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GET INVOLVED
GET RESULTS**

**Make a Difference for People
with Developmental Disabilities.**

Join the Oregon Disability Network at www.oregonnetwork.org

Painting by Brad Eblston

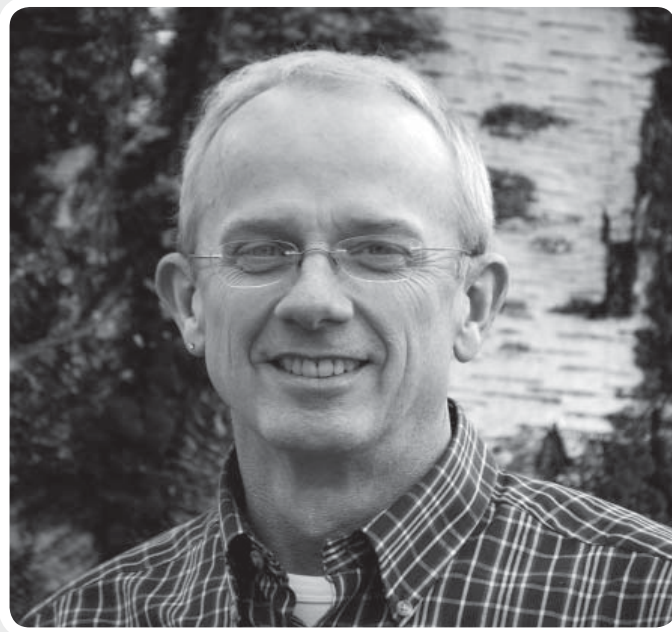
OREGON COUNCIL ON DEVELOPMENTAL DISABILITIES

THE ARC OF OREGON

OREGON COUNCIL ON DEVELOPMENTAL DISABILITIES

2009 ANNUAL REPORT

On the cover: The Council's 2009 awareness poster, co-produced with The Arc of Oregon. Contact the Council for free copies.



A MESSAGE FROM **BILL LYNCH**, EXECUTIVE DIRECTOR

2009 was another legislative year, which always means the Council works at warp speed to keep pace with what's happening at the Capitol while continuing other efforts to advance the advocacy goals in our Five Year Plan. But this was no ordinary legislative session. With the state budget in disarray and hot-button issues on the legislative agenda, passions ran high and patience ran short. By session's end, however, some significant outcomes for Oregonians with developmental disabilities were achieved. And by year's end, the Council and our partners had tallied up other significant program and policy outcomes in line with the Council mission and values.

Most of you who receive this report are advocates and contributed to our accomplishments in 2009. To paraphrase the poster on the cover, you got informed, got involved, and *together* we got results! So as you read this annual report, you should take pride in what we have achieved together.

— Bill

OUR MISSION & VALUES

The mission of the Oregon Council on Developmental Disabilities is to create change that improves the lives of Oregonians with developmental disabilities.

The Council envisions a state where all people from all the diverse populations of Oregon:

- Are valued equally
- Have the same legal and human rights
- Have self-determination, choice and control over their own lives
- Are included in community life
- Have the supports they need to live healthy, safe and fulfilling lives.



WHAT IS A DEVELOPMENTAL DISABILITY?

A developmental disability is a physical and/or mental impairment that occurs before a person is 22 years old. The impairment has continued or can be expected to continue indefinitely, and is likely to create barriers to the ability of the individual to function independently. Developmental disabilities include: cerebral palsy, epilepsy, autism, intellectual disability, and other neurologically disabling conditions.



PURPOSE & **MEMBERSHIP**

The Oregon Council on Developmental Disabilities was established by a Governor's Executive Order in 1971. The Governor appoints the Council's 25 members, sixty percent of whom must be individuals with developmental disabilities or family members of someone with developmental disabilities. Currently, eight full-time and four part-time staff support the work of the Council.

Councils exist in every state and US territory. They are authorized by Congress under the federal Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402). The majority of the

Council's funding comes from the federal agency authorized by this law, the Administration on Developmental Disabilities (ADD). The Council also receives administrative services, in-kind contributions and minimal financial support from the Oregon Department of Human Services, the Council's "designated state agency."

The DD Act directs Councils to "engage in advocacy, capacity building, and systemic change activities that... contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families." PL 106-402, SEC. 101 (b)

Interested in joining the Council?

