

Reflections On Full Participation

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By Tom Nerney

The aftermath of "The Alliance for Full Participation" deserves some reflection and commentary. The Center issued a widely distributed statement that asked for planned questions about attendee beliefs in full participation for persons with disabilities be turned into an affirmation of the fundamental right to participate fully, control the dollars in the human service system, as well as the freedom to work. Led by SABE and a vast majority of attendees with integrity and goodwill these issues were swiftly affirmed.

My reflections were then and are now from a distance. My initial anger has turned more to sadness. What may mark this pivotal meeting of so many professional and provider organizations is characterized more by lost opportunities and the failure to adopt bold strategies. Yet, I think if we see this meeting in a wider historical context we can all learn without painting with so wide a brush as to call into question the motivation of so many decent people.

I think it is important to reflect on how we use the word truth. In the context of this discussion it can take three forms. I was struck recently by the first form. The Rhode Island Supreme Court ruled in a case that attracted national attention involving fact-based truth. In that case a man who was adopted and now a practicing Mormon argued that he was entitled to obtain the name of his birth mother based on the teachings of Mormonism. The justices rejected his argument ruling instead for the higher value of confidentiality given to his birth mother and relied in part on what they called the "wisdom" of a 19th century opinion from the English Court of Chancery: "Truth, like all other good things, may be loved unwisely, may be purchased too keenly, may cost too much." This court was clearly saying that when **my truth impacts your truth there may be limits**. Even with regard to facts.

It seems to me that what some are referring to is the second form value-based truth. In many ways these truths are even more important to all of us personally. It is helpful to be reminded of its importance and the richness and variety of these personal truths. But, Marsha Katz from ADAPT got it precisely right when she said on the Alliance for Freedom and other list serves that she had no obligation to honor truths that potentially denied a huge segment of the population full citizenship. It would also be hard to argue that the voices of those uninvited and absent from this meeting with all their "great variety and the richness and strength that come with it"

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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

were intended to be heard at all.

But even more important is a third kind of truth. These are the unarticulated truths that may simply be too difficult to acknowledge. This meeting could be described as the provider and professional organizations in the field of developmental disabilities circling the wagons in a time of real trepidation. I thought hard of who was present, who was invited and not and who was absent. The context for these reflections was provided by the two bookends to this meeting. The Alliance for Full Participation started just as ADAPT was finishing another "in your face" Washington series of protests on what they justifiably call life and death issues. Arriving just following the Alliance are the members of Not Dead Yet for the Supreme Court hearing on whether or not (to put one clear interpretation on it) people with disabilities are entitled to the same services the general population receives from suicide prevention programs.

The context for me was stark. None of these groups and as far as I know (with the exception of SABE) none of the signatories to the Not Yet Dead brief were invited to present at the Alliance for Full Participation. Were these life and death issues not important enough to merit major discussion in a forum dedicated to fostering policy and practice for the foreseeable future?

Absent were the voices of so many leaders with disabilities from many organizations with much to contribute. Absent were the voices from grassroots parent groups. On the political level absent were representatives from the Congress and key administration officials. In this time of increasingly scarce resources where was the dialogue between disability representatives and Medicaid and Social Security officials?

An Alliance Medicaid policy statement was developed just for individuals with developmental disabilities. This ignores the reality of state Medicaid budgets where nursing home beds consume a disproportionate share of long term care dollars. And of course, missing from the program altogether, was one of the central ethical issues confronting all of us: a disproportionate share of Medicaid long term care dollars is directed to the population of individuals with developmental disabilities in spite of the fact that tens of thousands of these individuals remain un-served. At what point in this crisis of funding and misplaced priorities do we raise the question of equity across all disabilities?

Absent were any representatives from the many self-determination sites around the country who represent some of the most innovative systems-change efforts of the past ten years. New partnerships have emerged in critical counties that are demonstrating that the system can change (albeit slowly) and that individuals with disabilities can not only contribute but provide leadership in partnership with courageous professionals, dedicated workers and ordinary community members.

Not absent were corporate sponsors.

in a newly designed system

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And so, some truths remain unspoken.

Until we all recognize what leaders with disabilities have been saying about our common humanity and aspirations, until we recognize that we all share the same common grounding in what it means to be a citizen and fully experience the life of our communities as free men and women, then we will continually deny the promise of full participation to individuals who experience disability. We can only hope that the richness of this kind of common vision is a more powerful truth.

TASH-a common experience of belief

The [TASH Conference](#) always mobilizes vast numbers of folks from around the world together in a common experience of belief -- a belief in the presumed competence of every person, and in the powerful role that every person can play in empowering people with

disabilities and their families to build the life of their choosing. This year marks the 30th invigorating TASH conference in Milwaukee November 9-12, features 450 breakout sessions, exhibits, roundtable discussions, poster sessions and much more.

The Center is participating in this notable event by co-sponsoring a full day symposium on the **Re-Affirmation of Community**, coordinating the strand of sessions concerning self-determination, hosting an exhibit booth and assisting with the silent auction.

On November 9 at the **Re-Affirmation of Community** symposium, Jody Kretzmann from the Asset-Based Community Development (ABCD) Institute, with several Center for Self-Determination Resource Guides will look at the strengths of the individual and family, the community, and the paid systems. Together we will reflect how to shrink the latter and increase the importance of the former.

The original monograph -- [The Affirmation of Community](#) -- clearly states that the ultimate outcome of self-determination is having a meaningful life in the community.

Join once again to challenge our very concept of the meaning of community and to issue a Re-Affirmation of Community. For more information visit [Tash 2005 Symposium](#). If you will be attending the Milwaukee conference and want to assist with these activities- contact [Pat Carver](#) .

