



# Alliance for Freedom News

August 2004

Volume 1, Issue 10

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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

### **Rethinking Rehabilitation: Freedom**

A new paper by Patricia Deegan about a not so new concept has been added to the Center for Self-Determination website. *"Those of us with disabilities are too often forbidden our freedom to be and our freedom to become,"* says Dr. Deegan in this paper presented in Oslo, Norway at the 20th World Congress of Rehabilitation International. Deegan contends that life lived within the confines of the human and rehabilitation services is a life in which the freedom simply to be is diminished. Rejecting this loss of freedom is acknowledged silently, yet quite strongly, into a shared scream. Witness the scream as you read this powerful and moving account of what it means to live a life of forbidden being and why it is imperative that we not only re-think rehabilitation, but we reform systems that maintain it. [www.self-determination.com/pdf/rethinkingRehab.pdf](http://www.self-determination.com/pdf/rethinkingRehab.pdf)

Pat Deegan & Associates, LLC is a consumer/survivor/ex-patient run organization. [www.patdeegan.com](http://www.patdeegan.com)

### **National Down Syndrome Congress (NDSC) hears Promise of Self-Determination in Minneapolis**

At the 32nd annual convention of the NDSC, two new Center budget trainers will be joining Center Communications Coordinator Pat Carver to present "**Guaranteeing the Promise of Freedom through Redefining Quality and Creative Individual Budgeting**" at a special pre-conference session on Friday August 20. Angela Martin, Community Support Specialist from the Developmental Disabilities Institute at Wayne State University in Detroit and Tammy Finn, Self Determination Facilitator at MOKA, an agency serving persons with disabilities in a ten county area in western Michigan will be addressing this crowd of parents and family members of individuals with Down syndrome, self-advocates and other individuals involved with people with Down syndrome. These Center trainers have families that include members with disabilities and Mrs. Finn's daughter has Down syndrome. The purpose of the NDSC is to promote the interests of persons with Down syndrome and their families through advocacy, public awareness, and information dissemination on all aspects of Down syndrome. [www.ndsccenter.org](http://www.ndsccenter.org)

## News from Self-Determination.com

### **Pat Carver to Moderate Center Listserv**

On August 1, 2004, 2004 Pat Carver joined Tom Nerney as a moderator of the Center's ALLIANCE FOR **FREEDOM** listserv. This list is in place to host invigorating national discussion concerning the many facets of the movement for self-determination. The Center for Self-Determination is committed to provide a meeting ground for all those who seek to share in this important work. If you have any questions please feel free to contact Pat at [pocarver@chartermi.net](mailto:pocarver@chartermi.net) or Tom Nerney at [tomnerney@earthlink.net](mailto:tomnerney@earthlink.net)

**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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**Declaration of  
Freedom**

### **Lost Lives: Why We Need a New Approach to Quality**

In this thought-provoking paper, Tom Nerney proposes that the purpose of public funding must move to a more noble goal of assisting individuals achieve lives of high purpose deeply embedded in their communities, engaged in meaningful relationships and pursuing both economic and spiritual goals. [www.self-determination.com/pdf/lost\\_lives.pdf](http://www.self-determination.com/pdf/lost_lives.pdf)

### **Watch for Principles for Evaluating Your System**

A new simple tool for assessing whether a human service system is implementing self-determination will be available from the Center's website in September. Organized from three perspectives, the instrument illustrates:

1) what the individual with a disability can and should expect; 2) what a family can and should expect, and 3) what the system should offer.

This PowerPoint presentation will be available for downloading as a part of the Center's desire to make useful materials available to anyone who wants or needs accurate information about self-determination.

## **Self-Determination State Sites**

### **Arkansas Collaboration Addresses Guardianship**

Center for Self-Determination President Kathleen Harris, Esq, will present on Alternatives to Guardianship in Little Rock at the AARP headquarters September 14. [www.self-determination.com/states/arkansas/index.html](http://www.self-determination.com/states/arkansas/index.html)

This event is sponsored by a unique partnership of the Arkansas Chapter of the AARP and the Independent Living Council (CIL). Both AARP and CIL promote independence and work to enhance quality of life. For more information on alternatives to guardianship visit: [www.self-determination.com/publications/guardreform.html](http://www.self-determination.com/publications/guardreform.html)

### **Florida includes Self-Determination in Leadership Development**

On August 13, Center consultant Beth Spinning will conduct the session on Self-Determination for the Florida Partners in Policymaking 2004. Partners is an innovative, competency based leadership-training program for adults with disabilities and parents of young children with developmental disabilities. The purpose of the program is twofold: To teach best practices in disability, and the competencies necessary to influence public officials. For more information visit [www.partnersinpolicymaking.com](http://www.partnersinpolicymaking.com)

