

Department of Human Services

DEVELOPMENTAL DISABILITIES Program

MISSION

The Department of Human Services Developmental Disability program (DD) cover a lifespan of support to Oregonians with intellectual and other developmental disabilities (I/DD). Our mission is to help individuals be fully engaged in life and, at the same time, address any critical health and safety needs.

The program

DD strives to support choices of individuals with I/DD and their families within communities by promoting and providing services that are person-centered, self-directed, flexible, community inclusive, and supportive of the discovery and development of each individual's unique gifts, talents and abilities.

We are committed to work toward service options to assure that people with intellectual and other developmental disabilities have the opportunity to have fulfilling and meaningful lives allowing them to contribute and enjoy their communities.

We currently help over 21,000 children, adults and their families have the best quality of life possible at all stages of their lifespan. Due to their economic situation, most individuals with developmental disabilities are eligible for a Medicaid waiver which allows them to obtain community-based services instead of an institution.

We seek to achieve the following outcomes and goals:

- Provide an array of options that are properly distributed to assure access through equitable and culturally competent services.
- Be responsive to emerging consumer demands for individualized, self-directed services and sufficient service choices.
- Assure the health and safety of individuals served.
- Promote maximum consumer independence and engagement in homes and communities.
- Leverage use of available federal funding options.
- Address improvements in business practices such as payment and information systems to achieve overall operational efficiencies.

Individuals we serve

More than 21,000 Oregonians with I/DD access services each month. Individuals eligible for services must have an intellectual or other developmental disability that significantly impedes their ability to function independently. Most individuals meet Medicaid financial eligibility requirements. Most of the services are administered under Medicaid home and community-based waivers. Intellectual and other developmental disabilities include mental retardation, cerebral palsy, Down syndrome, autism and other impairments of the brain that occur during childhood. These disabilities must be

expected to be lifelong in their effect and has a significant impact on the person's ability to function without supports. Some people with I/DD may also have significant medical or mental health needs.

SERVICES

Our service system is comprised of three basic components. There are two broad program service areas - support services and comprehensive services. The third major component is program design and delivery.

Program Services

DD offers a broad array of services in order to optimize consumer choice and arrange cost effective services based on need. The array includes a variety of in-home, congregate care, and ancillary services.

Support Services programs are designed to provide in-home and community supports for a child or adult with I/DD. Supports are things such as respite care, daily staff support and access to assistive devices and equipment. When families are supported to provide the core care, even individuals with the most significant needs have active and engaged lives in their community.

One purpose of support services is to defer the need for full, 24-hour programs or comprehensive care, which represent the higher cost models of service system. Support services are designed to partner with families or other already existing supports, relying on the continuing existence of those supports and filling in the gaps of care and needs with public-funded services.

Services may also include in-home staffing, behavior specialist, job support or community access and equipment. All support services programs are designed to be self-directed, which means the individual and their family identify the type of service, the amount of service and who provides it with a certain fixed amount of funds available to purchase those services. The individual or their family directly hire or contract with providers. Without these services many individuals will enter into a crisis status and require much more expensive out-of-home services such as group or foster homes. In-home support services average approximately \$680 per month per individual while out-of-home services average approximately \$5,472 per month.

For both children and adults, support services are provided through personal support workers, certified provider agencies, general community businesses, behavior consultants, and respite providers. Personal Support Workers were provided collective bargaining rights in 2010 through HB 3618.

Adult Support Services supports those adults with I/DD who are living at home with families or in their own home and are Medicaid eligible. The majority of support services, approximately 7,300, are provided to adults in this particular program. These services are provided through certified entities called Support Service Brokerages across the state. The program operates under a Medicaid Home and Community Based Waiver. Costs for this service are about \$650 per month. The current annual cap is set at \$21,562 per person, per year for support services. The individual receives case management from a Brokerage and works with staff to identify necessary supports a person requires to remain in their home

and live in the community. Within a funded benefit level the person may use funds for services such as respite, in-home staffing, job support, community access, and equipment.

The General Family Support Program support services are offered to any family of a child under age 18. The program offers minimal support services with the most common request being for respite services. The average amount spent per family is \$625 per year. Our surveys tell us this support is of great value to families. All children in these programs have case managers through their county Community Developmental Disabilities Program (CDDP) and support services are allocated based on need. Most children are also in school programs and the case manager coordinates between school and home.

