



**Policy Statement
Approved
December 2006**

Self-Determination

Summary of the Issue:

Self Determination, a philosophy embraced by human rights groups, guides services to people with developmental disabilities in Oregon. The primary purpose of self-determination is to protect the rights of people with disabilities to make fundamental life choices, to enhance their authority to act in accordance with those choices, and to support them in becoming participating and contributing members of the community.

To achieve self-determination, several things need to happen. People with developmental disabilities and families need to have information, skills, supports and experiences that enable them to make choices. At the same time, communities must have a range and variety of services for individuals and families to choose from. And finally, flexible systems must be in place to allow individuals and families real control over resources to purchase the services that they need and want.

Council Position:

The Council believes that self-directed services and supports driven by the philosophy of self-determination should be available to all Oregonians with developmental disabilities.

Self Determination is reflected in these principles:

Freedom: People must have freedom and the power to make basic life choices. This involves balancing the risks and possible consequences.

Authority: People must have control over their lives and meaningful options if they are to exercise freedom of choice.

Support: Supports must be available to help people connect with opportunities for increased personal and social inclusion.

Responsibility: As people gain control over their lives, they will also be able to take on their obligations as citizens and give back to their community.

Essential elements in self-determination for people with developmental disabilities:

- People must have a primary role in choosing, directing and overseeing their supports, at the level they choose.
- People must have real choice about where they live, with whom they live, and how they occupy their time.
- People are an essential part of quality monitoring and any state and local oversight.
- People should have access to community resources, including natural supports.
- People must receive flexible personalized supports that respond to needs as they change over time.
- People should have individualized budgets that reflect need and move with the person.
- People must receive the support necessary to exercise their freedom, authority, and responsibility.

For self-determination to be successful the system must provide people with:

- Training and information to learn and exercise self-determination, including assessing quality, making choices, and participating in policy making.
- Assistance to develop personal life plans that reflect unique needs and wants, which may change over time;
- Resources to achieve the goals in their personal life plan;
- Support to implement personal goals;
- The opportunity to make changes as life needs and desires change without losing services.

- A resource and payment system that is flexible, efficient, and supports payment for individual outcomes.

Background:

In 1998, Oregon received a Robert Wood Johnson grant to implement a model for the delivery of services to adults based on the philosophy of self determination including customer control and choice. As a part of the grant, Self Determination Resources, Inc. (SDRI) developed a model brokerage and provided services to a small number of people with developmental disabilities.

Self-determination is a philosophy about individuals and families exercising choice and control. Power shifts of this nature usually involve some measure of controversy. For a variety of reasons, service systems with authority have difficulty sharing power with people who have traditionally not been involved in decision-making. And those who have never had real power sometimes have difficulty knowing how to use it.

The SDRI model provided critical information about the challenges and the successes of this approach and laid the foundation for the creation of an entire system of supports based on the philosophy of self determination.

In 2000, the State of Oregon settled a lawsuit brought against them by Medicaid eligible people with developmental disabilities and their families who had been waiting for access to services for many years. The Staley Settlement Agreement included universal access to support services delivered by a service system based on the philosophy of self determination.

In 2006, the State of Oregon received a Real Choices Systems Transformation grant to bring the philosophy of self determination into the 24/7 Comprehensive service system. The State and its partners are focusing efforts on the development of systems to support individualized assessments, individualized resource allocations, and a rate setting mechanism that will be easy to understand, allow choice and portability in Comprehensive services.

Implementing a philosophy always results in compromises. Choice is never without limitations. Funding levels, state and federal rules, brokerage system workloads, provider system culture, lack of creativity and local capacity are both perceived and real barriers to achieving full self determination in publicly funded services.

Despite the challenges, success stories from brokerage staff, families, individuals with developmental disabilities, providers, advocates and others demonstrate that a commitment to self determination must remain a driving value in Oregon.

Possible Future Council Activity:

Education: Identify and share best practices that reflect the values and essential elements of self-determination.

Training and technical assistance: Advise and collaborate with others to provide skill-building training and technical assistance to families, individuals and other key groups.

Legislative/Administrative:

- Promote the creation of consumer-driven quality assurance mechanisms that measure individual outcomes and consumer satisfaction.
- Promote continuous quality improvement and technical assistance and training.
- Advocate for modifications in rule and statute necessary for full implementation of self-determination.
- Monitor the planning and implementation of support services for adults.
- Advocate for a system that supports all essential elements of self determination.