
Oregon Council on Developmental Disabilities

New Member Handbook

October 2022



Better Together.



Oregon Council on
Developmental Disabilities

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Welcome to the Oregon Council on Developmental Disabilities (OCDD)!

We are a federally funded state agency whose purpose is to serve as an advocate for persons with developmental disabilities. We also advise the Governor, Legislators, state agencies and the public on matters relating to the needs and rights of people with developmental disabilities and their families to be independent, productive and included in all aspects of community life.

Our mission is to advance social and policy change so that people with developmental disabilities, their families and communities may live, work, play and learn together.

Our vision is that all communities welcome and value people with disabilities and their families.

Guiding principles

We believe disability is a natural part of the human experience.

We believe people with developmental disabilities and their families...

- Define their own families and sources of support.
- Are successful when they make informed choices and control their lives.
- Are most effective when they work together for social and policy change.
- Are more likely to succeed when we expect them to succeed.

We believe communities...

- Are welcoming when everyone is valued.
- Are better when members act together.

- Thrive when everyone contributes.

We believe support service systems are most effective when...

- Families are supported to raise children in stable and loving homes.
- People are supported to live the lives they want in their communities.
- Supports are based on individual strengths, goals and community assets.
- They are accountable to the people they serve.

The Council's authority

Councils were created in 1970 and are currently authorized by federal law in the *Developmental Disabilities Assistance and Bill of Rights Act of 2000*. We call this the “DD Act,” which President Kennedy signed into law in 1963.

The Oregon Council on Developmental Disabilities (OCDD) was established in Oregon on October 23, 1974 by Governor Tom McCall’s Executive Order 74-18. Governor McCall established the Council as a unit of state government and named the Department of Human Services (DHS) as our “designated state agency” or DSA.

Our Executive Order describes the roles of the Council and our DSA consistent with DD Act requirements. DHS reviews the Council’s state plan, provides fiscal support, accounting and keeps records as needed by the Council and the federal government. In short, we have a financial relationship with DHS. However, we also collaborate with DHS and its agencies to advance policy change in the best interests of people with developmental disabilities and their families.

Interagency agreement between Department of Human Services (DHS) and the Council

The Council has an interagency agreement with DHS, which describes the details of our relationship consistent with the DD Act. We renew this

agreement every two years. The agreement says that the Council must be free to act without interference from DHS and any other state agency. This allows the Council the freedom to do its job without influence from any person, group, or agency. However, we also operate within state rule, law and policy.

Purpose of the Development Disabilities (DD) Act

The purpose of the DD Act is to assure that people with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of community life.

The DD Act also establishes the direction and funding of Councils on Developmental Disabilities, Protection and Advocacy organizations and University Centers on Excellence in Developmental Disabilities (UCEDDs). These entities carry out the purpose of the DD Act in every state and US territory and are expected to collaborate to this end.

University Centers on Excellence on Developmental Disabilities (UCEDD)

The UCEDDs provide training and education to professionals, conduct research, evaluation and public policy analysis, disseminate information and provide a variety of community services such as training and technical assistance or demonstration projects. Oregon's UCEDDs include:

- The University Center for Excellence on Developmental Disabilities at the University of Oregon in Eugene
- Oregon Health Sciences University Child Development and Rehabilitation Center in Portland

Protection and advocacy organizations

Protection and advocacy organizations (P&As) protect the personal, legal and civil rights of people with disabilities. They also conduct legislative and policy advocacy. Oregon's P&A is Disability Rights Oregon.

Councils on Developmental Disabilities

Councils on Developmental Disabilities are required to engage in advocacy, capacity building, and systems change activities.

Advocacy

In their advocacy role with and alongside people with ID/DD and their families, DD Council members and staff provide valuable information including examples of lived experience to policymakers at all levels of government to provide education prior to legislative or systems decisions being made.

Examples of advocacy include:

- Speaking up on behalf of yourself, your family member, or others with developmental disabilities.
- Providing legislative testimony.
- Educating policymakers

Capacity Building

Capacity building efforts include:

- Strengthening the skills and ability of people and communities to address an issue or goal.
- Helping policy makers understand issues and barriers.
- Increasing access to services that people with developmental disabilities and their families need to live and work in their communities.

The Council builds leadership and advocacy capacity with self-advocates and family members through leadership development trainings (i.e., Partners in Policy Making, Strong Start). Another example of capacity building is the Council's policy and systems change efforts with the Developmental Disability (DD) Coalition to inform policy makers, legislators and other stakeholders about relevant issues.

