



Alliance for Freedom News

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April 2004 E-Newsletter

Immersion Learning Ship has Come In

The Center for Self-Determination is proud to announce that we have hit full capacity for this year's Immersion Learning about Self-Determination. With the gracious support from the Georgia Governors Council on Developmental Disabilities, the event promises to be precedent-setting within the newly designed Planning Stream and informative and thorough for those who will participate in the Foundation Stream.

We are especially honored this year to welcome Lois Curtis and Elaine Wilson the two ladies who were the plaintiffs in the Olmstead case. Lois and Elaine should help remind us of the meaning of freedom and the restoration of full citizenship as hallmarks of the self-determination movement.

In addition to the participation of state officials like Fred Deconsentis and Shelly Brantley, DD Directors of Colorado and Florida respectively, Shawn Terrell, CMS point person on these issues will serve as a resource consultant and Glen Stanton, who heads the Medicaid Waiver program for CMS, will be available for limited consultation after his presentation. Planning groups with burning questions about Medicaid Waiver interpretations should bring them to Tom Nerney at the start of the Immersion Learning. We will also initiate a learning process with CMS after the meetings are over so that groups and individuals can get quick and accurate responses to questions about Medicaid.

Initial Stats on Atlanta Immersion Learning

25 planning teams from across the country

30 states represented

First year of scholarships awarded to self advocates and parents from seven states including a father and daughter from New Jersey

Key state Medicaid, Developmental Disability and Mental Health officials to participate together with advocates, family members and individuals with disabilities. Four state legislators will participate.

(Note: While all Teams have been formed, individuals may still register to

participate in the Foundation Stream.)

Governor of Georgia

On Thursday April 28, the Governor of Georgia will address the participants of the Immersion Learning about Self-Determination during the luncheon. Governor Sonny Perdue began his public service career in the 1980s when he served on the Houston County (GA) Planning and Zoning Board. He then successfully ran for the state senate and after four years, was selected as majority leader and in 1997 was elected president pro tempore. Perdue campaigned for governor on a platform of restoring public trust in state government and empowering all Georgians. He was elected in November 2002 - the first Republican to serve as Georgia's governor since 1872. Since his election, Perdue has dedicated his administration to attracting new businesses and jobs, improving the quality of programs that touch the lives of children, and fighting for a comprehensive ethics reform package. Governor Perdue supports the concepts of self-determination for people with disabilities and has instructed the Georgia Department of Community Health and Human Resources to develop an initiative to allow people to be more self-determined. At the Immersion Learning event, Governor Perdue will talk about why he supports self-determination. For more information about Governor Sonny Perdue visit <http://gov.state.ga.us/>

Nationally Renowned Expert on Psychiatric Disability Joins Immersion Learning Collaborative

Saturday's plenary session on Psychiatric Disability and Self-Determination will now include Judith A. Cook, Professor of Psychiatry at the University of Illinois at Chicago (UIC). Dr. Cook directs the UIC National Research and Training Center (NRTC) on Psychiatric Disability which is funded for five years to conduct a series of research and training projects addressing self-determination and self-directed services. With staff at the NRTC, Dr. Cook has created a series of self-determination tools in areas such as: talking with mental health care providers, self-directed life planning, choosing a supported employment program, reduction of seclusion and restraint in inpatient settings, community safety for women with mental illness, hiring consumers as direct service providers, and job coaching in psychiatric rehabilitation. She served as expert consultant to the President's New Freedom Commission on Mental Health, and has consulted with numerous federal agencies and administrations including the White House (Clinton and Bush administrations), the Office of the Surgeon General, the Department of Labor, the U.S. Department of Education, the Veteran's Administration, the Centers for Disease Control, Health and Human Services Office of the Inspector General, and the Social Security Administration. Dr. Cook joins panel members Larry Fricks,

Director of the Office of Consumer Relations for the Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases and Shawn Terrell, Technical Advisor for Self Directed programs with Disabled and Elderly Health Programs Group, at the Centers for Medicare and Medicaid Services.

More about Self-Determination and Psychiatric Disability

On March 22nd and 23rd leading psychiatric disability advocates, key program specialists, university contributors and key federal officials met in an "invitational" summit on self-determination in Washington, DC in order to accept recommendations for a behavioral health approach to establishing self-determination within the mental health arena. Center Director Tom Nerney was commissioned to develop one of six invited papers. Tom's paper was on establishing a new foundation for quality in human services. The meeting was sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA) of the federal Department of Health and Human Services. Tom's call in his paper was to establish a new foundation for quality across all disability that rests securely on universal human aspirations, moves from shallow concepts of satisfaction with human services to measuring whether people with disabilities have meaningful lives, and addresses the forced impoverishment of individuals. Tom's paper and several others that firmly endorsed self-determination will soon be available on our web site.

