



Alliance for Freedom News

February, 2004

Volume 1, Issue 4

Features

- [Register Planning Teams Early](#)
- [Immersion Learning Scholarship Stipulations](#)
- [Make Guardianship Unnecessary](#)
- [The Promise of Self-Determination for Persons with Psychiatric Disabilities](#)
- [Centers for Medicaid and Medicare Services Conference: March 2-3, 2004](#)
- [First National Emerging Workforce® Conference](#)
- [Monthly State News](#)
 - [West Virginia](#)
 - [Wyoming](#)
 - [Michigan](#)
- [Center Newsletter in the Mail](#)
- [New Address and Phone for COA](#)
- [Quote of the Day](#)

Today's Top Story

February 2004 E-Newsletter

Welcome to the 4th Issue of the Center for Self-Determination E-Newsletter.

Please note the important registration information about the 2004 Immersion Learning April 28-May1, 2004 in Atlanta.

Happy Valentine's Day, Everyone!

This month you will find:

1. Register Planning Teams Early
2. Scholarship Stipulations
3. Make Guardianship Unnecessary
4. The Promise for Self-Determination for People with Psychiatric Disabilities
5. State Information
6. Managed Care vs. Self-Determination
7. New Address Announcement - Center for Outcome Analysis
8. Quote for the Day

Register Planning Teams Early

We'd like to advise you now - get your registration in as early as possible. The Embassy Suites is a quaint hotel. It's easy to manage. No long hallways leading to more long hallways lined by impersonal meeting rooms. For the April 28-May 1, 2004 Immersion Learning about Self-Determination (www.self-determination.com/immersion/southern/index.html), the Center has reserved every meeting space in the hotel to assure privacy and enough room to gather and plan according to what registrants indicate they want to achieve at this learning opportunity. The Foundation Stream participants will stay together (except for some small group work) while the Planning Stream teams will venture out into private areas and meeting rooms to work with Center Resource Consultants. Because of the intense nature of this year's Immersion Learning Planning Stream, it is strongly recommended that teams wishing to participate register as early as possible. Center Associates will be contacting teams to begin planning their Immersion work sessions well before we depart for Atlanta. Don't be fooled by the extra Leap Year day we're all getting this month - the

Immersion is coming up sooner than you think!

Immersion Learning Scholarship Stipulations

An earmarked donation was made to the Center last year to provide financial assistance to those in need of money to attend the 2004 Immersion Learning about Self-Determination. www.self-determination.com/immersion/southern/index.html The donor stipulated that the money -- up to ten scholarships at \$500 -- be used for: - Individuals with disabilities, family members or personal assistants - Those who will have impact on the self-determination movement in their community - Have sought additional assistance elsewhere - Understand the tools of self-determination and clearly have implementation as a goal To obtain a scholarship application contact Pat Carver pcarver@chartermi.net Phone interviews can be arranged. Call Pat at 810-231-6364 to schedule. Submit scholarship application by March 15, 2004. Notification will be made March 20 and no late applications will be accepted.

Make Guardianship Unnecessary

In the Winter 2004 issue of "Making a Difference" a publication of the Georgia Governor's Council on Developmental Disabilities, Center for Self-Determination board president Kathleen Harris, a long-time advocate and an attorney in private practice in Michigan, provides the counterpoint to the question "Guardianship-Does it Work?" Ms. Harris challenges many of the myths and misunderstandings that have arisen around the topic of guardianship as it is applied toward persons with developmental disabilities. She reminds us that while provider agencies oftentimes urge families to seek court appointed guardianships, "There is generally no legal requirement that a person who is acting as a decision maker must be a guardian," says Harris. True person centered planning and the supportive participation of friends and allies can negate the perceived need for a guardianship. In fact, the imposition of guardianship can actually interfere with the creation and the maintenance of circles of support. To read the full text of Kathleen Harris' article -and to read the opposing viewpoint-click on:
<http://www.gcdd.org/pi/publications/mad/MakingADifference.winter04.pdf>