Systems Change

Our systems change efforts focus on improving the way services are delivered so that people with developmental disabilities can experience self-determination, independence and full participation in their communities. Systems change also includes working with policymakers to:

- Improve laws, rules, policies and practices.
- Educate people families, providers and others.
- Bring people together to address an issue.
- Promote community education.
- Strengthen individual knowledge and skills.

Examples of Council systems change efforts include staff and Council Member participation on state-level policy work groups, providing community education and advocacy talking points through the GO! Bulletin, fact sheets and convening community forums to educate people with disabilities and their families about critical issues.

Key values in the Developmental Disabilities (DD) Act

The DD Act gives Councils powerful direction and broad authority to set priorities in their individual states and territories. Councils work toward public policies that promote several key values for people with developmental disabilities.

Self-determination:

- To make personal decisions;
- To exercise choice and control over services, supports and other assistance;
- Authority to control resources to obtain needed services, supports and other assistance;
- To contribute to the community; and

- To advocate for themselves and others, develop leadership skills, participate in coalitions, educate policymakers, and play a role in the development of public policies that affect people with developmental disabilities.

Independence:

Personal choice and control; freedom from the control of others.

Productivity:

To work or make other contributions to a household or community.

Integration:

Access to the same opportunities, services and community resources as other Americans.

Inclusion:

To fully participate and be welcomed in social, education, work and community life.

The Council's five-year state plan

Councils are required to develop a five-year state plan and use their funds accordingly to implement the state plan. The plan is the “big picture” of how the Council will fulfill its role within a five-year period. The plan:

- Provides guidance to the Council about how to spend its resources.
- Identifies community or systems barriers that need to be improved.
- Includes long-term goals that may be accomplished within five years.
- Includes measurable outcomes that the Council reports to our funder, the Administration on Community Living Office of Intellectual and Developmental Disabilities (OIDD).
- The plan must include a goal or objective to support a statewide self-advocacy organization.

- Councils must also include a goal or objective to address a targeted disparity experienced by an underserved group within the DD population.

Developing goals and desired outcomes

Every five years Councils are required to develop a new state plan. To do so, we gather information from people with disabilities, their families, service providers, public agencies and other organizations to determine what actions we should take over the next five years.

Staff share related information with Council members and members to develop goals, objectives and the outcomes we want to see. Staff also help develop activities needed to accomplish the goals and objectives. The new plan must be submitted to OIDD for approval during August of the final year of the current plan.

Our current plan expires September 30, 2026. We will begin planning for our next five-year plan about 18 months before this date.

Annual work plans

Each federal fiscal year (October 1st to September 30th), the Council develops an annual work plan that outlines what we plan to accomplish. Any significant amendments the Council would like to make to our goals or objectives must be sent to OIDD by August 15th of that year. Otherwise the annual work plan is due in December with our annual program performance report.

Annual program performance reports (PPR)

Each December, the Council must submit a program performance report (PPR) to OIDD. The report describes progress the Council has made towards its goals over the past year.

Ongoing initiatives

The Council supports two ongoing initiatives that help us fulfill our role. These include the Oregon Self-Advocacy Coalition, the Oregon Consortium of Family Networks. Each initiative is described below.

The Oregon Self-Advocacy Coalition (OSAC)

The Oregon Self-Advocacy Coalition (OSAC) is an independent 501c3 nonprofit organization led by self-advocates. Their members include several individual self-advocates and self-advocacy groups located throughout the state. OSAC's mission is to advocate for the rights of people experiencing developmental disabilities. They want people with developmental disabilities to have a unified voice on issues that are important to them. This work is based on the following priorities.

- All people with developmental disabilities should have living wage jobs in their communities.
- All people have the right to access good, quality, affordable health care services. Many people with developmental disabilities do not get the services they need.
- No decisions that impact our lives should be made without hearing our voices. Essentially, we ask for “nothing about us without us!”

The Council is required to support a statewide self-advocacy organization and self-advocate leadership development. Subsequently, we provide ongoing funding to help OSAC meet their goals. Additionally, OSAC and its members are critical partners in our work to educate policy makers and legislators about critical issues that impact the lives of people with DD and their families. We could not do this work without them!

