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# **Organizing A Movement**

*by Dennis Harkins*

## **Preface**

The following outline is written in hopes of generating discussion and encouraging action. Its genesis was a discussion of grassroots organizing that emerged during a Self-Determination Immersion Learning event last April in Nevada. Participants in that event from across the country identified a need to find ways to come together within their communities, their states, and across the country to create needed changes in their agencies, communities, and service systems based upon the idea and principles of self-determination. For the sole purpose of furthering and widening that discussion, this paper attempts to sketch an outline of how we might create and sustain a movement among people with disabilities, families and other allies in support of self-determination.

## **Organizing a Movement and Supporting Leadership for Self-Determination**

There is a long history of accumulated learning and successful organizing on issues concerning human and civil rights, labor conditions and wages, environmental protection, peace, and a host of other social concerns. A major thrust of organizing in the 20<sup>th</sup> century may be briefly characterized by the following paragraph from the Midwest Academy manual, *Organizing for Social Change*:

The people with the problem organize. They agree on a solution that meets their needs and with the strength of their numbers, pressure the politicians and officials responsible. The people directly affected by the problem take action to solve it.

Leadership throughout history and including the 20<sup>th</sup> century, has primarily been viewed as the province of individuals who wield power through positions of authority as monarchs, generals, popes, elected officials, CEOs and the like; or individuals with vision and charisma. On rare occasions people in positions of authority have acted with vision and charisma, and are generally perceived as our "great leaders" in history.

As we work towards reforming the system of services to people with developmental disabilities, we will continue to utilize strategies, tactics and skills that have led to successful organizing for social change. We will continue to seek to influence the behavior of those with power and authority, and to cultivate leadership among those without it. And, we will draw upon promising new approaches to organizing and leadership development.

The following brief reflections suggest an evolving model of organizing and of leadership development in support of self-determination for people with developmental disabilities. The most significant features of this emerging set of activities are:

- The intentional linking of organizing for social change with a more inclusive understanding of leadership as two necessary elements of change strategy;
- Including, but adding to historic approaches to effective organizing and leadership;
- Expanding who is included in both organizing and leadership, specifically:
  - For organizing, the focus on who to organize goes beyond "... the people with the problem" and includes from the start families of people with developmental disabilities; paid and unpaid advocates; service providers; other organizations and individuals; and when possible public agencies responsible for the administration of services;
  - For leadership, the focus is on leadership as a verb as well as a noun, and upon a definition of leadership proposed by Margaret Wheatley as "... anyone who wants to help at this time;" and
- Defining the "help that is needed at this time" as what is needed to transform our system to enable people with disabilities who rely upon services to experience self-determination in their lives. *Self-determination in this context is defined as assisting people who receive support from the human services system to compose their own lives, in the company of others they care about, in the company of others who care about them.* The changes needed are based upon four primary principles:
  - Freedom of individuals to choose where and with whom they will live as well as what important things they will do with their lives;
  - Authority of individuals over a targeted amount of dollars sufficient to provide necessary supports;
  - Support that is individually designed to meet the unique needs of the individual with a disability and support from freely chosen family and friends in obtaining and monitoring this support;
  - Responsibility for the wise use of public dollars and for exercising the benefits of citizenship.

In practical terms, this model of organizing and leadership development on behalf of organizing to support self-determination requires support for learning and sharing both old and new skills. Such activities include:

- Seeking immediate, concrete changes in people's lives;
- Assisting the many people who have not viewed themselves as leaders and powerful agents of social change to view themselves as such;
- Supporting people as they begin to act as leaders and change agents;

- A particular focus upon supporting people with disabilities as leaders and change agents;
- Negotiating the currently unequal power relationships among various elements and individuals who would compose local, state, and national coalitions for self-determination;
- Willingness and capacity to invoke historically successful political and advocacy strategies to oppose policies, procedures and behaviors which segregate, isolate and disempower people who rely upon the system for support;
- Willingness and capacity to engage in the long term changes needed to strengthen relationships within communities and change community attitudes;
- Recruiting people to be involved in activities that focus on learning and long term change, including changes in culture and community;
- Providing opportunities to learn new ways to organize and to lead; and
- Creating connections among circles of leaders locally, statewide, and across the country.

