



## **Policy Statement Adopted in April 2004 by Oregon Council on Developmental Disabilities**

### **Health Care**

#### **Summary of the Issue:**

Oregonians with developmental disabilities face many barriers to quality health care and frequently lack access to basic medical coverage and health care providers trained to meet their needs.

One of the challenges to consistent provision of quality health care is the instability of publicly-funded health insurance. Services for Medicaid-eligible individuals under the Oregon Health Plan (OHP) have been reduced and are in danger of further reductions due to budget cuts. Vital services, such as dental care and prescription drug coverage, considered optional under Medicaid, risk total elimination when budgets are tight.

Limitations in benefit packages, and the rise of health care costs, have reduced access to health care for people who have private insurance.

In addition, thousands of adults and children with disabilities have no health insurance and cannot access even basic health care in Oregon.

#### **Council Position**

Oregonians with developmental disabilities must have access to appropriate, affordable, accessible, timely, and comprehensive medical, dental, and mental health treatment throughout their lives.

The Oregon Council on Developmental Disabilities believes that if health care systems are to meet the needs of people with developmental disabilities, they must include the following components:

### Access to Basic Services and Benefits

- Health care systems must offer comprehensive benefits packages that meet the needs of people with developmental disabilities, including such basic benefits as prescription drug coverage, preventive services, rehabilitation services, durable medical equipment, orthotics /artificial limbs and mental health services.
- Disability must not be a factor in the decision to provide, delay, or withhold treatments or to provide or receive organ transplants.
- Services should be provided to treat acute and chronic conditions, to promote and maintain health and the best possible functioning, and prevent deterioration and secondary disabilities.
- Health care professionals must have access to specialized training that prepares them to:
  - treat people with developmental disabilities respectfully
  - assure the best possible health for patients with developmental disabilities
  - prevent secondary conditions among people with developmental disabilities.

### Access to Specialty Services

- Health care systems must provide access to specialized services. Those services must be coordinated with other systems and supports used by people with developmental disabilities.

### Consumer Choice

- All consumers must have the right to choose healthcare providers.
- Reasonable accommodations must be available to permit full access to services.

- An appropriate surrogate decision makers should be available and recognized for those who do not have the capacity to make health care decisions.

### Strong Quality Assurance Measures

- Consumers must be provided understandable basic information on their health care services, including their rights and responsibilities.
- A simple, understandable, timely grievance and appeals process should be available. Consumers should have the right to appeal any benefit decision, including denial of services, withholding of experimental or investigational treatments and forced or unwanted treatments.
- Health care systems should collect and report a uniform set of data that allows public officials and consumers to evaluate and compare performance of health care providers. This should include data collected over time to measure overall outcomes for people with disabilities.

### **Background:**

Accessing appropriate medical care is an ongoing challenge for people with developmental disabilities. Medical equipment is often not available for people with mobility limitations or physical disabilities. Health information is regularly inaccessible for people who have cognitive, vision or hearing disabilities. Negative attitudes and misconceptions, often based on inadequate training of health care providers, further limits access. Systems are not set up to accommodate someone with exceptional health care needs. As a result, people with developmental disabilities often struggle to obtain vital health services.

The high cost of health care and problems with insurance create further barriers. People with developmental disabilities and families with children with developmental disabilities often face discrimination by insurers that impose high premiums and deny or limit coverage for disabling conditions.

Access to necessary services for families and consumers with developmental disabilities can be denied or severely limited by health care organizations because they do not understand the health care needs of individuals with disabilities.

Oregon's public and private health care systems and funding strategies have been in a state of reform for many years. In an effort to extend health care coverage to as many Oregonians as possible, the state developed unique strategies, such as the Oregon Health Plan and its package of benefits based on a prioritized list of conditions and treatments. Continued changes in the health care system, as well as the state and federal budget shortfalls, have increased the challenges for people with developmental disabilities in accessing appropriate and accessible medical care.

#### Activities:

- Advocate for full funding of the Oregon Health Plan.
- Monitor implementation of OHP and any proposed reductions in services.
- Oppose reductions in Medicaid optional services such as dental care or durable medical equipment for people with developmental disabilities.
- Track insurance and other legislation that might limit access to health care for people with developmental disabilities.
- Encourage training of health care professionals on specific health care needs of persons with developmental disabilities.