



National Leadership Summit on Self-Determination and Consumer-Direction and Control

Summary of Proceedings and Draft Principles

***"Self" involves consideration of who individuals
are as a people and how they arrived there.
Power comes from people with disabilities
claiming themselves as a community.
Determination involves power, taking control,
and demanding real choice.***

Marca Bristo

Summit Sponsors

National Alliance for Self-Determination: A grassroots coalition of leaders of self-determination And consumer-control initiatives

- Administration on Developmental Disabilities, US Department of Health and Human Services
- Bill Sackler Center on Self-Determination, The Arc of the United States
- Center on Self-Determination, Oregon Institute on Disability and Development, Oregon Health Sciences University
- Disabilities Studies and Services Center, Academy for Educational Development
- Institute for Child Health Policy, University of Florida
- Institute on Disability, University of New Hampshire
- National Council on Independent Living
- National Council on Disability
- National Council on the Aging
- Office of Special Education and Rehabilitative Services, US Department of Education
- Presidential Task Force on Employment of Adults with Disabilities
- Robert Wood Johnson Foundation and RWJF Program Office on Self-Determination for Persons with Developmental Disabilities
- Rehabilitation Research and Training Center on Aging with Mental Retardation, University of Illinois at Chicago
- Rehabilitation Research and Training Center, Virginia Commonwealth University
- Social Security Administration
- World Institute on Disability

5. Many individuals with disabilities have not had their self-determination supported by their family members, however some family members have been major allies for self-determination. We should be cautious in over-generalizing and assuming that all families are unsupportive.

6. Many factors, such as traditional societal expectations that families should be responsible for lives of individuals with disabilities and a lack of professional and system support, have made it difficult for many families to support, and individuals to express, self-determination. We need to learn more about the barriers that families and individuals have faced and what they believe would increase their support for self-determination.

7. The foundations for self-determination are laid in the earliest years. Therefore, families should be made aware from the earliest years of ways to facilitate the self-determination of their children with disabilities.

8. It is in the best interest of the national self-determination movement for cross disability individual and family leaders to build a common vision for self-determination.

9. Individuals with disabilities should have the primary national leadership role in setting the self-determination agenda, and family and individual leaders should work together to move the agenda forward.

10. Disability organizations should make self-determination a priority, including focusing on it in their conferences, publications, advocacy and research, and looking at ways to promote partnerships among individuals and families

People need to spread the word about how important self-determination and leadership is. It is not a one time event.

**Tia Neils and
Essie Pederson**

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Draft Principles For Individual and Family Self-Determination Partnerships

Families are defined as two or more people who regard themselves as a family and carryout the functions that families typically perform. They may or may not be related by blood or marriage; they may or may not live together; and they are almost always influenced by their own definition of family.

The following principles relate to the definition and expression of self-determination within families and the development of partnerships among family and individual leaders to advance self-determination.

1. Everyone should have the choice to be part of some type of family. Relying on other people can be a good thing so long as the parties agree to it.
2. Families usually hold generational expectations for the expression of self-determination by all family members, including grandparents, parents and children.
3. How families and individuals view self-determination and work together to express it will be based on their culture and values. Self-determination should be defined, expressed and respected within the culture of individuals and families.
4. Individuals with disabilities and other family members may vary in their commitment to, and expression of, the principles of self-determination due to factors such as nature and extent of disability, experience with the service system and the other environmental challenges they confront.

Summit Background and Goals

The National Leadership Summit on Self-Determination and Consumer-Direction and Control was held in October, 1999. The Summit was attended by 120 leaders of self-determination and consumer-direction initiatives in physical, developmental and psychiatric disabilities, aging and youth development.

For over 30 years, the disability community has been working to advance self-determination and consumer control. These activities have been spearheaded by leaders from the independent living movement, self-advocates, families and professionals in developmental disabilities, psychiatric survivors, leaders advocating for community based services for seniors, and youth leaders and educators committed to self-determination by young people.

The goals of the Summit were to share information and ideas, and to develop recommendations for advancing self-determination among all people with disabilities. Work groups also organized to move forward the recommendations.

There can be no self-determination when force exists. Every person who has experienced the mental health system first hand knows this at a deep, profound, internal level... Involuntary treatment is the battleground... because it is the fear of civil commitment that drives each of us.

Rae E. Unzicker

This pamphlet summarizes the issues and recommendations from the Summit, including drafts of principles for self-determination and for building successful partnerships among individuals and families to advance self-determination. Summit proceedings are posted at www.ohsu.edu/selfdetermination/proceedings.shtml. Please give us your feedback on the principles by e-mailing your comments to loeschc@ohsu.edu.

Consensus Issues

Key issues discussed by Summit leaders included:

- ◆ Self-determination is a basic human and civil right for all. It is a birthright, not learned or earned. Self-determination involves real choice and control; equal access, opportunity, authority, support and responsibility. It means defining and reaching your own quality of life, free from forced services or treatment. Denial of self-determination is a basic human rights violation.
- ◆ Self-determination impacts the child, youth, adult, and older adult. Everyone has the right to rich experiences, learning opportunities and freely-given relationships.
- ◆ There is a need for ongoing education to build self-determination awareness, skills and attitudes. We must create attitudinal and behavioral change and inform all people about self-determination.

The development of knowledge, beliefs and skills that lead to self-determination should be considered an important educational outcome...

Sharon Field

- ◆ Self-determination may take different forms in different cultures as a function of language, family and community values.
- ◆ Self-determination is a community issue: behind "me" is "we". To move forward self-determination, we must form alliances across disabilities, generations, and the nondisabled community.

