

Aging and Developmental Disabilities

Summary of the Issue:

There are increasing numbers of aging persons with developmental disabilities who need to be supported, valued and included in our communities. Current service systems are not well prepared to anticipate, understand and address the needs of this growing population.

Council Position:

The Oregon Council on Developmental Disabilities believes that aging persons with developmental disabilities should be valued and included members of their communities and the larger society.

The Oregon Council on Developmental Disabilities believes that persons with developmental disabilities who are growing older should have access to:

- community supports to live, learn, play, work, retire and worship according to their choices, values, interests and cultural background;
- health care that addresses their age-related concerns, disabilities and physical and mental wellness;
- caregivers and others who provide support who are knowledgeable about aging and developmental disabilities including age-related changes and death and dying;
- generic services available to all older Americans;
- the right and support to prepare for their retirement while young without jeopardizing their public benefits;
- information on the full range of end of life supports to make individual choices about advanced directives, do not resuscitate directives, hospice, and other end of life plans; and
- choice about after death arrangements.

The Oregon Council on Developmental Disabilities believes that providers of support and services to individuals with developmental disabilities who are aging should have access to:

- information and training about aging and developmental disabilities, including age-related changes and death and dying;
- person-centered, aging-focused planning with individuals and families;
- information about healthy lifestyles for people who are aging; and
- flexible funding to provide appropriate supports for individuals as they age.

Background:

The aging of the Baby Boom generation, medical advances and better health in general mean that, in recent years, older people have become a larger and larger percentage of our state's and our nation's population. Like the rest of the population, more healthy adults with developmental disabilities are also living into old age.

People with developmental disabilities who are aging need community supports and services. Current systems are not prepared to accommodate the needs of older adults with developmental disabilities. Supports for a productive retirement for people with developmental disabilities is typically not available.

Some persons with disabilities (e.g., Down Syndrome, Cerebral Palsy) may experience age-related changes earlier than the general population. Also, aging people with developmental disabilities may experience higher rates of mental health problems. This increases the number of persons with developmental disabilities who need additional supports and health care due to age-related changes. Information on these issues is often not readily available to individuals, families, health care and other service providers.

The majority of persons with developmental disabilities live in the family home. Many aging persons with developmental disabilities receive care from parents who are elderly and also in need of support. Parents are concerned about what will happen to their son or daughter with developmental disabilities when they die or become incapacitated. Other family members and friends have similar concerns. They seek answers to questions about legal, financial and long-term support issues. Likewise, people with developmental disabilities wonder what will happen to them

when their family members and friends are no longer living or able to provide support.

In Oregon, there are few people with developmental disabilities who were identified and receiving some type of aging-appropriate services through Services to Seniors and People with Disabilities.

For people receiving services from the current developmental disabilities comprehensive service system, the rate structure and provider experience do not address aging issues and the needs of people with developmental disabilities including increased support costs and changes in service design.

The merger of the state agency for aging with services for individuals with developmental disabilities offers potential opportunities for more effectively addressing the needs of individuals with developmental disabilities who are aging.

Possible Future Activity:

Advocacy / Administrative:

- Raise the visibility of the issues of individuals with developmental disabilities who are aging, with policy makers and task forces identified to study and recommend options for the long-term care system.
- Advocate that all personnel working in Services to Seniors and People with Disabilities develop the expertise to anticipate and understand the needs of the aging population with developmental disabilities.
- Collaborate with other organizations to encourage greater access to other generic and aging services for individuals with developmental disabilities who are aging.

Education:

- Support training for family members, service providers and health care providers in specific issues related to aging and developmental disabilities including age-related changes; legal, financial, long-term support issues and health care.

Research:

- Support research on the demographics and epidemiology of aging and developmental disabilities.
- Support a needs assessment of aging persons with developmental disabilities in Oregon.

