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Change for Prosperity

RENAISSANCE CHICAGO HOTEL

December 7-10, 2004

What does it take for children and youth to become less financially dependent on others/systems? Economic self-sufficiency - having savings and assets - can increase hope and a sense of ownership and mastery over one's life and future. Young adults with disabilities or special health care needs from low-income backgrounds have some of the highest rates of financial dependency of any group in the United States. Imagine how different their experience might be, how better prepared they might be, if they entered adulthood with some financial resources at their disposal and a savings account for their future. This and more will be examined and planned with teams attending the **Immersion Learning about Change for Prosperity** - a collaborative effort with the University of Iowa's Center for Disabilities and Development and the Center for Self-Determination with support from the Iowa Department of Human Services and the U.S. Department of Health and Human Services/Centers for Medicare and Medicaid Services. To register visit <http://www.e-epg.info/conferences/>. For an updated agenda please visit <http://www.self-determination.com/pdf/illinoisPrelimAgenda.pdf>

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New Quality Assessments Tools

The Center for Self-Determination and Sabine Valley Center, Texas have entered into a unique arrangement that will seek to pilot a new set of quality standards based on the principles of self-determination and an outcome based set of quality indicators outlined in Lost Lives. http://www.self-determination.com/pdf/lost_lives.pdf

The draft quality assessment tool is organized around six domains consistent with both the principles and the Center's budgeting guidebook *Guaranteeing the Promise of Freedom The Promise of Freedom* (<http://www.self-determination.com/pdf/guidebookad2.pdf>)

- Health and safety
- Where and with whom a person lives

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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

Responsibility for the wise use of public dollars

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

Editors

- Connections to the community
- Relationships
- Generating private income
- Control of transportation

Five individuals from Sabine Valley Center have volunteered to help pilot these quality standards. In addition to the more traditional "before and after" data collection Sabine Valley Center personnel will maintain dairies of what actually happens during the implementation of self-determination during this one-year period. This ongoing narrative will be extremely helpful in documenting both the positive and the pitfalls in the complex work of changing an existing system in order to make self-determination a reality for individuals with disabilities.

Dorothy Hull of Sabine Valley will oversee the project along with key individuals with disabilities, families and staff. Center resource guides will journey to Texas by mid October to begin this exciting project.

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ALLIANCE FOR FREEDOM

Please welcome Tiffany Devon in her new additional role as ALLIANCE Coordinator for the Center for Self-Determination. As Public Relations Director for Community Living Services, the non-profit organization that sponsors the Center, Tiffany is a natural for building membership and heading up the **Alliance for Freedom**. She has 16 years of experience in public relations and television news and was formerly the executive vice-president at a large Detroit Public Relations firm, as well as news producer at two local stations in Detroit and one in Las Vegas. Rather than evolve into a formal membership organization with exclusive categories, the Center has chosen to gain strength in numbers by inviting all those persons interested in supporting our work to simply come together and join the **Alliance for Freedom**. Contact Tiffany to join at TDEVON@comliveserv.com

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Self-Determination State Sites

California

- Keeping the Promise of Inclusive Communities

Lead Center for Self-Determination Planning Consultant and member of CIRCL, Vicki Vining showed her talents at clarifying complex situations at the 18th annual Supported Life Conference held last week in Sacramento. "From the Regional Center's Perspective" Ms. Vining led participants through complex vrending process, developing service designs, who pays for what and how; and helping

[Pat Carver](#)

[Tom Nerney](#)

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people understand what Supported Living means for them. Vickie Vining's expertise include building circles of support; values and philosophy; risk and choice; budgets; policies and procedures; quality assurance and service evaluation. vvining@earthlink.net

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Michigan

- Economic Development: A Disability Issue

Since the publication of the **Poverty of Human Services**, <http://www.self-determination.com/pdf/povertyPrint.pdf> the Center has highlighted the link between the poverty of people with cognitive or intellectual disabilities and their lack of community and personal relationships. We regularly help promote the recognition the role of money has in our own relationships and community connections and the hope an economic future promises. In the recent issue the **Michigan Disability Rights Coalition** quarterly publication, "Our Voice" - an informative article outlines some basic concepts that support economic development in ones community. <http://www.copower.org/tools/ourvoices/ovfall04/econ.htm>

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Ohio

- Progress in the Buckeye State

The Center is working with the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD) to assist in the development and subsequently the implementation of an Independence Plus Waiver, and to assist Ohio in working with federal agencies on the system changes needed to implement self-determination.

The Center recently collaborated with the ODMRDD and with the Ohio Self-Determination Association to provide a Self-Determination Immersion Training in Akron. Evaluations indicate that 98% would recommend Center presenters and 93% found the written material helpful during the presentation and thought to be helpful upon return to work.