Long Term Family Support Program services are offered to a family whose child is in a crisis status and without support to the family the child would have to enter more expensive out-of-home services. This program is limited to a maximum of 250 families and each family cannot exceed a service cost of more than \$1,000 per month. Like the general family support program, all children in these programs have case managers through their county Community Developmental Disabilities Program (CDDP) and support services are allocated based on need. Most children are also in school programs and the case manager coordinates between school and home.

Family-to-Family Networks, These family-driven networks provide training, information, referral, and general support from one family to another. Just having another family to connect with or problem solve is often what it takes to be supported. Networks also help if a child cannot continue to

live with the family because of their care needs or the family circumstance changes. Often, once a child moves out of the family home into a foster care or group home care, they stay in 24-hour care for the remainder of their lifespan.

Comprehensive Services are for individuals with the highest level of care needs and those who can no longer remain at home. These services are 24-hour supports, mostly provided in settings outside the family home such as group homes, supported apartments or foster care. Of the 21,000 individuals enrolled in services, 7,000 are living in 24-hour group homes or foster care.

Services are funded under a Medicaid Home and Community-Based Waiver. These waivers provide a statutory alternative to institutional care. Community-based, as opposed to institutional care, remains a more cost effective program as well as being the most desirable by clients and the State.

Individuals usually receive these services when they are unable to stay at home on their own or with their family. This is usually due to a change in the person's needs or the change in the caregiver's ability to continue providing services. There is a period of 90 to 120 days before comprehensive services are offered, where crisis services may be provided to determine if we can divert long term placements or behavior consultation to determine if an intervention can turn the crisis around.

For children with disabilities, they enter comprehensive service as a voluntary placement because the intensive needs of the child can't be met in the family home or is involuntary through child welfare action. Fifty percent of the children in comprehensive care come in through the child welfare system.

Child Welfare programs maintain responsibility for court relationship but DD provides the specific disability related care.

Within comprehensive service, there are also services ancillary to the residential programs. Most adults get day services at 20 - 25 hours a week for out of home activities, including work related services. Non-Medical Transportation is also provided to help individuals with I/DD when public transportation is not available or not feasible to help individuals participate in employment or other services. DD, service advocates and our stakeholder community have identified that individuals who are engaged in employment have better health and social outcomes.

All day services for adults are based on the *Employment First Policy*. This policy holds the general philosophy that individuals with developmental disabilities have the ability, with the right supports, to be productive and contributing members of their communities through work. This philosophy also recognizes intrinsic and financial benefits of paid work to the individuals with disabilities and their families.

Comprehensive Services are structured to meet the person's needs on a 24-hour basis. Individuals are assessed using either the Supports Intensity Scale or the Support Needs Assessment Profile to determine the extent of support needed and resulting provider payment. The use of a statewide rate assessment tool is a requirement of the Waiver. Services include both residential and day programs if the person is over 21 and out of school.

Group homes, apartment programs and day programs are run by 120 private agencies, the majority being non-profit organizations. There are approximately 1,200 foster providers. The field services are provided through the county Community Developmental Disabilities Program (CDDP). Case managers determine program eligibility, develop and monitor plans of care, and provide crisis and protective service work.

State Operated Community Program (SOCP) is another component of the Comprehensive Service system. SOCP provides a safety net for Oregon's most vulnerable, intensive, medically and behaviorally challenged individuals with developmental disabilities. SOCP provides services when no other community-based option is available for an individual with I/DD. This includes people with developmental disabilities coming out of the Oregon State Hospital, correctional systems, and from crisis situations where counties and private providers cannot meet the needs of the individual to ensure their health and safety. SOCP focuses on supporting people in community-based settings and enabling them to return to less intensive service levels as quickly as possible.

SOCP provides 24 hour residential and day supports to individuals with I/DD from all across the state who have significant medical or behavioral care needs. The services are provided in small group homes located across seven counties. The SOCP cannot refuse to serve anyone because their needs are too high.

SOCP started in 1987 when Oregon moved all children living at the state institution for people with developmental disabilities to private providers. There were a small number of

individuals with complex medical or behavioral needs who could not be supported by private providers.

From the first homes that were opened by SOCP to today, the profile of the individuals served has changed. As private agencies increase their skills to meet challenging needs and agree to provide services, the person who needs a safety net has changed. In 2000, SOCP had six homes serving 30 people that were considered “medical,” which means they serve people with high medical needs. Today there are three homes for 15 people. In the past, the numbers of people with intensive behaviors had a diagnosis of autism. Today, intensive behaviors are more related to co-occurring mental health diagnosis and/or criminal convictions.

Recent budget reductions have resulted in six homes being closed. This has reduced overall client capacity by 22 percent.