Spinning is the program manager for the Georgia Governor's Council on Developmental Disabilities and has successfully promoted self-determination in a variety of ways in the Southern United States. She recently completed the Center for Self-Determination's budget training course- Guaranteeing the Promise of Freedom through Redefining Quality and Creative Individual Budgeting. [www.self-determination.com/consulting/individual\\_budget.html](http://www.self-determination.com/consulting/individual_budget.html)

### **Ohio Sponsors Immersion Learning**

In Akron, Ohio on September 14 & 15, the Self-Determination Association and The Ohio Association of Adult Services - Ohio Department of MRDD, in partnership with the Center for Self-Determination will present a two-day, two-track training. Based on the Center's immersion learning opportunities and featuring Center consultants from California, Michigan, New Hampshire and Wisconsin, participants can choose between a curriculum highlighting the fundamentals of self-determination or a more in-depth examination of the administrative issues within self-determination and individualized funding.

For more information phone: 740-965-9822 or e-mail: [ohiosda@earthlink.net](mailto:ohiosda@earthlink.net)

*Freedom is what you do with what's been done to you.*

**Sartre**

**Promise of Freedom**

*True individual freedom cannot exist without economic security and independence.*

**FDR**

**Alliance for Freedom Fund**

**Pennsylvania- First Microboards Formed**

Paul Saulino of Networks for Training and Development, Inc. (Networks) in Valley Forge, PA, recently reported that the first two microboards in Pennsylvania have incorporated. Microboards are legal entities which are empowered to direct and manage the legal and financial affairs of people with disabilities. Members of their boards of directors are typically family and friends and interested others who have a concern for the welfare of the person with a disability around whom the microboard has been formed. [www.self-determination.com/publications/microboard.html](http://www.self-determination.com/publications/microboard.html)

The concept has been discussed and employed as an option for self-direction for over a decade now. It is not a common practice, although it is becoming more well known. These microboards developed as part of the "All Our Own" project, which is funded by the Delaware County Office of Mental Retardation through a grant from the County Commissioners' Association of Pennsylvania.

For more info, visit: [www.networksfortraining.org](http://www.networksfortraining.org)

Or call Paul at (610) 935-6627

**Tennessee - Good News for Ruthie-Marie Beckwith**

Ruthie Marie Beckwith and Tony Records are assuming responsibility for Tennessee's Self-Determination project. Established five years ago as part of an Agreed Order between the State of Tennessee and plaintiffs in the Dept. of Justice v. Arlington Developmental Center, the project will be now done in collaboration with state policymakers who are currently at work on a Self-Determination Waiver for individuals on Tennessee's waiting lists for Home and Community Based Services. Next month Center consultants Jan Lampman and Carol Wallace will be assisting the Tennessee project in reviewing and revising individual budget procedures.

Further good news from Tennessee is the marriage announcement of Ruthie-Marie and long-time advocate and People First supporter Mark Friedman. Share in the congratulations by contacting Ruthie at [empfanatic@aol.com](mailto:empfanatic@aol.com)

**New Mexico Has Two New State Contacts**

**Priscilla Salinas** is a parent of a 16 year old, lives in the southern part of the state, understands the Hispanic culture, is involved in community building through the Arc of New Mexico, and promotes transition of students in the schools. [psalinas@arcnm.org](mailto:psalinas@arcnm.org)

**Lester Kien** lives near Gallup in the western part of the state, has been a direct care staff person for a local provider, is an activist who supports self-advocates, knows the native American culture - particularly Navajo, and serves on the Statewide Adult Services Task Force and the board of the Arc of New Mexico. [blukind@yahoo.com](mailto:blukind@yahoo.com)

State contacts are Center members who serve as sources of information and support for citizens in their state looking for assistance concerning self-determination. If you live in New Mexico, feel free to notify the new state contacts listed above with news about self-determination. Mike Allen, also a New Mexico State Contact, joined the Center staff last month as information coordinator for the Western States (Missouri not Mississippi) see story in July e-newsletter [www.self-determination.com/publications/eneews/archive.html#news](http://www.self-determination.com/publications/eneews/archive.html#news) and email Mike

[mikepatallen@earthlink.net](mailto:mikepatallen@earthlink.net)

**California Self-Determination Pilot Projects**

*By Russ Rankin - California State Contact*

California has had five Self-Determination pilot projects operating since 1998 serving 150 of the 200,000 Regional Center clients with developmental disabilities in California. The