Individuals use funds to purchase the supports they require and can select and direct their support providers at the level they choose. Fiscal intermediaries are available to assist individuals with the administrative tasks associated with employing support providers and paying for supports. Fiscal intermediaries are conflict of interest free.

Support

Individuals with disabilities may desire support to care for themselves and meaningfully participate in their communities. Each individual can determine the unique supports that work for him or her. Trusted others may assist individuals to identify life goals and supports that are needed, to develop individual support plans and budgets, to prepare advanced directives or to choose other trusted individuals to assist in the management of their plans and resources. Those who assist focus on providing individuals with support and access to life opportunities at their highest potential. Independent brokers are also available to assist individuals to design, arrange and manage their supports. A broker works for the person with a disability and is free from conflict of interest.

Responsibility

Individuals with disabilities, like all Americans, have the responsibility to fulfill all the ordinary obligations of citizenship (e.g., voting, obeying laws). Individuals are responsible for directing their lives and participating in their communities as much as possible, including using supports in ways that are wise, fiscally responsible, and life affirming. Policy barriers must be removed that prevent employed individuals from receiving needed supports (e.g., health insurance, personal assistance services) or that prohibit individuals from producing income through the world of commerce and business.

Draft Principles of Self-Determination

The Self-Determination movement has its roots in the broader human and civil rights movements. The principles of self-determination must be broad enough to include all individuals with disabilities and concrete enough to guide policies and practices. The following principles go to the heart of self-determination:

Freedom

Freedom for individuals with disabilities is no different than it is for all Americans—freedom to take advantage of any of life's opportunities and to exercise all rights guaranteed under the Constitution (e.g., deciding where, how and with whom one lives, works, recreates, etc.). Individuals determine what important things they will do with their lives, the relationships they establish, how they will contribute to their communities, and any supports or services they will use. They do not have to accept pre-determined programs or actions imposed based on a

label of disability, such as

segregated schooling, institutionalization, service slots or aversive treatment (e.g., shock therapy, forced medication).

Authority

Individuals have the authority to determine and direct their lives, including controlling their money, registering to vote and entering into contracts for activities such as buying a home or marriage.

They also have authority to decide how funds available for their support will be used. Funds are assigned to individuals based on support agreements developed by individuals and funders.

Arrangements for self-determination are changing, from the past traditional model of nondisabled allies having most decision-making power, to the current model of shared decision-making, to the future model of persons with disabilities making their own decisions with the support and input of nondisabled allies.

Carol Gill

◆ The roles of individuals and family members must be clarified to move forward the self-determination agenda.

◆ Individuals shall run their own lives and control their money, services, and assistance. Existing laws and regulations (Medicare, Medicaid, SSI, TANF, etc.) must be reexamined through the lens of self-determination.

◆ The self-determination agenda must include economic justice, including real work incentives, a living wage, access to capitol, opportunity to own a business, job creation and career development.

◆ Individuals with disabilities should lead and govern organizations that receive federal dollars for people with disabilities.

◆ We must promote leadership development among people with disabilities by recruiting, training and supporting new leaders, particularly young people.

◆ We need a political agenda to achieve self-determination for all people: initiate rather than react to laws, pick people for public office, register voters, and connect with civil rights groups.

... it is imperative for the field to not only recognize, but to honor, cultural diversity in defining self-determination and the appropriate roles for families.

Ann Turnbull

The simple idea that care dollars should follow the person rather than the care program or care setting is slow to come, but seems an obvious step towards greater autonomy, control and choice for seniors.

Rosalie Kane

Recommendations for Advancing Self-Determination

Summit leaders developed recommendations and action steps in three major areas:

Recommendation #1: Define Common Principles of Self-Determination.

There was general agreement that the definition of self-determination must be specified for a shared agenda. We must adopt a vision of self-determination based on the principles of freedom, authority, support, and responsibility, including no forced treatment. Care is needed to take all points of view into account. Principles should be developed that describe self-determination within the context of how all the groups at the Summit looked at it, including the building of successful partnerships among families and individuals.

Recommendation #2: Advance Self-Determination in Public Policy.

Leaders agreed that we must organize and participate in the political process, focusing on leadership development and coalition building. This includes working with the agencies that supported the Summit to incorporate self-determination principles within their plans and grant announcements, and to fund a continuing effort to move forward a shared agenda.

A template should be developed, based on self-determination principles, for reviewing existing state and Federal statutes, policies, and procedures.

Funding policy across federal and state agencies should be consistent, non-categorical, accessible and flexible.

HCFA should identify and eliminate discrepancies in Medicaid policies as they apply to self-determination, including:

- ✓ Increase access to personal assistance services for all disability groups;
- ✓ Enable people to control the dollars necessary for their support; and
- ✓ Support policies that fund people, not programs; end institutional bias and promote community-based services.

Work with policy makers and organizations to ensure that people with disabilities have meaningful employment.

Establish leadership councils in each state that include representation from cross-cultural, multigenerational, cross disability groups for the purpose of advising and educating policy makers.

Recommendation #3: Disseminate the Principles and Practices of Self-Determination.

We must make a commitment to gather diverse groups together and continue dialogue that identifies specific strategies for advancing self-determination. A conference on self-determination best practices and successes, and effective communication with policy makers should be convened as well as a broad-based White House Conference on Self-Determination.

Conduct a massive public campaign to educate people about self-determination, including materials for families and curriculum in schools that builds leadership, self-determination skills and disability awareness. Encourage newsletters, journals and other publications to reflect the principles of self-determination.

Advocate for the use of people first, accessible language at all times.