

In This Issue

Feature Stories

- [Innovative Medicaid Waiver Promotes Work & Safe Housing](#)
- [From Values to Practice Guidebooks Available](#)
- [Center Retreats & Looks Ahead](#)
- [Deborah Crowley Joins Center Staff](#)
- [New Broker Resource Guidance](#)
- [International Center Affiliate](#)

Self-Determination State Sites

- [Florida](#)
- [Georgia](#)
- [Iowa](#)
- [Michigan](#)
- [Minnesota](#)
- [Texas](#)

Innovative Medicaid Waiver Promotes Work & Safe Housing

Within the State's new 1115 Waiver, Kentucky is launching a model self-determination demonstration that is the most innovative in the country. Designed to promote employment and self-employment as well as safe and affordable housing, this Waiver demonstration will be carried out under the experimental or demonstration section of the Social Security Act that permits states and the Centers for Medicare & Medicaid Services (CMS) to waive practices that would otherwise be prohibited. It represents a challenge never undertaken before to test whether or not typical Medicaid funding and service categories serve only to increase the costs of long term care without many discernable positive outcomes. The twin goals of this experimental demonstration changes what can be purchased with Medicaid in order to set high expectations and real cost effectiveness. It proposes a ceiling on personal allocations that is 5% less than typical service costs and it includes a fiscal incentive for promoting savings at the individual and family level.

It will cover all disabilities and aging. Using a complete self-determination foundation, including free choice of broker and fiscal agent, persons with disabilities enrolled in the Kentucky self-determination waiver will be able to:

- - Use Medicaid funds to supplement room and board in order to promote safe, affordable and personal housing in regular homes, apartments or condos
- - Use Medicaid funds to begin to capitalize a micro-enterprise or tiny business
- - Pay employers directly for any needed assistance
- - Pursue post secondary training and education
- - Purchase the means of transportation including cars, accessible vans etc.
- - Purchase necessary communications and/or mobility technology
- - Use one half of any money saved for critical one-time purchases

It seems only a short while ago that Center Director, Tom Nerney, met with Kentucky Governor Ernie Fletcher in a meeting set up by the Secretary of the Cabinet for Health and Family services and requested by advocate Glenna Taylor and Patty Dempsey, ARC Director of Kentucky. Following this positive half-hour

Announcements

- [Alliance for Freedom Offers Chance to Connect](#)
- [8th National Self Advocacy Conference](#)
- [Website Not Dead Yet](#)
- [TASH Issues a Call for Papers](#)

[Closing Quote](#)

[Fund Membership](#)

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

meeting, another longer meeting took place with key state officials led by Mark Birdwhistell (now Secretary of the Cabinet for Health and Family Services) and attended by Medicaid Commissioner Staff. As a result the demonstration within Kentucky's new 1115 Waiver was developed and planning is now beginning. Some issues will differ depending on type of disability and age and certainly the allocations available to develop personal budgets will vary. But, this approach narrows the focus of public spending to control of one's home (when the person does not live in a family home), long term relationships, community connections, and, for those of working age, the production of income,

A 24 person stakeholder group has been created and it is co-chaired by Deborah Anderson from the state office and Pat Seybold, Director of the Kentucky Developmental Disabilities Council. Both the Council and the Kentucky P & A, directed by Maureen Fitzgerald, have offered to support this important endeavor.

While this demonstration holds the potential for important reforms to the Medicaid program it is fraught with danger. It requires an unprecedented degree of cooperation and trust between the advocacy community and the state. Similar attempts in the past have resulted in critical compromises and failures. As this project begins it is hoped that Kentucky will lead the nation in re-thinking the purpose of public funding for individuals with disabilities based on high expectations, increased quality and better use of a rapidly dwindling supply of public dollars.

From Values to Practice Guidebooks Available

This important self-determination guidebook series is organized to assist in understanding both the work of system transformation and the possibilities for the personal exercise of freedom and responsibility. Each guidebook is structured to be part of an ongoing learning effort by all system stakeholders. Four of the five guidebooks are now available on the structural changes necessary, brokering, personal budgeting and new quality standards. To download order form visit: self-determination.com/products or contact [Billie Nagi](#). Ms. Nagi also arranges resource guidance and comprehensive training based on each topic.