The Oregon Consortium of Family Networks (OCFN)

The Oregon Consortium of Family Networks (OCFN) represents an ongoing agreement between the Department of Human Services (DHS) and OCDD to

develop local family-to-family peer support networks across the state. The purpose of the Networks is to ensure that families have access to peer support and opportunities to engage fully in their communities.

Family-to-family peer support networks were formally established with legislative funding in 2010, before Oregon developed Medicaid-funded services for all children with developmental disabilities (under age 18). The Council and state leaders recognized that families of children with DD experienced isolation, significant barriers to accessing their communities, and lacked needed support.

Each biennium, the legislature allocates funds for this initiative to be paid through DHS. Subsequently, DHS maintains an interagency agreement with the Council to support local Networks. Meanwhile, OCDD oversees contracts with each Family Network. Council staff provide technical assistance to help each network meet contract deliverables and implement Network activities utilizing principles of Asset-Based Community Development and the LifeCourse Framework (see sidebars).

Collectively, the Networks are engaged with thousands of families and community partners across Oregon. Each Network supports families to have a vision for a whole life for themselves and their children, to use Medicaid-funded services effectively, and to access existing resources in their local communities. The Networks also support local community businesses and organizations to enhance how they welcome people experiencing disability and their families.

Asset-Based Community Development (ABCD)

Asset-Based Community development is a large and growing movement that considers local assets as the primary building blocks of sustainable community development. Building on the skills of local residents, the power of local associations, and the supportive functions of local institutions, asset-based community development draws upon existing community strengths to build stronger, more sustainable communities for the future.

Learn more at:

<https://resources.depaul.edu/u/abcd-institute/Pages/default.aspx>

Council members

The DD Act requires Councils members to represent people with developmental disabilities, family members and agencies that serve people with developmental disabilities. We have up to 33 Governor appointed membership positions that help the Council meet these requirements. Our members are appointed for up to two four-year terms (required agency representatives may serve ongoing terms). Some representatives fit more than one category but only represent one position on the Council.

People with developmental disabilities and family members

At least 60% of our members must be people with developmental disabilities and immediate family members of people with developmental disabilities. Membership positions include:

- People with developmental disabilities (9)
- A person who lived in an institution (or guardian/relative of such a person) (1)
- Family member of people with developmental disabilities (10)

Agency representatives

Other membership positions are reserved for representatives of state agencies that receive federal funding on behalf of people with developmental disabilities. These include:

- Vocational Rehabilitation (1)
- Office of Developmental Disabilities (1)

The LifeCourse Framework

The LifeCourse Framework is an approach to help families of children with developmental disabilities “plot a course” for their wholes – for their children and for themselves.

Learn more at:

<https://ocdd.org/looking-for-support/>

www.lifecoursetools.com

- Oregon Department of Education (1)
- Oregon Health Authority (Medicaid state agency) – Title XIX (1)
- Maternal and Child Health – Title V (1)
- Aging and People with Disabilities – Older Americans Act (1)

Administration on Intellectual and Developmental Disability (OIDD) network partners

We are also required to have representation from our OIDD Network partners. These are entities also established in the DD Act.

- University of Oregon, Center on Human Development – UCEDD (1)
- Oregon Health Sciences University, Child Development and Rehabilitation Center – UCEDD (1)
- Disability Rights Oregon (Protection and Advocacy organization) (1)

Finally, we have four positions reserved for community partners that have an interest in people and families experiencing developmental disabilities.

Council member responsibilities

The Council meets six times per year. During meetings, members learn about policy issues, hear from guest speakers, and provide input to shape the Council’s work. Council members are responsible to:

- Read the membership handbook and attend a new member orientation.
- Regularly attend each Council meeting or notify staff if they cannot attend a meeting.
- Participate in discussions and ask questions.
- Request accommodations and support to participate, as needed.
- Get to know other Council members and support new members.
- Help develop and approve the Council’s state plan.

- Help develop and approve our annual budget.
- Monitor the annual budget and make decisions as needed
- Watch progress being made toward the State Plan goals and objectives.
- Review and abide by the Council by-laws.
- Formally announce any potential conflict of interest (financial benefit) related to being a member of the Council (like working for an organization that has a contract with OCDD).
- Participate in Council-sponsored activities whenever possible.
- Identify community partners or leaders with whom the Council could build strategic relationships to achieve our goals.
- Evaluate the Executive Director each year.

Council officers

The Council is governed by two officers – the Chair and Vice Chair. Officers are elected every two years (during odd years) by majority vote. They may serve no more than two consecutive terms. Their roles are described below.