Self-Determination State Sites

Arkansas

- Arkansas on the Move

The Self-Directed Waiver (SDW) Committee made up of family members, self-advocates, waiver services providers, DDS administrators and Medicaid representatives has recommended to amend the Arkansas Alternative Community Services (ACS) Home and Community Based Services (H&CBS) Waiver instead of an Independence Plus application. The committee wanted parity across the board for all waiver users, so instead of having a separate waiver that would allow only so many people to have self-direction due to the limited amount of slots, they included the self-directed option into the traditional waiver. To read about the options at [Arkansas Waiver](#) on the What's Happening page. Straightforward training about Waiver revisions, self-directed options, and direct support personnel was conducted this summer by Center Resource Guides Dennis Harkins and Peter Leidy. More about [Arkansas](#).

Florida

- The Florida Freedom Initiative

Individuals in the Miami and Broward areas have been working on updating their plans for their lives, including finding ways to earn income and become more financially independent. The project is awaiting word from CMS on the changes to the Medicaid Waiver to allow people more freedom to purchase supports that will lead to greater self-sufficiency. They are also still seeking banking resources and matching funds for FFI Freedom Account deposits. The first individuals will be enrolled in the FFI by October 1, 2005, in the Miami and Broward areas. The project will be extended to the additional areas of Tampa, Orlando and West Palm Beach in the coming months.

- INCLUSION MATTERS!

The Center assisted TASH in hosting the INCLUSION MATTERS conference of the Florida Developmental Disabilities Council Task Force on Community Living and Service Coordination. Close to 500 participants at the three-day event enjoyed a relaxing yet motivating event, that ensured that they not only return home with enhanced knowledge and skills for change, but with new ideas of what is possible for everyone. Each day was structured with a keynote event, breakout sessions, opportunities to network, and access to table top exhibits.

Georgia

- Georgia Independence Plus Initiative

The Center is partnering with the Georgia Governor's Council on Developmental Disabilities and the Department of Human Resources, Office of Developmental Disabilities on statewide self-determination training. Visit the [Georgia](#) state page.

Michigan

- LEARN IT. EARN IT. In Michigan

Community Living Services, the Center for Self-Determination and the Washtenaw County Community Support & Treatment Services is hosting a money-making business seminar. The conference will focus on starting a small business, working with banks, and marketing products and services. This one-day event is specifically designed for students in the "transition" from school to work. Presenting is David Hammis of [Griffin-Hammis Associates, LLC](#) a full service consultancy specializing in developing communities of economic cooperation.

New Mexico

- New Mexico Self-Directed Waiver Concept Paper

State Contact Michael Allen reports that the Concept Paper for the Mi Via Self-Directed Waiver on the New Mexico Human Services Department website can be view at the [New Mexico](#) Human Services site. Click on Self-Directed Waiver Program. According to Allen, "the interagency design process was totally inclusive and open to everyone's input".

Ohio

- Power of the People - October 25 & 26 in Ohio

This unusual opportunity for Ohioans involved in self determination is designed for self-advocates, staff, family members and experts from across the country to renew efforts in support of individuals with developmental disabilities. Center Resource Pat Carver will offer a keynote address at Power of the People Conference of the Ohio Self Determination Association. Visit the [Power of the People](#) Registration for more information.

Kentucky

- Paradigm Shifts Discussed in Kentucky

The [Kentucky Developmental Disabilities Council](#) with Center Resource Guides sponsored "Forum on the Consumer Direction Option" last week. Designed to highlight providers, the Forum explored the many ways providers of the future

respect self-determination.

Texas

- Self-Determination for Texas

Because of a Center project, local groups in Longview, Lubbock, Plano and Alvin have been meeting to learn more about how individuals receiving support in their area can gain more control of their lives by having more authority over their plan for their life and their support resources. A small number of individuals in each of those areas has volunteered to use their life experiences as a learning process for understanding how the current system can support self-determination and for identifying where barriers to self-determination exist that need to be addressed. Visit [Imagine Enterprise](#) for more info.

Wisconsin

- The Western Wisconsin Alliance for Self-Determination

Advocates have organized their commitment to ensuring that people with disabilities and their family members are given a full voice in creating a meaningful and successful life within Western Wisconsin communities. As a part of the Centers ALLIANCE for FREEDOM, The [Western Wisconsin Alliance for Self-Determination](#) mission is to serve as a networking and educational resource for people wanting to learn more about local grassroots politics and the Self-Determination movement.

Updates and Announcements

We Had A Dream: Now We Have The Power!

2006 National Self Advocacy Conference is May 25-28 Atlanta, Georgia. [Register now!](#)

Oct. 5th Disability Rights Rally

People with disabilities will make a big first impression on the "new" U.S. Supreme Court during oral arguments in two major disability cases scheduled for October 5th, 2005: [Gonzales v. Oregon \(assisted suicide\)](#) and [Schaffer v. Weast](#) (burden of proof in education).

Supporting the Promise of Freedom: The New Broker

Forty individuals from across the nation gathered in Midland, Michigan this summer to become Resource Guides for the Center for Self-Determination New Broker education effort. Watch for complete information about this effort in next issue of this newsletter!

Thanks to Lindsay Exhibit Groups

Sincere appreciate for tangible support goes [Lindsay Exhibits](#) The Center's display at the Summit of the Alliance for Full Participation (see lead story) was donated by this dynamic supplier of trade show exhibits, graphics, and marketing communications materials. Tracey Lindsay is a Partners in Policymaking graduate.

Closing Quote

"Demonstrate What You Advocate."

- Marsha Katz, ADAPT Montana, People First Missoula, The Rural Institute