California State Center Contact Addresses Group in NYC

Russ Rankin, Center contact for California, will present findings from his Self-Determination Pilot Project at an Annual International Conference on May 3rd in New York City. Russ and his colleague and Executive Director of the Kern Regional Center, Michal Clark will discuss lessons learned from the experiences in the evolution of the pilot project, the high level of satisfaction reported by participants, and data concerning outcomes, costs, and the challenges in determining individual budgets. Specific challenges in transitioning to the 1115 Waiver will also be examined. For more info contact Russ at rrml@verizon.net

State Info

FLORIDA

Freedom Initiative Director Appointed

Renee Whaley was recently hired by the Florida Freedom Initiative to coordinate and promote the concept of consumer-directed care through the Real Choice Systems Change Grants for Community Living. Ms. Whaley will work with the Center for Self-Determination, Developmental Disabilities Program Office within the Department of Children and

Families, the Florida Developmental Disabilities Council, the Southern Movement for Independence, the Agency for Health Care Administration, the Department of Elder Affairs, and the Department of Health. Renee Whaley has spent 25 years in Human services. The driving force behind all her work was the diagnosis of her only son with autism. Like many activists, she began in the parent movement as a volunteer. She participated in the founding of Arizona's Parent Training and Information Center (Pilot Parent, Inc.) She utilized the traditional grassroots tools including grant writing literally at her kitchen counter. Ultimately, she became the Training Director. While in Arizona, she served on multiple appointed governance and advisory committees and boards to include the Arizona Developmental Disabilities Council during the period when Arizona was among the last states to become part of the Medicaid system. Her formal education is Economic, but her true education is a lifetime of working with families as she also experienced the same barriers, frustration and successes. "Experience is a great teacher; Experience with a vested interest is a far more effective teacher," states Renee.

Her family relocated in Florida. The next fourteen years she worked with Family Network on Disability. She became the Parent Education Network Director. During this time, she served on a number of statewide boards and advisories to include projects as diverse as Florida State Advisory Committee (SAC), Florida State Positive Behavior Support Team, Center for Autism and Related Disability Board (CARD), and the Florida Alliance for Assistance Services and Technology (FAAST) Renee has spent long enough in the field to work with a group of students who have now graduated to life after school. She is quick to say, "This is a wonderful opportunity to assist those persons with disabilities who became adults without the benefit of an appropriate education or real opportunities and to also assist those individuals for whom we have created the expectation that everyone is absolutely entitled to a meaningful life that must happen."

New Director for Southern Movement for Independence

Center Consultant Denise Payne has been hired as the Executive Director of the Southern Movement for Independence (SMI).

<http://southernmovement.org/index.cfm> As an organization run by and for persons with developmental disabilities in Florida, SMI is sponsored by United States Department of Health and Human Services Administration on Developmental Disabilities and the Florida Developmental Disabilities Council, Inc. and is dedicated to promoting the self-determination of individuals with developmental disabilities Ms. Payne will present in the Foundation Stream and serve as a Resource Consultant in the Planning Stream at the Immersion Learning in Atlanta.

TEXAS

Center Executive Director Tom Nerney will facilitate an extensive meeting of the Texas Self-Determination Policy Planning Team in the state capital of Austin on April 15, 2004. Sponsored by Texas Council on Developmental Disabilities, the Arc of Texas and Texas Center for Disability Studies the meeting agenda includes close examination of the vision, guiding principles, current programs, opportunities and challenges in Texas. Approximately 2/3 of this team will travel to Atlanta to continue developing goals, defining outcomes and honoring the states growing commitment to self-determination at the Immersion Learning Conference. The next day April 16, the Arc of Texas will host its 2004 Bi-Annual Conference with Tom Nerney delivering the keynote titled What is Self-Determination?

http://www.thearcoftexas.org/Conferences/Arc_Conference/2004Conf.html

According to the conference promo the answer to Tom's question is -"It's the common thread that runs through the entire human race... "The flyer goes on to read "We all have wants and needs, hopes and dreams. Whether rich or poor, young or old, black or white, with disabilities or without, we all desire to grow and change and reinvent ourselves. The Arc of Texas believes that all people have the right to choose where they will live, how they will live their lives and with whom they will share them. They have both the right and the responsibility to use their lives to contribute to their communities in meaningful ways. Self-determination is possibly the best tool to help us all move toward making our dreams a reality."