Contact the Council or visit our webpage www.ocdd.org for a copy of the membership application.

WHAT **WE** DO



Support Self-Advocacy Leadership and Engagement

The Council, along with Seniors & People with Disabilities Division, provides financial support and training dollars to Self Advocates as Leaders (SAAL) through a contract with the Regional Research Institute at Portland State University. SAAL is a statewide organization dedicated to leadership development and systems change through self-advocate involvement in public policy. In 2009, SAAL provided technical assistance to local self-advocacy organizations and conducted numerous trainings for hundreds of individuals throughout Oregon on topics such as leadership, self-determination, consumer empowerment, and legislative advocacy. SAAL members participate on numerous coalitions and committees dealing with all areas of disability policy, as well as on governing boards of many disability organizations.

SAAL and the Council collaborate on *The SAAL Connection*, a quarterly magazine written by and for self-advocates. Most of the magazine's contributors have attended My Story Workshops sponsored by SAAL. With more than 3,400 subscribers, *The SAAL Connection* has become a significant vehicle for sharing personal stories of self-advocates in Oregon.

Want to get involved in SAAL, subscribe to *The SAAL Connection*, or attend a My Story Workshop?

Contact SAAL at 503-589-1664 (Salem) or 888-589-1664 (toll free). Visit the SAAL webpage at www.asksaal.org.



WHAT **WE** DO | Support and Work with Coalitions and Partnerships

The Council conducts most of its advocacy in partnership with other organizations, including the following:

Oregon Developmental Disabilities

Coalition: The DD Coalition has been a major force in legislative advocacy and public policy issues for many years. The mission of the DD Coalition is “to influence policy to create adequate funds and sustain quality services and supports that respect families and furthers the rights, equality, justice and inclusion for all Oregonians with developmental disabilities.”

The Coalition, with significant support from the Council, continued to conduct the Training Series on Direct Supports with funding from the state. In 2009, the training series reached another 450 direct support workers.

The Coalition was very active during the 2009 Legislative session tracking and testifying on bills that would have a direct impact on people with developmental disabilities. Highlights include:

- Restored \$8 million of the proposed \$13 million reduction in Early Intervention/Early Childhood Special Education. The program will not be required to return to

the Emergency Board for funding of case load growth and the Subcommittee on Ways and Means approved the use of formula based funding for future budgets.

- Passed legislation that establishes conditions when a confession alone is sufficient for prosecution. This bill is intended to assist in situations where the victim is not considered competent to testify.
- Passed legislation that expands the definitions of abuse and strengthens the abuse investigation system. The bill modifies definitions; creates local multidisciplinary teams to develop protocols related to investigations; establishes timelines and communication requirements for investigation and notification; increases statewide consistency in abuse investigations; protects employers when disclosing information about prospective employees to another employer; and increases fines.

- Passed legislation that strengthens anti-bullying policies in schools.
- Passed legislation to close the Oregon School for the Blind. OSB was not accredited to provide a high school diploma. Establishes the Blind and Visually Impaired Student Legacy Fund and appropriates funding for community education supports for the 30 OSB students.
- Opposed legislation to include domestic employees hired by brokerage customers and others under the Home Care Commission and set a process for establishing a bargaining unit for union representation of these workers. The DD community opposed the bill because of potential reductions in services to pay for the additional costs of the program and concerns that it might significantly change the nature and governance of services. A budget note requires the Department of Human Services to seek legal opinion on whether some DD self-directed community based services should already be covered by the Home Care Commission. Additionally, the House Human Services Committee is to create a workgroup to address the relationship of DD client-directed community-based services and SEIU / Home Care Commission.
- A package of Autism Spectrum Disorder bills was introduced early in the session. The bills did not move because the Governor issued an Executive Order creating the Oregon

Commission on Autism Spectrum Disorder. The Commission is expected to address many of the issues identified in the proposed legislation.

Want to learn more about the DD Coalition?

Visit the coalition webpage at www.oregonddcoalition.org.

Want a copy of the 2009 Legislative Report?

Contact the Council.

