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Then we come over then to the right of self-determination, the right to be listened to, to be heard, and to express yourself; to have the groups, to have the clubs; to have the right as citizens, to form your own associations, to form your own clubs, and have a say so; the right to be a citizen and the right to take part in the legislative process as a citizen. And that was in the background of the People First."

Bengt Nirje. 1993

Note

We're working on a series on self-determination. We'll start with a brief historical perspective from some of the leading lights of the movement when it started to pick up momentum in the mid 1990s. A reminder that the journey to self-determination for people with developmental disabilities has been a long one.

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Self-Determination: An Historical Perspective

In 1972, Bengt Nirje wrote about the rights of people with severe disabilities. He called for a wide range of actions that would enable people with severe disabilities to have better control of their lives and destinies, including choices and personal activities, education, independence, participation in decisions, and information upon which to make a decision and solve problems. According to Nirje, self-determination equates with the respect and dignity to which all people are entitled.

Excerpt from *Self-Determination*

[You Teach Me Website](#)

On the Meaning of Self-Determination by Michael Kennedy, Advocate

I really started to learn about self-determination when I went into an institution when I was five years old. I am one of four children and I lived in three different New York State institutions for a total of 15 years. In the institutions, I had to learn to speak for myself and the other residents because of the attitudes of the staff who worked there. Very early on, watching how people were treated, I decided that I would have to learn to advocate on my own behalf. It was hard at first because I didn't have to do that until that point. Living in the institution is a totally different world than living at home. **Continued on page 2,**

Find the The California Gatherings Archive of all newsletters and resource notes at [here](#).

About Self Determination

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Michael Kennedy, continued

The meaning of self-determination has changed for me over the years. When I was in the institutions, I had to make sure I got the basic care I needed, like my personal hygiene and three meals a day, so that was what self-determination meant at that time. There, the caregivers seemed to think people didn't know what they wanted or how they wanted it done. Now, self-determination means running my own life and directing my personal care assistants on how best to assist me in my personal care. Now, people treat me like a human being who knows what I want and who needs support to live my life. They ask me what I want and how I want it done. They also ask me what is the easiest way to get things done, so that I feel comfortable and they feel comfortable as well. So self-determination doesn't mean you have to do everything yourself, but it does mean you have to be in charge of your life to the fullest extent that you possibly can be.

The Four Principles

The self-determination movement was founded on four basic American principles:

FREEDOM: the exercise of the same rights as all citizens. People with disabilities with assistance when necessary will establish where they want to live, with whom they want to live and how their time will be occupied. They do not have to trade their inalienable rights guaranteed under the Constitution for supports or services.

AUTHORITY: the control over whatever sums of money are needed for one's own support, including the re-prioritizing of these dollars when necessary. This is accomplished through the development of an individual budget that "moves" with the person.

SUPPORT: the organization of these resources as determined by the person with a disability. This means that individuals do not receive "supervision" and "staffing." Rather, folks with disabilities may seek companionship for support and contract for any number of discrete tasks for which they need assistance.

RESPONSIBILITY: the wise use of public dollars. Dollars are now being used as an investment in a person's life and not handled as resources to purchase services or slots. Responsibility includes the ordinary obligations of American citizens and allows individuals to contribute to their communities in meaningful ways.

[RWJ Foundation for Self-Determination](#)

The Seattle 2000 Declaration on Self-Determination & Individualized Funding

(This Declaration was developed during the First International Conference on Self-Determination and Individualized Funding, which was held in Seattle in July 2000, and was presented in draft form to the 1250 attendees at the closing plenary.)

This conference has been founded on the certainty that people with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honoured if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.

Many people require personal supports or other services to ensure their full citizenship and inclusion. These supports and services must be funded and provided at a level and in ways that uphold the rights of the individual.

This conference is no less certain that these rights have often been disregarded. Citizens who have disabilities experience oppression in many aspects of their lives. The causes of oppression include poverty, other people's attitudes, and the systems of publicly and privately funded support services, comprising –

- laws, policies and regulations;
- state and private sector funding bodies;
- agencies which provide services.

These systems operate in ways that deny control to those they are intended to serve. Without accountability to those who require their assistance, these systems decide how, where and with whom people shall live and spend their days. While this situation persists, people of many nations will not be able to exercise their rights or fully participate in their communities.

The complete declaration can be found [here](#).

Emerging Best Practice in Self-Determination

Excerpt from

COMMUNICATING SELF-DETERMINATION: FREEDOM, AUTHORITY, SUPPORT AND RESPONSIBILITY

By Thomas Nerney, Center for Self-Determination, 1999

Two relatively innovative assumptions are beginning to under gird the self-determination movement for all individuals with disabilities. One is that all persons will “have their own place”, and, two, that virtually all individuals can work in meaningful employment and/or produce income through the development of micro enterprises. Folks with disabilities may indeed want to live with another person but that is always a freely chosen situation and one susceptible to re-negotiation when necessary. More and more projects across the country are gradually changing the goal from “getting a job” to one of “producing income.” This enables everyone to understand that there are many ways to secure employment and to start a small business. Individuals within their budgets can (with assistance from a variety of sources) contract directly with employers for co-worker support, transportation and even training. Individual budgets can be used to help secure or pay down the cost of equipment necessary for a small business.

IDEAL STANDARDS FOR INDIVIDUAL BUDGETS, SUPPORT BROKERING AND FISCAL INTERMEDIARIES

INDIVIDUAL BUDGETS

Based on current best practice individual budgets meet ideal requirements for self-determination when the budget is actually controlled by the person and their freely chosen allies. Public dollars are now seen as an ongoing investment in the person’s life and the obligation to be responsible as well as contribute to one’s community becomes part of the budget development. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. This means that the following is in place:

- **Individually created.** The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability.
- **Authority over Personnel.** Any person who works for the individual with a disability is hired and can be fired as well. In fact, all employees and consultants work for the person and that person’s social become the employer of record, all personnel and consultants work for the person with a disability.

Complete article [here](#).

Program Results Report - RWJ Foundation

Self-Determination for Persons with Developmental Disabilities

October 25, 2007

Author(s): Sunderland, A

Field of Work: Working toward a more cost-effective system for serving persons with developmental disabilities while simultaneously giving those persons and their families more choice in determining the services they receive.

Problem Synopsis: In the mid-1990s, state programs serving individuals with developmental disabilities faced three serious problems: rapidly rising costs for services, insufficient resources to serve everyone who needed help and fixed sets of services that gave individuals and their families little control over what services were provided, when or how.

Synopsis of the Work: Four elements were central to Self-Determination for Persons with Developmental Disabilities (November 1995 through August 2001):

- **Person-centered planning**, where each individual defined his or her own needs; learned about available services and providers; and received assistance in planning services.
- **Independent support brokerage**, meaning that independent professionals (brokers) helped individuals and their families identify their needs and find services and providers who could meet those needs.
- **Individual budgets**, wherein participating states allocated a pool of money that the individual could use to pay for the services and supports he or she chose.
- **Fiscal intermediaries** to act as business agent, purchasing services and managing wages, taxes, fringe benefits, accounting and compliance with labor and tax regulations.

Key Results

- There was a **shift in decision-making** from professionals to individuals with disabilities, and **improvement in some but not all quality-of-life indicators**.
- **Flexibility, a system-wide approach and the availability of direct support workers** were critical factors in the success of self-determination initiatives.