The Promise of Self-Determination for Persons with Psychiatric Disabilities

This paper by Tom Nerney is now available on the Center for Self-Determination website at: www.self-determination.com/publications/psychiatricDis.html To review the full collection of papers from the University of Illinois-Chicago / National Training and Resource Center's National Self-Determination and Psychiatric Disability Invitational Conference, click on:
www.psych.uic.edu/UICNRTC/sdconfpapers.htm

Centers for Medicaid and Medicare Services Conference: March 2-3, 2004

This event - Building Systems so that Money Follows the Person - is intended to showcase grantee efforts to improve services and supports for individuals with disabilities and long-term illness, and to facilitate the sharing of lessons learned across states. The conference will also highlight important Center for Medicaid and Medicare Services (CMS) initiatives and New Freedom Initiative activities across Federal departments. Tom Nerney in the session titled "Addressing the Complexities of Individual Budgeting" will attempt to clarify in his presentation the difference between individual budgets and individual allocations. For more information about the conference visit www.nashp.org/cmsconference2004/

First National Emerging Workforce® Conference

The National Emerging Workforce® Conference coincides with the third anniversary of the President's New Freedom Initiative, which promotes full integration of people with disabilities into American society. The goal of the two-day event held at the Wyndham Bonaventure Resort & Spa in Westin, Florida February 8-10, 2004 is to shed light on an untapped labor pool of more than 54 million people with disabilities by building a strong foundation between policy makers, service providers, families and people with disabilities. Tom Nerney will join presenters Florida Governor Jeb Bush; JoAnne B. Barnhart, Commissioner of the Social Security Administration; Josefina G. Carbonell, Assistant Secretary, Administration on Aging, U.S. Department of Health and Human Services; Cari M. Dominguez, chair of the U.S. Equal Employment Opportunity Commission; W. Roy Grizzard, Jr., Assistant Sec., for the Office of Disability Employment Policy at the U.S. Dept. of Labor; and Margaret Gianinni, Director for the Office of Disability, U. S. Dept. of Health and Human Services. For registration information, please visit the conference web site at www.fgse.nova.edu/workforce

Monthly State News

West Virginia

A new coalition, the Self-Determination Initiative (SDI) has formed in West Virginia. Visit the WV State Page to learn more. Click on: www.self-determination.com/states/westvirginia/index.html

Wyoming

Crece Palmer and another Wyoming self-advocate, Darin Dungan, have offered to act as contacts for self-determination efforts in their home state. Crece Palmer: Work: 307-766-2787 (Tuesday-Thursday 7:30-12:30), Home: 307-745-3570, Cell- 307-760-4991, E-mail addresses: CPalmer@uwyo.edu or CrececPalmer@yahoo.com Darin Dungan, Work: 307-532-5911, Home Phone: 307-532-4500, Email address:

bdungan@communicomm.com Crece says, "Our state information we got several adults with disabilities who are interested in self-determination and formed a collaboration with the DD Council, Developmental Disabilities Division we will be working on trainings to train our self-advocates, parents, teachers and community members on self-determination. The trainers will be the core group of collaboration." Thank you very much, Crece! We look forward to hearing more about your work. And we hope that this notice will help you be in contact with others, especially those from states with large rural populations.

Michigan - Academy on Self-Determination

In 2003, fifteen people with disabilities, accompanied by their personal and professional support team members, attended a series of two-day and weekend training dates conducted by national and local leaders in the self-determination movement. Sessions were highly individualized and interactive and provided both a foundational knowledge of the concept of self-determination as well as more in-depth information on systems change and utilization. Several sessions included the participation of guest speakers from the Midland area who had achieved self-determination in their lives. On-site visits were also made to local homes and businesses. Each Academy member developed a Person Centered Plan, including a timetable and team member assignments. The individuals enrolled in the Self-Determination Academy were prepared to return to their homes with information and tools to enhance their own self-determination, initiate systems change, and to actively participate in grassroots self-determination efforts in their communities. The grantee for this project is the Arc of Midland, Michigan, Executive Director Jan Lampman. The Academy on Self-Determination is an Enhancement and Mobilization Project, funded by the Michigan Developmental Disabilities Council. Additional support for the 2003 Academy was provided by the Center for Self-Determination, Executive Director Tom Nerney, and Center Associates Pat Carver and Doreen Rosimos. Year 2004 sessions have begun with participants attending from several different regions of the state To read the First Year Report on the Self-Determination Academy click on [www.self-](http://www.self-determination.com/states/michigan/ddcouncil/enhance.html)