The Center has developed expertise in immersive learning events and is prepared to assist others in developing these intensive learning sessions. See related lead article Immersion Learning about Change for Prosperity or visit: <http://www.self-determination.com/events/index.html>

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Texas

-We Want Freedom

"We want to pursue a life of our making; we want what you have. We want Freedom!" writes Mike Halligan in his **E.D.'s Message** of the Summer Issue of the **Texas Mental Health Consumers (TMHC) Texas Network** newsletter. The mission of Texas Mental Health Consumers is "to organize, encourage, and educate mental health consumers in Texas. TMHC supports and promotes the mental health recovery process through peer directed and operated services, advocacy, economic development, and participation in public mental health policy design."

Executive Director Halligan attended the 2004 Immersion Learning about Self-Determination in Atlanta and returned home with a clear command concerning self-determination. See Halligan's full article at

http://www.tmhc.org/newsletters/tmhc_txnetwork_04_fall.pdf

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Update and Announcements

Quality Discussion at AAMR

At the AAMR Region X Annual Conference in Mystic Connecticut October 17- 19, Center Executive Director Tom Nerney will address the group about a topic important to persons who receive support services -- the *quality* of those services. For more information contact Terry Macy at tuxis@cshore.com

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Midwest Immersion Learning Event about Self-Determination

Plans are underway for a Midwest Immersion Learning about Self-Determination July 20-23 at the Bloomington Sheraton in Minneapolis. Contact Pat Carver pcarver@chartermi.net or Rebecca Rooker remarkabler@comcast.net for further information. See LINK TO EVENTS PAGE for a SAVE THE DATE flyer suitable for distribution—Please feel free to do so!!

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TASH holds TECH Workshop on Individual Budgeting

Guaranteeing the Promise of Freedom through Redefining Quality and Creative Individual Budgeting with **Mary Bryant , Michael Allen and Vickie Vining** will be presented at 2004 TASH Conference *Blazing the Trail!* in Reno, Nevada November 17-20. This session is based on the guidebook developed by the Center

for Self-Determination. It incorporates issues of new planning assumptions about living in one's own home and generating income; getting better connected to one's community; and, facilitating relationships. The TASH TECH presenters bring new voices to the disability rights movement -- family members and individuals who have utilized this planning tool. Saturday session was chosen in recognition that most family members work regular Monday – Friday jobs and cannot always take weekdays to attend conferences. <http://www.tash.org/2004reno/>

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A personal note from Tom Nerney:

I would like to bring the following quote from the recent press release from Cash & Counseling to everyone's attention:

"Providing more choice and control to people who are capable of managing these very personal daily activities makes a tremendous difference in improving their quality of life," said Kevin Mahoney, PhD, director of the national office of the Cash & Counseling program and a professor of social work at Boston College. **"With 11 new states launching programs, we hope we're that much closer to the day when every state will make this voluntary option available to Medicaid beneficiaries who have disabilities."**

Kevin's words need to be understood in two dimensions. First, we need to applaud the work that has been done and will continue under the Cash and Counseling program. Second, we need to be wary of the great danger that this underlying philosophy may hold for those with intellectual, psychiatric and other disabilities including those who are elderly and experience loss of memory or intellectual ability. I specifically refer to the words that indicate that cash & counseling is for those **"...who are capable of managing these very personal daily activities..."**

From its inception self-determination has been predicated on the promise of freedom for every individual with a disability. The original demonstration very deliberately included both those with very significant intellectual disabilities as well as with multiple disabilities including those with acquired brain injury. One of the few things we got right from the beginning was recognition of the danger that only those who could articulate their desires in traditional ways would be eligible in the future to control the resources necessary for their supports. We were determined to eschew any "test" for self-determination. The original first principle "freedom" clearly expressed this sentiment by adding words that made it clear that freedom could be exercised with assistance.

I tried recently in Lost Lives to explicate some of the differences between self-determination and "self directed services" by contrasting the means (control of the dollars) with **the end or goal of self-determination: the pursuit of a meaningful life deeply embedded in our communities and suffused with community and**

relationships. For us control of the money is a necessary means to a more important goal. Control of the resources still remains the primary goal of self directed services.

I happen to believe that Kevin Mahoney would not object at all to our interpretation of what we mean by self-determination. However, policy makers and elected and appointed officials may very well settle on an interpretation of this movement that gradually excludes those with very significant disabilities. **We need to be vigilant.**

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Closing Quote

"The right to vote...is the primary right by which other rights are protected"
– Thomas Paine

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