Center Retreat & Looks Ahead

Late last year, key contributors to the creation and ongoing operation of the Center for Self-Determination gathered to set a course for the future. Many present were instrumental in the early formulation of the principles of self-determination as they relate to support for individuals with disabilities. Also joining this gathering were representatives of NConSD (The National Coalition for Self Determination) to talk about strengthening our efforts around self-determination. Out of this gathering came the beginnings of a road map to focus the intentions and activities of the

public dollars

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

Editors

[Pat Carver](#)

[Tom Nerney](#)

Center for
Self-Determination
734-722-6262

www.self-determination.com

[Kathy Homan
webmaster](#)

Center. Contact [Tom Nerney](#) for further information.

Deborah Crowley Joins Center Staff

As a result of the retreat, Deborah Crowley joined the Center professional staff as a Special Assistant to Executive Director Tom Nerney. Deborah brings to the Center over 15 years of systems change and advocacy experience. Currently she is the President of the Board of Directors of Louisiana's Protection and Advocacy Agency and formerly the Executive Director of Family Helping Families of Greater Baton Rouge and Louisiana Self-Advocacy Project advisor.

In her home state of Louisiana and on a national level Deborah Crowley works closely with families and self-advocates in organizing grassroots advocacy and promoting self-determination and inclusion for persons with disabilities. Deborah's email is selfdetermination1@gmail.com

New Broker Resource Guidance

A new cadre of Center Resource Guides is ready to conduct *Supporting the Promise of Freedom: the New Broker* training sessions. At the Center Summer 2005 Institute in Midland Michigan, representatives from ten states became equipped to guide others through the evolution of case management to brokering and all that is entailed by this shift. The New Broker training includes instructional analysis of long and short term brokering as well a comprehensive review of what really constitutes quality in a life based on universal human aspirations. For more information visit [Technical Assistance and Resource Guidance](#)

International Center Affiliate

The Center welcomes Canada affiliate [Bonnie Pacaud](#) and [Jean Richards Carter](#). For many years Jean and Bonnie have been working towards the common goal of self-determination and the pursuit of self-determination through individualized funding for people in Alberta and Canada.

Self-Determination State Sites

Florida

- At the **Florida Asset Development Summit** March 3 in Orlando, Center Executive Director Tom Nerney will be providing one of the keynote addresses. Building the bridge between finance and disability, national and state policy initiatives, employment, financial education and asset building are among the meeting topics. The two day Summit is sponsored by the [Florida Developmental](#)

[Disabilities Council](#) and the [National Disability Institute](#).

Georgia

- In preparation for the near term implementation of "**Consumer-Directed Natural Supports Enhancement Services**" within a current Home and Community-Based Services (HCBS) Waiver, and two new waivers Georgia's Department of Human Resources is preparing, the Center recently completed a six month series of self-determination trainings. Funded through the Georgia Governor's Council on Developmental Disabilities and headed by Center Resource Guide Dennis Harkins in concert with Georgia DHR and DD Council, the primary audience for this training were families and support coordinators.

The Center also made presentations on Self-Determination at a statewide provider conference, to a graduate reunion of Georgia's Partners in Policymaking, and to a statewide conference in Savannah focused on community connections and direct support professionals. Georgia's Division of MHDDAD is making significant strides towards the implementation of self-determination within Georgia's state system. The working relationship between the Division and the Georgia DD Council in this regard has been an excellent example of how the resources and responsibilities of a state developmental disabilities services agency and a Governor's DD Council can blend effectively to work towards systems change based upon self-determination.

Drafts of Georgia's potential new HCBS waivers may be seen by going to <http://mhddad.dhr.georgia.gov/portal/site/DHR-MHDDAD/> and clicking 1st on "services", then "developmental disabilities" and at the bottom of the developmental disabilities page finding the link to the drafts of the new waivers which have self-determination as a foundation.

Iowa

- To see Attorney Kathleen Harris presenting **Alternatives to Guardianship** at the Employment Policy Group, the employment policy arm of the Center for Disabilities and Development at the University of Iowa visit the [News Room](#). The Center for Disabilities and Development is nationally designated as Iowa's University Center for Excellence on Disabilities. Kathy Harris is the President of the [Center for Self-Determination](#) and attorney who consults with non-profit organizations about alternatives to guardianship.

Michigan

- **The Provider of the Future** - a retreat facilitated by Center Resource Guide Vickie Vining, was sponsored by the Michigan Assisted Living Association, Community Living Services (CLS) and the Provider Alliance of Wayne County

early in February. Using the Real Life Quality Standards, the group developed a strategic plan and path to move systems forward. Derrick Dufresne, President and CEO of the Institute on Public Policy for people with disabilities joined Center Resource Guides at this special event just for providers. This first provider retreat was the brainchild of CLS Director, Jim Dehem and Kathleen Kovocho, CLS Vice President of Operations. For information about the Center for Self-Determination capabilities at facilitating provider retreats contact [Billie Nagi](#).