Chair

- Presides at all Council and Executive Committee meetings.
- Works with the Executive Director to prepare agenda for Council Meetings and Executive Committee Meetings.
- Calls special meetings, as needed.
- Appoints chairs and members of committees and work groups.
- Works with the Executive Committee to conduct the Executive Director’s annual performance review.

Vice-Chair

- Serves as Chair during meetings when the Chair's is absent.
- Serves on the Executive Committee.
- Performs other duties assigned by the Chair.

Committees and work groups

Executive committee

Executive committee members generally serve a two-year term. When a new Chair and Vice Chair are elected, they recruit a new Executive committee. This committee:

- Meets at least quarterly.
- Provides direction to the Executive Director.
- Oversees implementation of the five-year plan.
- Assists the Chair with the Executive Director's annual review.
- Plans activities to support Council member participation.

Ad hoc committees or work groups

Ad hoc committees are formed as needed. The Chair may choose to form ad hoc committees or work groups to address a time-limited project. For example, the Chair may form an ad hoc committee to review a draft annual budget before presenting it to the full Council.

The Grassroots Oregon (GO!) Bulletin

We distribute the Grassroots Oregon (GO!) Bulletin to our listserv most frequently during legislative session. This publication is produced in collaboration with the Developmental Disabilities (DD) Coalition (oregoniddcoalition.org). The Bulletin provides information about critical issues, advocacy events and policy and budget bills that impact people with developmental disabilities and their families. Council members are automatically signed up for the GO! Bulletin when they become members.

Council operations

Bi-monthly meetings

The Council meets for a full day on the third Friday of every other month (during even months). Our meetings are a combination of in-person meetings and virtual meetings on Zoom.

Quarterly activities

The Council operates on the federal fiscal year (FFY), which begins October 1st and ends September 30th of each year. What follows is a summary of major Council and staff activities that take place each quarter.

First quarter: October 1st through December 31st

- Agenda planning; Council meetings in October and December
- Agenda planning; Executive committee meeting
- Internal quarterly reporting on activities for PPR
- National disability employment awareness month (October)
- Anniversaries of the DD Act and OCDD (October)
- Complete Annual Program Performance Report (PPR) (December)
- Reconcile ODHS's accounting of our budget

Second quarter: January 1st through March 31st

- Agenda planning; Council meeting in February
- Agenda planning; Executive committee meeting
- Internal quarterly reporting on activities for PPR
- Director presents any budget changes to Council (may require a vote if changes are significant)
- Annual evaluation of Executive Director

- Legislative session and updates; GO! Bulletin and activities
- March DD Awareness activities

Third quarter 3: April 1st through June 30th

- Agenda planning; Council meetings in April and June
- Agenda planning; Executive committee meeting
- Internal quarterly reporting on activities for PPR
- Chair and Vice Chair elections during odd years
- Review what happened during the legislative session
- Begin review of annual work plan for any necessary amendments

Fourth quarter: July 1st through September 30th (end of FFY)

- Agenda planning; August Council meeting
- Agenda planning; Executive committee meeting
- Internal quarterly reporting on activities for PPR
- Review proposed annual plan and draft budget for coming FFY. Council vote to approve final budget.
- Develop annual work plan and submit to OIDD; Submit annual five-year plan amendments, as needed
- Update the Council's history document

Elections and voting

The Council uses a relaxed version of Robert's Rules during meetings and works towards consensus on issues so that everyone (or most everyone) can agree. Council business is completed by majority vote when a quorum of current Council members is present. A quorum is half of current membership plus one. (For example: if we have 30 members, a quorum is 16.)

Policy Governance

The Council operates using a model called Policy Governance. It is a way for a part-time, volunteer board to lead an organization effectively without getting bogged down in management issues. Under a full Policy Governance model, the Council discusses issues and makes decisions as a full body without standing committees that have decision-making authority. The board, in this model, speaks with one voice and the Director is accountable to the full body. The exception to this model are our one standing committee.

- The Executive committee may make a decision on behalf of the full Council in an emergency when the full Council cannot meet.

Conflict of Interest

A real or potential conflict of interest happens when a decision made by the Council may help a Council member benefit financially. A common example happens when a Council member is an employee of an organization that is a Council-funded contractor. Another example happens when a Council member becomes a Council contractor.

