress, and the Commissioner of Social Security on matters related to the Social Security and Supplemental Security Income (SSI) programs. Marsha Katz is an active member of the Center for Self-Determination, ADAPT and Not Dead Yet. She is an experienced trainer in all aspects of the Social Security Disability Insurance (SSDI) and Supplemental Security Income programs and currently works as an Organizational Consultant for the Rural Institute at the [University of Montana](#). To contact [Ms. Katz email](#)

Self-Determination in Massachusetts

In Massachusetts, Representative Tom Sannicandro has filed legislation to support the growth of self-determination in the Commonwealth. Representative Sannicandro is a great ally in the state legislature and has a personal commitment to self-determination for people with disabilities with his vision for his son, who is a 22 year-

734-722-7092

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old man with a developmental disability. The legislation is now being reviewed by the Joint House and Senate Children, Families and Persons with Disabilities Committee. The legislation supports the work of the Massachusetts Community-Based Personal Assistance Services and Supports CMS grant. More information will be available next month. If there are any questions, you can contact [Jeff Keilson](#) at 781 910-7216 or at or the Office of Representative Sannicandro at 617 722-2210.

Integration of individuals, families, communities and services

Early in March, the Dane County Department of Human Services Adult Community Services hosted an exciting learning event bringing together asset based community development with self-determination. Organized by [Dennis Harkins](#) from A Simpler Way, [Pat Carver](#), with Community Drive, Inc and [Mike Green](#) from the [ABCD Institute](#) to deliberately combine the strengths of individuals we serve, their families, the individual budgets and resources available to them, community mobilizing, and our services system. Teams from Dane County explored techniques of asset based community development and began to seed ideas about collective action at building community through individual budgets. (based on the Center's Guaranteeing the Promise of Freedom). To inquire about how this future learning might unfold in your community contact [Dennis Harkins](#)

Imagine Enterprise Holds Steady in Texas

The Center participated in a two day training on self-determination and individual budgeting in Corpus Christi in April. The event was sponsored by American Habilitation Services (AHS) in conjunction with [Imagine Enterprises](#). Participants were very enthusiastic about how the principles of self-determination and personalized supports could change people's lives. The second day Center Resource Guides Vickie Vining and Jan Lampman worked with the AHS staff of to think about strategies to bring their organization closer to the principles of self-determination. They made commitments in each department to pursue ways that people with disabilities could have more control over their lives. To support self-determination [Imagine Enterprises](#) hosts a sister website [Self-Determination for Texas](#).

Peter Leidy has new website and Human Serviceland CD

Leidy writes and sings humorous and thought-provoking songs about life in the human service system. His songs touch self-determination, advocacy, personal care assistance, hiring employees, and the human services bureaucracy. In many learning events sponsored by the Center Peter Leidy's songs are played. Often through song, the message for change is heard in ways that previously could not penetrate deep defenses often inherent in human service. Leidy recently released his third Human Serviceland CD: [The Great Escape](#).

Closing Quote

"We just need to stop accepting what is and start creating what should be."

- Dale DiLeo in “[Raymond’s Room: Ending the Segregation of People with Disabilities](#)” Training Resource Network, St. Augustine, Florida In this compelling book, DiLeo uses research, anecdotes, and stories, to take aim at the billion-dollar “disability industrial complex” that segregates people with significant disabilities from mainstream life.

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