[determination.com/states/michigan/ddcouncil/enhance.html](http://www.self-determination.com/states/michigan/ddcouncil/enhance.html) For more information concerning the Academy and registration for upcoming sessions, contact: Jan Lampman, The Arc of Midland 220 West Main, Suite 101, Midland, MI 46640, phone: 989-631-4439, fax: 989-832-5528, Email jlampman@thearcofmidland.org

Managed Care vs. Self-Determination

Sixteen months ago, in October of 2002, the Detroit/ Wayne County Community Mental Health Agency became the first in the nation to switch over its operations to a system of traditional managed care for the delivery of all its services to people with disabilities, people with mental illness and for the treatment of substance abuse. Six Managed Care Provider Networks were formed and all consumers in the region were

enrolled in a network of their choosing. Newspaper articles at the time touted the new system -and Michigan - as both a model and a bellwether for the rest of the nation. Among the more comprehensive and astute assessments of this emerging challenge comes from Norm DeLisle. DeLisle, a long-time advocate in Michigan and the current executive director of the Michigan Disability Rights Coalition, frames the conflict felt by all stakeholders in the human services system in a new presentation entitled, "Person Centered Planning Vs. Managed Care: Walking the Tightrope". He sums up by supporting self-determination and Person Centered Planning as the only ways to meet the growing need for services in an environment of shrinking resources. "How do we marry the unavoidable regulation of managed care and the unstoppable quest for self-determination? Not easily, that's for sure", says Norm. This presentation examines the realities of this struggle and describes tools that can be used to mesh these disparate realities. Aimed at Community Mental Health staff, administrators, and advocates, it is a 3 hour tour of what we face and how, working together, we might support people with disabilities in living their lives the way they see fit. For more information, contact Norm DeLisle at: ndelisle@voyager.net The Disability Rights Coalition maintains "Communities of Power" www.copower.org and several other programs including the Green Initiative (Grass Roots Education and Empowerment Network) and Assistive Technology Projects which provide all aspects of technology access and maintenance for organizations which give priority to projects that work with other groups and systems to impact the greatest number of people through systemic changes in Michigan communities. The Center for Self-Determination Listserv, the FREEDOM List, is provided through collaboration with the Disability Rights Coalition.

All Center members are invited to send us articles which pertain to self-determination efforts in their home states. Please help us develop this valuable resource and keep things up-to-date. Sharing both factual information and analysis on the Center website's State Pages can help others engaged in similar work, whether it is in a different part of your own state or in a different region of our country. Submit articles for the State Pages- or questions you may have-directly to:
kcopeland@twmi.rr.com

Center Newsletter in the Mail

If you have not received your Winter 2004 issue of the Center for Self-Determination newsletter in the mail yet or you want multiple copies for distribution, contact Kris Copeland at kcopeland@twmi.rr.com

New Address and Phone for COA

The Center for Outcome Analysis, Inc., (COA) non-profit firm founded in 1985 to perform evaluation, research, and demonstration projects in the

human services and health care services has moved. The new address is Center for Outcome Analysis, 426B Darby Road, Havertown, PA 19083. The phone number is 610-668-9001, FAX 610-668-9002
www.outcomeanalysis.com COA creates, maintains, and builds capacity for continuous feedback loops between management and customer, by using state of the art quantitative and qualitative information collection methods. For more information contact Jim Conroy at:
JConroyCOA@aol.com

Quote of the Day

"Time is too slow for those who wait, too swift for those who fear, too long for those who grieve, too short for those who rejoice, but for those who love, time is eternity." -Henry Van Dyke