This is an ambitious list of activities, with obvious inherent challenges. Should the potential "targets" of change be able to serve as members of the coalition? Is there sufficient focus on making an immediate difference in people's lives? Can a social change movement be sustained without a better defined "target" to oppose and around which to organize? How does a coalition organize with leadership shared among virtually all members? And perhaps the biggest question, why proceed with such an approach?

There would appear to be several reasons to proceed:

- Despite the reforms in services to people with disabilities over the past 35 and more years, the overall pattern of services funded by \$30 billion of tax revenues remains rooted primarily in services that segregate and exclude people from community life; that contribute to keeping people in a life of poverty; and that arbitrarily restrict the capacity of individuals and families to compose typical and reasonable lives when they are dependent, at least in part, upon public funding.
- Current pressure for change towards community membership and self-determination is balanced by growing pressure in many states towards maintaining or increasing segregated services.
- What we have been doing to create needed social change in services to people with developmental disabilities over the past 35 years has been successful in many ways, but clearly insufficient in many others. Organizing around the idea and principles of self-determination has the potential to accelerate both the pace and the depth of needed change.
- Organizing and leadership based upon the principle of "The people with the problem organize..." fails to openly take into consideration both the historic social rejection and powerlessness of most people with cognitive disabilities who have needed assistance, and the challenges to organizing and leadership presented by many people's cognitive impairments.

*This is a critical area of discussion that should not be misunderstood to suggest that people with cognitive disabilities are not capable of exercising leadership in creating the changes needed for self-determination to become a reality.* It seems important, however, to discuss the reality that the aspect of cognitive impairment is a dimension that needs to be addressed in supporting the leadership of individuals with cognitive disabilities within this social change movement.

- More so than in most (but by no means all) past successful social movements, "the people with the problem" *begin* this movement with many important and necessary allies. These allies typically include families, and also many individuals who have assumed paid positions as advocates, service providers, and government officials. There are obvious problems associated with each of these "groups" and individuals within them in terms of both their greater historical power than "the people with the problem" and the many ways they may assert or pervert that power. Just pick up any issue of *The Mouth* if you need a reminder.

However, failing to recognize the current and potential allegiance of so many families and other individuals both ignores past reality in terms of where powerful changes have occurred in support of people with cognitive disabilities, and ignores the current reality of where we are likely to find allies willing to engage in the hard work of creating change.

- Over the past 10 years, and more so each day, there are new structures, processes and ways of organizing emerging across the globe. They hold in common a belief that, in the words of Paulo Friere "reality doesn't change itself," and that people can *co create* a desired future. They focus on the real power of vision, purpose and principles to guide day to day action and practices. They work to actively bring people together at a community level, while using face to face gatherings and internet technology to accelerate learning and strengthen connections.

Perhaps the best example of this process at work is the work of From the *Four Directions* in creating local circles of leadership across the world. A summary of this and other similar initiatives can be found at Margaret Wheatley's web site, *Turning to One Another* at <http://turningtooneanother.net/world.html>.

Promising efforts to engage these processes to create coalitions for change related to disabilities services can be seen in the People Can't Wait campaign in Wisconsin ([http://www.dawninfo.org/co/com\\_people\\_cant\\_wait.cfm](http://www.dawninfo.org/co/com_people_cant_wait.cfm)), and the fledgling Advocates Needed Today organizing effort in Arkansas. These ways of coming together to create the future may offer important learning for how we might organize our efforts around a vision of self-determination and the principles that support it.

## **Summary of Recommended Action**

A brief summary of an already too brief paper suggests the following approach:

- Self-determination offers a powerful idea and guiding principles around which to organize;
- Leadership for change will be consciously sought and supported from "anyone who wants to help at this time;"
- Specific "targets" of change will be identified at the community, state, national (and international) level by those who choose to come together;
- Those who come together at any level will be linked to one another for the purposes of shared learning and increased power, to the degree they wish to be; and
- Both historically effective and new models of organizing for change are needed.

## **Continuing the Discussion**

This paper is placed on the website of the Center for Self-Determination (<http://www.self-determination.com/>) and has been sent via email to a listserv of Center members, including participants in the April, 2002, Immersion Learning. An open discussion of this approach to organizing a movement and supporting leadership for self-determination has begun. We welcome your comments and suggestions. Feel free to join the listserv by becoming a member of the Center, or send your thoughts directly to the author of this attempt to inspire our creating a way to organize our efforts: Dennis Harkins via [dwharks@aol.com](mailto:dwharks@aol.com).