Family and Community Together (FACT):

With a membership of nearly 20 advocacy organization, FACT has become a strong voice for Oregon families of children and adults who experience a broad range of disabilities. The mission of FACT is to “ensure that people with disabilities and their families are central in all policy and systems development and implementation, resource allocation, leadership development, and collaborative decision-making involving people with disabilities.” FACT has collaborated with other family groups and organizations to bring national speakers to Oregon. In 2009, FACT was awarded a state grant to create the FACT Family Center. This family support and information center serves families of children from birth to age 18 years, who experience a developmental disability in Clackamas, Multnomah, and Washington counties.

Want to know more about FACT?

Call 888-988-FACT (3228) or visit their web site at www.factoregon.org.

WHAT **WE** DO | Maintain and Expand a Grassroots Network

The Council's grassroots network, called the Oregon Disability Network, includes more than 5,800 people with disabilities, family members, advocates, service providers and other interested Oregonians. Network members receive Council publications and become members of the DD Coalition's GO! Project (Grassroots Oregon). The GO! Project allows advocates to easily respond to action alerts and communicate their concerns to policy makers at the state and national levels. The DD Coalition website includes GO! Project fact sheets and other information for advocates. The GO! Bulletin provides timely information about current issues and resources. The GO! Project also organizes advocacy trainings in Salem and around the state.

Want to join the Oregon Disability Network, receive GO! Bulletins and get involved?

Log on to www.ocdd.org or call the Council for a copy of the Oregon Disability Network sign-up form.



Participate on Advisory Groups

The Council had a leadership role on many disability policy and advisory groups at the state and national levels, including...

DD Quality Assurance Committee: This committee advises DHS about how to ensure quality outcomes for children and adults with developmental disabilities who are in community-based services, including comprehensive (24-hour) services, support services through brokerages and in-home services for children. A top priority in 2009 was to advise on implementation of HB 2442, which is designed to address the high rate of abuse and neglect of people with developmental disabilities.

Staley Implementation Group (SIG):

The Council's oversight role in the implementation of Support Services for Adults (mandated by the Staley lawsuit settlement agreement) has resulted in more people entering self-directed services, more dollars leveraged for those services and significant policy changes/program improvements. This year 1,696 individuals received Support Services, effectively ending the waitlist for these services. Now all eligible individuals are to be served within 90 days.

Want more information about Self-Directed Support Services?

Log on to The Arc of Oregon web site at www.arcoregon.org or contact your County Developmental Disabilities Program office at: http://www.oregon.gov/DHS/dd/county/county_programs.shtml

Restructuring Budgets, Assessments and Rates (ReBAR) Stakeholder Advisory Group:

The Council also advises Seniors & People with Disabilities Division (SPD) on this major systems change project. The goal of the project is to build fairness and equity into Oregon's provider rates system and build self-determination into comprehensive services through individual budgets based on individualized needs assessments. SPD contracted with the Council to provide orientation to individuals and family members who will receive Supports Intensity Scale (SIS) needs assessments by professionally trained assessors. The Council developed orientation materials, including a brochure, a narrated

PowerPoint presentation for family members, and an illustrated booklet for people with developmental disabilities. Nearly 350 attended orientation sessions about the interview process.

Want more information about ReBAR?

Go to www.oregon.gov/DHS/dd/rebar

Oregon Disabilities Commission: ODC is composed of 15 members appointed by the Governor, the majority of whom are people with disabilities. Two Council staff persons were appointed as commissioners, including one who serves as chair. The commission is charged by state statute to advise the Department of Human Services, the Governor, the Legislative Assembly and appropriate state agency administrators on issues related to achieving the full economic, social, legal and political equity of individuals with disabilities. This year ODC formed the Employed Persons with Disabilities (EPD) Subcommittee, chaired by Council staff, to advise SPD on this program. EPD allows people with disabilities to earn significant wages and still retain important medical benefits.

Want the ODC 2009 Report to the Governor or more information about EPD?

Go to www.oregon.gov/DHS/spd/adv/odc/index.shtml

Competitive Employment Project (CEP) Leadership Council: The Oregon Competitive Employment Project is funded by the Oregon



Vocational Rehabilitation Division through a Medicaid Infrastructure Grant. The purpose of the project is to address systemic barriers to competitive employment for people with all types of disabilities. In 2009, the project continued to operate the Work Incentives Network (WIN), which assists individuals on Social Security benefits who want to work but are worried about what will happen to their benefits. CEP also participated in the development of a national media campaign targeted at employers. The campaign will be launched in 2010.

