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Free to Choose

An excellent report from Substance Abuse and Mental Health Services Administration (SAMSHA) **Free to Choose: Transforming Behavioral Health Care to Self-Direction** is now available. The easy-to-read summary includes important issues raised in the working papers and workgroup recommendations resulting from the **Consumer Direction Initiative** Summit last year.

The workgroup *Adults with Mental Illnesses* reported in their recommendations that self-determination was the goal of a transformed mental health system, and self-directed care is one methodology to achieve that. Additionally, the workgroup acknowledged that "money follows the person" is too narrow a focus when talking about self-determination. This report of presentations and participants thoughts and perspectives provide a strong foundation for those working to develop consumer direction initiatives at any level - local, State, and Federal. To view report [Free to Choose Report](#)

TASH Connections

The most recent issue of TASH Connections has a comprehensive collection of self-determination articles including information on innovative Medicaid program trends, support systems of the future and creative individual budgeting. The Center for Self-Determination is recognized as the primary clearinghouse training and technical assistance center in the country. The Alliance for Freedom is also featured. [TASH Connections](#)

U.S. Supreme Court Hears from Not Dead Yet

Several prominent disability organizations filed a friend of the court brief late last month with the U.S. Supreme Court in the Oregon assisted suicide case. Not Dead Yet, the leading national disability rights organization opposing legalization of assisted suicide, filed the brief, which supports the U.S. Department of Justice (DOJ) appeal of the decision in the lower court, which upheld Oregon's assisted suicide law. The following organizations joined the brief filed May 9th in the matter of Oregon v. Gonzales:

Update and Announcements

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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

Not Dead Yet
ADAPT
Center on Disability Studies, Law and Human Policy at Syracuse University
Center for Self-Determination
Hospice Patients Alliance
Mouth Magazine/Freedom Clearinghouse

National Council on Independent Living
National Spinal Cord Injury Association
Self-Advocates Becoming Empowered
Society for Disability Studies
TASH
World Institute on Disability

Assisted suicide raises serious ethical concerns regarding the medical profession's treatment of people with disabilities. According to attorney Max Lapertosa, assisted suicide is a "dangerous distraction from policies that really enhance people's independence and dignity – access to palliative care and other forms of community-based long-term care." [Friend of the court brief.](#)

Ticket to Work & Work Incentives Advisory Panel

The quarterly public meeting and strategic planning of the Ticket to Work and Work Incentives Advisory Panel received testimony from Tom Nerney, Center Executive Director, concerning the New Freedom Initiative on May 24 in Washington, D.C. At the meeting which is designed to receive briefings, deliberate and hear public testimony on the implementation of the Ticket to Work and Work Incentives and Improvement Act, Nerney commented "*It is only by addressing the intersection of Medicaid and Social Security and creating a dynamic new approach to work that we can begin to forecast a positive change in the employment status of individuals served by both programs.*" To see complete comments visit [Ticket to Work & Work Incentives Advisory Panel](#)

Self-Determination State Sites

Arkansas

- Helpful Waiver Training

"A New Day for Waiver" Arkansas Waiver Association Conference will be held July 7 - 8, 2005 at the Clarion Resort on the Lake in Hot Springs, Arkansas. Speakers including Center Resource Guides Dennis Harkins and Peter Leidy. [Arkansas Waiver Association Conference](#)

Florida

- Florida Freedom Basics

The first set of the Florida Freedom Initiative Basic Training Series were completed late last month in Tampa, Orlando, West Palm Beach, Broward County and Miami.

Responsibility for the wise use of public dollars

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

Editors

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Focus is on individuals with developmental disabilities currently enrolled in the Consumer Direct Care Plus program. For related information see **Ticket to Work & Work Incentives Advisory Panel**.

Hawaii

- Update from Well-Connected State Contact

Peggy Proffitt Hawaii reports *"Our Hawaii Community Personal Assistance Services and Support (CPASS) grant is well under way. The grant was awarded to the Center on Disability Studies (CDS) at the University of Hawaii. People in Leeward Oahu, Molokai, and Hilo on Hawaii have the option of joining the CPASS groups and learning to direct their own services and money. **It is such a new concept.** We had a statewide CPASS conference where folks who are directing their own services spoke and really got others excited about how their lives can change. The state CPASS council is all self-advocates and family members except for the Department of Health (DOH) and Department of Human Services (DHS) representatives who have the money."* Contact [Peggy](#).