*Freedom is not something that anybody can be given. Freedom is something people take, and people are as free as they want to be.*

*James Baldwin*

**Alliance for Freedom**  
(coming soon)

*It is possible to read the history of this country as one long struggle to extend the liberties established in our Constitution to everyone in America.*  
*Molly Ivins*

original pilots were created via California Senate Bill 1038 and designed to measure how Self-Determination and self-directed services might work in California. See California Pilot Projects Background Information, [www.dds.cahwnet.gov](http://www.dds.cahwnet.gov)

The five pilots include:

Eastern Los Angeles Regional Center [www.elarc.org](http://www.elarc.org)

Kern Regional Center [www.kernrc.org](http://www.kernrc.org)

Redwood Coast Regional Center [www.redwoodcoastrc.org](http://www.redwoodcoastrc.org)

San Diego Regional Center [www.sdrc.org](http://www.sdrc.org)

Tri-Counties Regional Center [www.tri-counties.org](http://www.tri-counties.org)

The pilots are funded through the California Department of Developmental Services (DDS) [www.dds.cahwnet.gov](http://www.dds.cahwnet.gov)

Each Regional Center designed their own pilot with informal guidance from the Robert Wood Johnson Foundation Self-Determination initiatives, Tom Nerney, and the Center for Self-Determination. Each pilot supports the Principles of Self-Determination: Freedom, Authority, Support, Responsibility, and Confirmation. Each pilot participant has a Person Centered Plan, Broker, and Fiscal Intermediary. In some of the pilots, Regional Center staff provide the Broker and Fiscal Intermediary services. The five pilots report a high level of satisfaction and recommend that Self-Determination continue in California, See "A Report to the Legislature," May 17, 2002, [www.dds.cahwnet.gov](http://www.dds.cahwnet.gov)

California is currently in the process of applying to CMS for a 1915(C) waiver for Self-Determination services.

Redwood Coast Regional Center was recently awarded a grant from the California State Council on Developmental Disabilities for "Project LEADERS: (Learning, Educating, Advocating, and Directing Efforts for Responsible Self-Determination). For more information on the grant contact Pam Jensen at Redwood Coast Regional Center at [pjensen@redwoodcoastrc.org](mailto:pjensen@redwoodcoastrc.org) or (707) 462-3832 x 265.

Submitted by Russell Rankin, Pilot Coordinator, Kern Regional Center [rrml@gte.net](mailto:rrml@gte.net) or (909) 336-6730

## **Updates and Announcements**

### **Training Administrative Assistant**

Louise Dennis has joined the Center staff as Administrative Assistant for Training. Following Louise's first-rate assistance during the Atlanta Immersion Learning, we knew we could not let her go. In a newly created position, her responsibilities are to organize Center training opportunities. Louise lives in Powder Springs Georgia and can be reached at: [lfdenis@ngcsu.edu](mailto:lfdenis@ngcsu.edu)

Please contact her to arrange Center learning opportunities for your advocacy organization, policymakers, provider agencies etc.

### **Center for Self-Determination Supports "Terri's Law"**

A coalition of national disability rights groups, including the Center for Self-Determination, has joined in a friend of the court brief which is seeking to overturn a Florida judge's ruling that "Terri's Law" is unconstitutional. The Florida Supreme Court has agreed to take the

case and oral arguments are scheduled to begin on Aug. 31. *"This case reflects whether our society and legal system value the lives of people with disabilities equally to those without disabilities,"* says the lead attorney. The lead plaintiff among the disability groups is Not Dead Yet, an organization founded as a response to the 'right to die movement' and opposes legalized assisted suicide and euthanasia. [www.notdeadyet.org](http://www.notdeadyet.org)

For more information on the legal issues and human struggles surrounding this case, visit the website of the Terri Schindler-Schiavo Foundation. [www.terrisfight.org/](http://www.terrisfight.org/)

### **Sprechen zie Self-Determination (in Deutsch)?**

Ulrike Gritsch recently contacted the Center to let us know of a new self-advocates group, which has been formed in Germany. Ulrike and colleagues have also translated some of Tom Nerney's writings into German. To visit their homepage and view the German translation of 'Our Declaration of Freedom': [www.selbstbestimmt-leben.net/wibs/index.php?content=Standpunkte](http://www.selbstbestimmt-leben.net/wibs/index.php?content=Standpunkte)

## **Closing Quote**

*"Is Freedom Anything Else Than Living How We Choose?"*

**Epictetus** - Roman Philosopher