- As a part of the [Autism Society Spring Focus Workshops](#), Resource Guide Patricia Carver will cover the basics of self-determination and what they can mean for individuals with autism and those who support them in managing their lives as part of the community in which they live.

- **Self-Determination and Recovery for Persons with Psychiatric Disabilities** with Medicaid Support held Monday Feb 27 in Lansing covered the most up-to-date information regarding self-determination and recovery for persons with mental illness. SAMSHA sponsored research was presented by Judith Cook, PhD, Director of the [National Research and Training Center](#). Judith was joined by Center for Self-Determination Executive Director Tom Nerney and the full afternoon panel was moderated by Oakland County Mental Health Director, Bill Allen. NTRC is working on a five year program of research, training, technical assistance and dissemination activities designed to promote best practice and self-determination among people with psychiatric disabilities.

Minnesota

- Newly available Partners in Policymaking course: "[Partners in Time](#)" is an eight-hour self-directed e-learning course created to help people with developmental disabilities, their parents, family members and friends, educators and service providers understand the history of society's treatment of people with disabilities from ancient times through the present. In the section **Visions for a Brighter Future**, Tom Nerney, executive director of the Center for Self-Determination is listed as "[Change Maker](#)" - people who played pivotal roles in igniting change over the years.

- On Feb 23 [Minnesota Partners in Policymaking](#) graduates gathered for a full day to interact and cover the principles, tools, critical elements and outcomes of self-determination. Pat Carver, director of **Community Drive** - a firm dedicated to building circles of support and former coordinator of Michigan Partners in Policymaking, facilitated the day of learning and activity.

Texas

-The **Self Determination for Texas Project** is hosting a '**Mini-Immersion**' project conference to continue regional and state work on increasing Self Determination for

Texans with disabilities on March 8 & 9, 2006

The conference will assist project regions develop road maps to sustain efforts and have more opportunities for self-determination in Texas. Among the key players in the Immersion Learning will be Texas' Policy Team for Self-Determination. Tom Nerney, Vickie Vining, Dennis Harkins, Kathy Harris and Cori DiBiase from the Center for Self-Determination will be providing resource guidance. The project is operated by Imagine Enterprises and the Center for Self-Determination and is funded by a grant from the Texas Developmental Disabilities Council.

- Self-Determined Speakers, another collaboration between Imagine Enterprises and the [Center for Self-Determination](#) and partially funded through a grant from the Texas Council for Developmental Disabilities is underway. A register of talented individuals who have powerful stories of self-advocacy and aspects of self-determination is being developed. Here motivational presenters can seek audiences and event sponsors may find new voices. To register [Self-Determined Speakers](#).

Announcements

Alliance for Freedom Offers Chance to Connect

To join the Center's national list serv Alliance for Freedom contact [Debbie Prockner](#) or download [Alliance for Freedom](#) free membership form.

8th National Self-Advocacy Conference

The May 2006 National Self-Advocacy Conference "We Had a Dream, Now We Have the Power" will be hosted by the Southern Collaborative on Self Determination, Self-Advocates Becoming Empowered (SABE) and [People First of Georgia](#) and held over Memorial Day weekend in Atlanta, Georgia May 25-28. Contact [We Had a Dream, Now We Have the Power](#).

Website Not Dead Yet

NDY believes that legalized medical killing is really about a deadly double standard for people with severe disabilities and advocates that people with disabilities must lead society from the isolation and despair of today into a renewed recognition of belonging and community for all. The [Not Dead Yet](#) website recently underwent a major overhaul and update.

-Tash Issues a Call for Papers

March 15 is the presentation proposal deadline for 2006 TASH Conference. Proposals supporting valued outcomes for individuals with disabilities are sought that address how policy, research and practice converge to produce the full

inclusion and active participation of individuals with disabilities in school, community, and employment. Living the **Vision Together: Today, Tomorrow & Beyond** will be held November 8-11, 2006 in Baltimore, Maryland. More info: [Call for Papers](#)

Closing Quote

"It is risk-takers who inspire and lead."

- Michael Bailey in his [MOUTH Magazine](#) article "**Once Upon a Week in Washington**" comparing the integrity of activities he experienced concurrently at the 2005 ADAPT action, the Cape Casey anti-war demonstration and the Alliance for Full Participation Inclusion Summit.