



**Policy Statement
Adopted
February 2007**

Services for Adults with Developmental Disabilities

Summary of the Issue:

Many people with developmental disabilities require few supports or services to live a life in the community filled with work, friends, and family. Others may require a more complex network of support. The major challenge facing the developmental disabilities system and its stakeholders today is the ability to fund and implement a flexible and consumer-driven system of supports to address the individualized needs of a varied population of people with developmental disabilities.

Council Position:

The Oregon Council on Developmental Disabilities is committed to a future where:

- all individuals with developmental disabilities have access to the individualized supports and services they need for full and productive lives as members of the community of their choice;
- individuals direct the design of services and supports through a person centered planning process;
- individuals and families oversee and control services and supports to assure consumer empowerment, choice and inclusion; and
- the system of services and supports is able to attract and retain skilled employees to support individuals with developmental disabilities.

Background:

Prior to the year 2000, adults with developmental disabilities in Oregon who required publicly funded services received 24-hour supports and services either in Fairview Training Center, Eastern Oregon Training Center or

community group homes. Thousands of eligible individuals with developmental disabilities lived at home and waited for access to services, often for many years.

The settlement of the Staley v. Kitzhaber waitlist lawsuit in March, 2000 brought new dollars into the system to develop a statewide program of Support Services for all eligible adults with developmental disabilities. Upon full implementation, eligible adults will receive Support Services within 90 days of application. Individual budgets for adults in the Support Services System are capped at \$20,000 per year with the majority of individuals only eligible for approximately \$9,600 per year. Most individuals receiving Support Services continue to live in their family home. In addition, the provisions of the Settlement provided for non-crisis access to Comprehensive Services for 300 adults with developmental disabilities. A statewide fiscal crisis in 2003-2005 resulted in a renegotiation of the lawsuit and a delay in full implementation of the agreement to 2009.

To provide a basic level of service to all adults with developmental disabilities waiting for services, the State of Oregon created a new structure of Support Brokerages to assist individuals to design their own support services based on the philosophy of self-determination, person-centered planning, and use of community resources. The successful development and implementation of such a system requires massive retooling of service infrastructures, retraining of personnel and consumers throughout the system, and the active involvement of all stakeholders, including individuals with developmental disabilities, families, advocates, providers, counties, the state, and others. Oregon still struggles to make the vision for Support Services a reality.

In 2000, the last resident of Fairview Training Center moved to the community. Except for approximately 50 individuals still living in Eastern Oregon Training Center, Oregon has eliminated all its institutions and Intermediate Care Facility - MR facilities. Community residential programs and foster care provide most of the services for individuals receiving services in the Comprehensive Services System. While individual providers may embrace the values of self determination, the system itself is based on slot rates and individual funding rates are not regularly adjusted to reflect true costs. Individual rates are not regularly adjusted to reflect true costs of services. Individuals cannot easily move from one provider to another and have little control in the design of their own services. The Comprehensive

Services System struggles with recruiting and maintaining staff, low wages, and the lack of funding sufficient to address the increased cost to deliver services. Stakeholders are currently engaged in a process to redesign the existing Comprehensive Service System by restructuring assessments, budgets, and rates.

Funds continue to be extremely limited and even with the highest degree of creativity and flexibility, the adult service system continues to face the issue of inadequate resources to meet the real needs of people. There is a lack of capacity in many communities to meet the needs of people with developmental disabilities including a lack of available, accessible transportation and affordable housing. Balancing access to services and flexibility while maximizing utilization of state, local, federal and other available funding is an essential challenge.

A comprehensive quality assurance system for all adult services is essential to evaluate current implementation and to plan for the future. This system must include components to address ongoing quality improvement and consumer satisfaction.

Possible Future Activity:

Legislative / Administrative Policy Advocacy:

- Support activities to increase available resources for adults with developmental disabilities and their families. These activities might include legislation and legislative activity, involvement in the state budget process, the development of new federal waivers and the promotion of inter and intra agency agreements and collaborations.
- Continue to support the activities of the Staley Implementation Group (SIG) to monitor the implementation of the Staley Settlement and to promote the philosophy of self-determination and person-centered planning in all aspects of service design and delivery.
- Support the Real Choices Systems Change Grant activities around individualized support assessments, individualized budgets, and rate restructuring in the Comprehensive Service System
- Support the development of data systems, including demographic information and identification of the needs of unserved and

underserved individuals and families, to assist in short and long range planning.

- Promote the development of a comprehensive Quality Assurance / Quality Improvement System that addresses all services, focuses on the consumer, and utilizes the strengths of all stakeholders.
- Support broad-based cross-disability efforts to address transportation, health care, housing, employment and other community capacity issues for people with all disabilities.

Training and Technical Assistance:

- Support efforts to improve training and increase wages for direct support staff.