DD Employment Task Force: This group of advocates and providers formed in 2005 to pursue a vision that every Oregonian with developmental disabilities has the opportunity, customized supports and incentives to achieve and maintain employment and pursue a career in the competitive workforce based on informed choice. The task force also serves as an advisory group to Seniors & People with Disabilities Division (SPD) and the Competitive Employment Project of the Office of Vocational Rehabilitation Services. A major focus of the task force in 2009 was to develop a strategic plan and advise SPD on implementation of the state Employment First Policy. The policy says that employment should be the first option considered when planning for services and supports with people with developmental disabilities.

Want a copy of the Employment First policy?
Go to <http://ocdd.org/index.php/ocdd/whatwedo/13/>

Oregon Commission on Autism Spectrum Disorder: A Governor's Executive Order created a Commission on Autism Spectrum Disorder in early 2009. The Departments of Human Services and Education contracted with the Council to support the creation and ongoing operations of the new commission. This is a time-limited commission directed by the Governor to develop recommendations for improved and/or expanded state services to individuals on the autism spectrum and their families. Approximately 75 individuals, including the 13 Commissioners, serve on the 7 committees. A final report with Commission recommendations will be submitted to the legislature in 2011.

Want to learn more about the Commission?
Go to www.orcommissionasd.org

Fairview Community Housing Trust Fund: The Council had a key role in the legislation that created this fund and has a leadership role on the trust fund advisory board. Proceeds from the sale of the Fairview Training Center property were placed in a trust fund. Interest from the fund is used to make small grants on an annual basis to individuals who do not receive state-licensed residential services. A variety of projects have been funded, including the ramp construction, bathroom remodels and

purchase of therapeutic equipment. In 2009, these funds helped 80 people become more independent and safe in their homes through home modifications and equipment purchases. Council leadership helped convince the legislature not to take money from the trust to help balance the state budget.

Want to apply for a Fairview Community Housing Trust Fund grant?

Contact Seniors & People with Disabilities Division at 503-947-5182 or visit the web at www.oregon.gov/DHS/dd/housing.shtml#fairviewtrust.

HB 2009 Transition Stakeholders Group:

Implementation of HB 2009 passed in 2009 requires the creation of a new state agency, the Oregon Health Authority. The legislation moves health care and mental health / addictions to the new agency. Services to seniors, people with disabilities, child welfare, TANF, and self sufficiency services will remain in the Department of Human Services. There are many issues to be resolved, including what happens when administrative structures like the Medicaid authority are separated from the policy focus. Stakeholder members of this group include representatives from the various divisions within the current DHS, as well as, local government, unions, legislative fiscal office, the office of budget and management, and advocates. A Council staff person is a member of the group.

“On The Move” Project Advisory

Committee: The committee provides advice to Seniors & People with Disabilities Division on this federally funded project that provides opportunities for people with disabilities to

move from nursing homes and institutions into community settings. In October 2009, the last resident left Eastern Oregon Training Center, Oregon’s last remaining institution for people with developmental disabilities. Oregon is now the only state in the nation that does not place people with developmental disabilities in Intermediate Care Facilities.

Oregon Health Services Commission: The Oregon Health Services Commission oversees the management of the Oregon Health Plan prioritized list of health services for the state Medicaid and Children’s Health Insurance Programs. Members of the Commission serve four years. They are appointed by the Governor and approved by the Senate. A Council staff person is serving a second term on the Commission.

National Association of Councils on Developmental Disabilities: NACDD is a national non-profit that supports the work of state DD Councils and is the voice of Councils on federal policy issues. In 2009, the Council was represented on the board of directors and on the Public Policy Team.

Want timely information on national disability policy issues?

Visit the NACDD website at www.nacdd.org and click on their Legislative Action Center.