ALABAMA

After four weekend learning sessions last year conducted by the Center and organized by Pat Carver with the Alabama Developmental Disabilities Planning Council, over 25 individuals came together several weeks ago to begin pre-planning for the Atlanta Immersion Learning. The Alabama Council brought together a wonderfully diverse group of state officials, including the state Medicaid office, the Attorney General's office, the Ticket to Work consortium (to mention just a few) who together with parent representatives and individuals with disabilities engaged in an extensive discussion with Center representatives in order to better prepare for the time in Atlanta. All of this work has been done under the leadership of the Alabama Developmental Disabilities Council with Elmyra Jones as the new Executive Director.

NEBRASKA

Center for Self-Determination Consultants Vickie Vining will join Center President Kathleen Harris and Center Treasurer Dohn Hoyle as presenters at the Nebraska Sharing Our Best Conference on April 20.

<http://www.hhs.state.ne.us/dip/ded/04regbook.doc>

Sponsored by Nebraska's Health and Human Services System and hosted by the Beatrice State Developmental Center, the conference aims to provide current and diverse information and support for those working in

the field of developmental disabilities.

Vickie's session *Regular Lives: Self-Determination and Person-Centered Services* will look at how services for people with developmental disabilities have changed over time and how the service system is moving to helping people have regular lives like other people in the community. Additionally, the principles and practices of self-determination, and the role of person-centered planning in making services relevant to people's own vision for their lives will be presented.

The presentation by Kathleen N. Harris, M.S.W., J.D. (Attorney at law), and Dohn Hoyle, President and CEO of the Association for Community Advocacy, titled *Mission Impossible: Guardianship and Self-Determination*, explores guardianship as the legal removal of a person's basic civil and legal rights and which minimizes personal autonomy and respect for the individual. As such, it is fraught with potential for abuse and misuse. Alternatives to this legal device will be explored in depth, including person-centered planning, family consent statutes and policies, powers of attorney, trust arrangements, and others. Potential legislative problems and solutions will be addressed as ways to minimize the use of guardianship. For more information about this issue visit <http://www.self-determination.com/publications/summernews2003.pdf>

MICHIGAN

As a part of the Rethinking Quality project supported by the Michigan Developmental Disabilities Council, focused interviews were conducted by the Center for Outcome Analysis in three Michigan communities April 5-8. Persons with disabilities gathered near Detroit, in the rural western county of Allegan and in the northern community of Gaylord to complete private interviews about one's own life, and then, in a group, tell about what they thought was right and wrong about the interviews. These test drafts led to actively fine tuning the survey instruments to uncover outcome-based quality standards that are derived from and therefore normed on universal human aspirations. This is a change from current quality assurances programs that evaluate services, not lives.

The categories, modeled after the individual budget template in *The Promise of Freedom* (see next article) hold universality and practicality and are intended only as a foundation for quality standards based on universal human aspirations. Rethinking quality in these new ways may help move the service system away from the "old" ways and toward new and better ways.

Sharing the written report of what has been learned and what was found about Michigan citizens with developmental disabilities and quality of life is the next step for this important project. Center staff are taking the lead in preparing this important monograph.

Guaranteeing the Promise of Freedom through Redefining Quality and Creative Individual Budgeting is available for sale!

This handbook is designed to be used as a guide to individual budgeting. Written in easy-to-understand language with six handy templates and accompanying keys that explain the meaning of certain line items, the guidebook offers basic direction in how to adopt a new tool for planning and budgeting simultaneously.

Guaranteeing the Promise incorporates new planning assumptions about living in one's own home and generating income; getting better connected to one's community; and, facilitating relationships. All of these concepts are laid out in a budget template that can be modified according to local custom for the system and then modified for each individual based on dreams, desires and ambitions that are personal. There are many blank line items acknowledging the uniqueness of every individual. To order copies visit <http://www.self-determination.com/pdf/guidebookad2.pdf>

Guaranteeing the Promise of Freedom through redefining quality and creative Individual Budgeting is best used in conjunction with the Center for Self-Determination two-day individual budget learning opportunity.

"Train-the-Trainer" based on Guaranteeing the Promise of Freedom will be held June 23-25 2004 in Midland, Michigan for selected individuals. To obtain an application to attend this limited opportunity with the Center for Self Determination, contact Pat Carver at pcarver@chartermi.net .

Quote of the Day

Experience is a great teacher; Experience with a vested interest is a far more effective teacher. - Rene Whaley

Coming Soon!

Watch for subscription information and archived issues of the Center for Self-Determination E-Newsletter: www.self-determination.com

Questions? To subscribe now: kcopeland@twmi.rr.com