In-Home Comprehensive Service are also provided in some specific situations. For adults there is a comprehensive in-home program individuals that can still be served in their family home but need a level of supports beyond the annual limit of \$21,562 imposed for support services for adults.

For children, there are three specialized in-home programs, each with limited capacity for no more than 200. Collectively these services are known as the Children’s Intensive In-Home Services (CIIS). One of these programs is for children with intensive behavioral issues and without supports would require specialized out-of-home services. The second program is for children with medical issues that without support would require nursing home services. The third program is for children with intense medical needs. These are children that are dependent

on life support technology such as ventilators and without these in-home services would require services in a hospital setting.

Diversion or crisis services are available to all individuals with I/DD regardless of the service types or settings they are receiving. These short-term services (which could include additional in-home support, respite or temporary out-of-home placements) are provided to individuals with developmental disabilities who are at imminent risk of being committed to the state for their care and custody due to potential harm to themselves or others. The purpose is to try and ameliorate the situation creating the crisis situation by focusing intense targeted supports and minimizing the need for costly long-term supports.

Program Design

Staff and services support the administration of ODDS programs through a central office providing strategic planning, program funding, policy development, general oversight, and technical support to community services and support and leadership for various advisory councils.

Program Delivery

The structure for service delivery and design includes a central program administration office and contracted services with Community Developmental Disabilities Programs (CDDP) and Adult Support Service Brokerages (Brokerages). Contracted Community Developmental Disability Programs (CDDP), usually operated by County government are responsible for service eligibility determination, program enrollment, case management, abuse investigation, provider development, quality assurance, and crisis response. CDDP’s are also responsible local planning and resource development, and

documentation of service delivery to comply with state and federal requirements. ODDS provides funding for nearly 497 FTE of CDDP staff.

For adults who are getting Support Services, the case management function is provided by the contracted Brokerages.

Community Developmental Disability Programs (CDDP) field reviews ODDS conducts field reviews in each county in a five-year cycle. Areas of review include accuracy and reporting of eligibility for developmental disabilities determinations, targeted case management functions, documentation and billings, incident reporting and abuse investigations, contract development and monitoring, client plan of care reviews and family support implementation. The reviews have assisted ODDS in identifying CDDP-specific strengths and weaknesses requiring more training and technical assistance, as well as common trends across the state that may suggest a need for system changes, improvements, best practices and training.

Adult Support Services field review ODDS conducts annual field reviews of the 13 Adult Support Services brokerages. Areas of review include completeness and quality of assessment and related plan development, timeliness of access to plan development and implementation, responsiveness to participant needs and choices, documentation of provider and staff qualifications, accuracy of benefit levels, fidelity to department-issued rate and expenditure guidelines, and comparison of plan authorizations to expenditures. The findings are reviewed with the individual brokerages, and the aggregate results are compared to established benchmarks. The outcomes often lead to practice changes and increased

understanding of ODDS policy within a specific brokerage. They may lead to overall system changes, focused training for individual or multiple brokerages, and refinement of ODDS policy.

History – future trends

The state of Oregon is recognized nationally as an innovative leader in developing community-based services for individuals with developmental disabilities. Oregon is one of only three states that have no state or privately operated institutional level services specifically for people with developmental disabilities. In fact, the majority of individuals with developmental disabilities in Oregon, approximately 67 percent, are served in their own home or their family's home.

That is the result of two decades of work to aggressively “re-balance” the developmental disabilities system -- moving from an institutional model with expensive “one size fits all” approach -- to a self-directed, family involved, individually focused and less expensive approach to service. Today, consumers and families report a high level of satisfaction through the increased control over services, the ability to more fully integrate in home communities and the benefits of home community life.

However, to maintain those high levels of satisfaction, to further advance the inclusion of people with intellectual and other developmental disabilities in their communities, and to serve the increasing number of people with I/DD requesting services, the system has an urgent need to continue its evolution in a fiscally sustainable manner.

Nationally and in Oregon, the number of people with developmental disability-related needs, such as the autism spectrum and alcohol and drug-related causes, is growing. There also is an increase in the number of people who need services and have co-occurring mental health or corrections needs. Over the past two years there has been a net increase of over 2,000 children and adults with developmental disabilities requesting new services. As a result of the increase in caseload and the nature of the presenting issues the number of children and adults requiring new or increased funding to meet crisis needs is also increasing.

The overall balance of who is being supported by the 24-hour service system is changing. While caseloads are increasing, access to existing resources based on client turnover is declining due to longer life spans. New services being developed are primarily for children and adults in crisis, whose needs are high, usually due to supports related to significant medical needs or behavior and mental health.