Per our by-laws, we must recognize potential conflicts of interest during a Council meeting. If a Council member becomes a contractor or an employee of an organization that is a contractor, we must discuss this during the Council meeting so it can be recorded in the meeting minutes.

Using our examples, when the Council discusses funding a contract, the Contractor, or employee of a Contractor, must excuse him or herself from participating in any discussion or voting.

Council budget

The Council receives funding from both the federal and state government. Federal funds may only be used to implement our state plan. Occasionally, we also receive funds from other sources, like interagency agreements with other state agencies.

Federal funds

Every federal fiscal year (FFY) we receive an annual grant from OIDD. During FFY 2022, we were awarded \$843,484. The DD Act allows the Council three years to spend each annual grant. We use these funds to operate the Council, pay staff and implement our five-year plan.

State funds

Per the DD Act, DHS provides financial and in-kind support to the Council. We also receive in-kind support, including rent and utilities, support with computers and technology, budget administration and record keeping, human resources services and contracting services. In FFY 2021, ODHS supported the council with \$216,427.02 in in-kind support. In return, the Council pays the state no more than 5% of our annual budget or \$50,000 – whichever is less.

Other Funds

Sometimes we apply for other funds. These funds may be contracts, grants or interagency agreements with other state agencies. The terms of such funds must align with the Council's state plan and help us achieve our goals.

For example, the Council has interagency agreements with the Department of Human Services, Office of Developmental Disabilities to operate the Family Networks.

Budget categories

The Council budget is divided into five categories:

1. Income

Our income includes our annual grant from OIDD, any unspent funds from previous fiscal years (carryover amount) and funds from DHS. The amount of our federal grant and carryover changes from year to year depending on appropriations set by Congress and our spending for the year. We may not

spend over 30% of our annual grant on administrative costs. This means most of our federal grant is spent on implementing our five-year plan.

2. Personnel expenses

Personnel expenses include salaries and benefits for staff.

3. Operating expenses

Operating expenses are the necessary costs of doing business. These include the amount we pay to DHS for administrative and other support services, in and out-of-state travel, meeting costs, office equipment rental, phones and supplies and membership dues.

4. Five-year plan expenses

This category includes the costs of any major initiatives we implement to help us reach our goals. Examples include:

- Funding for leadership development trainings.
- Funding for the Oregon Self-Advocacy Coalition.

5. Contracts and grants

This category includes any contracts or grants we enter into with other professionals or organizations to help us reach the goals in our five-year plan. For example:

- We provide a grant to the Alliance for Early Intervention to coordinate family education and advocacy for early intervention and early childhood special education.
- We contracted with an evaluation expert to help us develop an evaluation framework and plan to track our activities and outcomes.

Council staff

Leslie Sutton, Executive Director

Leslie believes that Oregon is strongest when all people have opportunities to succeed. At the Council, Leslie works to ensure that Oregon's policies and practices ensure that all people live full lives in their communities and that there are new leaders ready to support these policy efforts. Prior to joining the Council, Leslie worked for Disability Rights Oregon where she handled Medicaid, Social Security and disability matters. Before returning to Oregon in 2010, Leslie worked for the Northwest Justice Project, one of Washington State's legal services providers, where she represented clients in Medicaid and other disability law cases.

Contact: Leslie.Sutton@ocdd.org or 503-616-0349.

Emilie Wylde Turner, Public Policy Director

At the Council, Emilie is our liaison to the legislature, state policy makers, and human services coalitions. In this role, she leads legislative and policy advocacy and systems change efforts. She also develops legislative priorities and talking points and coordinates the GO! Project Bulletin and activities with the IDD Coalition. Contact: Emilie.WyldeTurner@ocdd.org, or (971)219-8566.

Ryley Newport, Communications Director

Ryley Newport is the Communications Director for the Council. He has worked for the past 10 years in the disability field. His primary role has been expanding the involvement of people with disabilities and their family members in social and policy change. Prior to joining OCDD, Ryley worked for the Oregon Self Advocacy Coalition (OSAC), the Association of People Supporting Employment First (APSE), U.S. Senator Tom Harkin, the Washington Initiative for Supported Employment (WISE) and Washington State's Developmental Disability Council. He currently is an At-Large Board Member of Oregon APSE and the Public Policy Liaison for the chapter. When not working, he spends his time exploring and surfing in Oregon with his family. Contact: Ryley.newport@ocdd.org or 503-949-7203.

Contact Information

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