WHAT WE DO | Conduct Projects, Programs, Campaigns and Trainings

Inclusive Child Care Program: This statewide program is a partnership between the Council, the Department of Human Services and the Oregon Employment Department's Child Care Division. The program provides supplemental child care subsidies for low-income families of children with disabilities who have exceptional support needs in a child care setting. This year the program helped 159 children receive care in inclusive child care settings. The subsidy pays for the extra supports a child might need to be in appropriate care. The program serves children through age seventeen with physical, developmental, mental, emotional, behavioral or medical disabilities. The program also provides training to child care providers; nearly 200 providers were trained in 2009. The program continues to disseminate *Open Hearts, Open Doors*, a pamphlet published in English and Spanish with tips and resources for providing inclusive child care.

Want information about how to apply for a subsidy?

Contact Inclusive Child Care Program at 971-673-2286 or toll free 1-866-837-0250.

Email inclusivecc@oregonchildcare.org

Want a copy of Open Hearts, Open Doors?

Request a copy from the Council or find it on our webpage at www.ocdd.org

Consumer Involvement Fund: The Council's Consumer Involvement Fund provided about \$7,100 in stipends for 35 self-advocates and family members to attend in-state and out-of-state conferences and trainings, and share what

they learn with their communities. A Council committee composed of self-advocates, family members and staff manage the fund. Besides individuals, conference organizers can also apply and receive funds so they can offer stipends to their events.

Want to apply for funding?

Contact the Council for an application form or download the form from our web site at www.ocdd.org.

Public Awareness Campaigns: Every year the Council launches a campaign to raise public awareness about a particular issue related to developmental disabilities. At a public event in March, a proclamation from the Governor is read that declares Developmental Disabilities Awareness Month, Developmental Disability Champion Awards are given to policy makers and advocates, and an awareness poster co-sponsored by The Arc of Oregon is unveiled. This year State Representative Chris Edwards was honored for his strong advocacy and support for individuals experiencing Autism Spectrum Disorders and their families. Roberta Dunn, Executive Director of FACT (Family and Community Together), was honored for her dedication as a long-standing parent advocate. The message on this year's poster, read "Get Informed, Get Involved, Get Results," and encouraged people to get involved on issues that are important to people with developmental disabilities.

Want a copy of a poster?

View, download or order a copy at www.ocdd.org or contact the Council.

HIGHLIGHTS OF COUNCIL ACCOMPLISHMENTS

The Council, along with its contractors, collaborators and partners, played a critical role in achieving significant outcomes for people with developmental disabilities in the following areas:



EMPLOYMENT

- 56 people were trained on person-centered employment.
- 5 employment policies/programs were created and/or improved.

EDUCATION AND EARLY INTERVENTION

- 6 policies/programs were created or improved.
- 3,000 children have services/supports needed to reach developmental goals.
- 74 people were trained in inclusive education.
- 73 parents trained on their child's educational rights.

HOUSING

- \$159,275 was leveraged for housing.
- 80 individuals have homes of their choice due to Council efforts.
- 3 housing policies/programs were created and/or improved.
- 36 individuals moved from congregate settings into homes in the community.

HEALTH

- 73 people have needed health care services through Council efforts.
- 5 health care policies/programs were created and/or improved.

CHILD CARE

- \$534,424 was leveraged for inclusive child care programs.

- 159 children were placed in inclusive child care settings through Council efforts.
- 150 child care policies/programs were created and/or improved.
- 197 people were trained in inclusive child care.

QUALITY ASSURANCE AND SELF-DETERMINATION

- \$58,669,504 was leveraged for quality assurance programs.
- 9,616 people benefited from quality assurance efforts of the Council.
- 14 quality assurance policies/programs were created and/or improved.
- 1,162 people were trained in quality assurance.
- 1,992 people were active in systems advocacy about quality assurance.
- 424 people were trained in leadership, self advocacy and self determination.
- 46 entities participated in partnerships or coalitions created or sustained as a result of Council efforts.

PUBLIC EDUCATION AND AWARENESS

- 107 public policymakers were educated by the Council about issues related to Council initiatives.
- 37,000 copies of products were distributed to policymakers and the general public about issues related to Council initiatives.
- Over 360,000 members of the public were reached through the media.

CONTACT US



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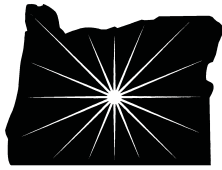
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To request additional copies of this publication, or for more information, please contact us. This publication is available in alternative formats upon request. DD Awareness event pictures courtesy of Claudean Schaeffer.

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