Kentucky

- Advocates Receive Recognition

Kevin Webb and Kim Brown were presented the Gayla Peach Advocacy Award on April 29 at the Arc of Kentucky's 50th Anniversary celebration. This award honors individuals who speak out and provide leadership to secure or maintain the rights, services, and supports for individuals with mental retardation and other related disabilities. Kevin Webb and Kim Brown are responsible for the [Kentucky Self-Determination Act](#) -House Bill 501. *"These two are true advocates in action!"* says Kentucky Arc Executive Director Patti Dempsey. For the past five years, Ms. Webb and Mr. Brown have been pagers on the Senate and House Floor. *"What a difference this has made with legislators"* proudly claims Kevin's mother, Glenna Taylor. *"I would highly recommend for people with a disability to ask to be a pager on the floor for their Senator or Representative while they are in session."*

Ohio

- Seminars for Independence Plus Pilot Counties

Center Resource Guides Jan Lampman from Midland, Michigan, and Dan Rossiter from Dane Co., Wisconsin joined Dennis Harkins in Ohio last month. Together they prepared for Independence Plus and looked at how support brokerage will work in coordination with the new entity of the OHCDS. A presentation of relevant ways in which support brokers have been identified, recruited, supported and organized was followed by a discussion of how each pilot county is approaching support brokerage. For more information contact [Dennis Harkins](#) On May 25, those working with Ohio's Independence Plus pilot counties attended training with Center Resource Guides Jim Dehem and Bill Yordy on payroll services, fiscal intermediaries, IRS

issues and sources of staffing and contracting. Dehem is the CEO and Yordy the CFO of [Community Living Services](#) in Wayne Michigan.

Texas

- Bringing Ideas to Life

Imagine Enterprises with training and guidance from the Center for Self-Determination has completed the first round of **Texas Regional Self-Determination Workshops** with the Arc of the Gulf Coast, LifePath Systems, Sabine Valley Center and Lubbock MHMR. Follow-up sessions with teams and individuals needing further consultation are scheduled for this summer. [Visit Imagine Enterprises.](#)

West Virginia

- PLUG IN to Self-Determination

In June, the West Virginia Developmental Disabilities Council and Center for Self-Determination will join forces to continue building self-determination in West Virginia. A one-day training session will be held at four locations around the state. For more information contact West Virginia Center State Contact: [Jan Lilly-Stewart](#). Event flyer and registration can be accessed at: [PLUG IN Event flyer and registration.](#)

News from Self-Determination.com

- Wow!

The new counter of Center for Self-Determination website hits went was placed on the site May 14, 2005. To date, there have close to 1200 hits!! If you have interest in working to gather information for the Center's communications effort, contact [Pat Carver](#).

In June watch for the new monthly feature "**Meet the Center Resource Guide.**" Learn about those working with the Center for Self-Determination to keep the movement flourishing. The methods, modes and manners used by the individual Resource Guides that promote self-determination will be reported.

Updates and Announcements

Medicaid Long Term Care Expenditures in FY 2004

State-by-state data on Medicaid long term care expenditures in Federal Fiscal Year 2004 (October 2003 through September 2004) is now available. Additionally, data on Medicaid Expenditures for Long-Term Care services from 1992 to 2004 and states rankings based on the proportion of LTC spending for community services can be studied. [2004 LTC](#)

Medicaid 1915 (c) Home & Community-Based Services Waiver Expenditures

In this memorandum, Federal Fiscal Years 1999-2004 is classified for each individual HCBS waiver by the target population served. The distribution of HCBS waiver expenditures across long term care populations is also included. [HCBS waiver 1999-2004](#)

Basic and Understandable Information about Medicaid

[The Medicaid Reference Desk](#) explains Medicaid in basic terms, state by state. Designed to give people with cognitive disabilities, family members and advocates information about what is available through their State Medicaid Plans and waivers.

Closing Quote

"Freedom is not an idea; it is not even a protection, *if it means* nothing more than freedom to stagnate, to live without dreams..." - Adlai Stevenson