

OREGON COUNCIL ON DEVELOPMENTAL DISABILITIES

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Oregon Council on Developmental Disabilities • 2007 • The Arc of Oregon

2006-2007 BIENNIAL REPORT

A MESSAGE FROM **BILL LYNCH**, EXECUTIVE DIRECTOR AND **JOE CARROLL**, CHAIR

In August 2006, after a year-long process, the Council finished crafting a new Five-Year Plan to guide our advocacy efforts and the investment of our resources through 2011.



As you will discover when you read this report, our advocacy work did not come to a halt while we planned for the future. Much of the work we committed to when we submitted our Five-Year Plan is a logical extension of the work we

Development of this strategic plan was no small task. We collaborated with our “sister agencies” (Oregon Advocacy Center, the Center on Human Development at U of O and the Oregon Institute on Disability and Development at OHSU) on a statewide needs survey. The results from the survey (more than 200 of you responded) and two community forums helped us decide on the goals and objectives to include in the new plan. After much drafting and redrafting, we put the plan up for public comment before being finalized and submitted to the federal Administration on Developmental Disabilities. (For a copy, visit our webpage or call the Council office for a hard copy.)

Along with the new plan, we also developed a new mission statement that briefly and clearly describes our core purpose: To create change that improves the lives of Oregonians with developmental disabilities.

had been doing for the previous five years. It recommits us to work collaboratively with our state and community partners to create systems changes that will improve the lives of Oregonians with developmental disabilities. It calls for us to continue our efforts to build self-determination and choice into our system of services.

We are now into the second year of our plan. We hope you will recommit to work with us as we continue our efforts to move this state in a positive direction that leads to full community participation for all Oregonians with developmental disabilities. If you are not already a member of our Oregon Network, please join. It is the best way to get involved and stay informed! (See page 4)

On the cover: The Council’s 2006 awareness poster, co-produced with The Arc of Oregon. Contact the Council for free copies.

OUR MISSION AND 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, MENTAL RETARDATION AND OTHER NEUROLOGICALLY DISABLING CONDITIONS.

PURPOSE AND **MEMBERSHIP**

The Oregon Council on Developmental Disabilities was established by a Governor's Executive Order in 1971. The Governor appoints the Council's 29 members, sixty percent of whom must be individuals with developmental disabilities or family members of individuals with developmental disabilities. Currently, nine full-time and three part-time staff support the work of the Council.



in-kind contributions and some 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-

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 Administration on Developmental Disabilities (ADD). The Council also receives administrative services,

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)

Interested in joining the Council? Contact the Council or visit www.ocdd.org for a copy of the membership application.

WHAT **WE** DO



SUPPORT SELF-ADVOCACY LEADERSHIP AND ENGAGEMENT

The Council, along with the Seniors and People with Disabilities Division, provides financial support and training dollars to Self Advocates As Leaders 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 2006-2007, 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 and consumer empowerment. 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 also produces the *People First 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 2,000 subscribers, the *People First Connection* has become a significant vehicle for sharing personal stories of self-advocates in Oregon.

Want to get involved in SAAL, subscribe to People First Connection, attend a My Story Workshop? Contact SAAL at 503-589-1664 (Salem) or 866-835-0659 (Portland) or 888-589-1664 (toll free). Visit the SAAL webpage at www.asksaal.com.



WHAT **WE** DO



WORK WITH COALITIONS AND PARTNERS

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

Developmental Disabilities Coalition of Oregon: The DD Coalition has been a major force in legislative and administrative public policy issues for many years. The mission of the DD Coalition is “to influence policy to create adequate funds and sustain quality service and supports that respect families and furthers the rights, equality, justice and inclusion for all Oregonians with developmental disabilities.” The DD Coalition’s GO! Project (Grassroots Oregon) allows advocates to easily respond to action alerts and communicate their concerns to policymakers at the state and national levels. The coalition Web site 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. Individuals get involved in the GO! Project by becoming members of the Oregon Network, which includes more than 5,200 members. Network members also receive Council publications.

In addition to working on public policy issues, the coalition also sponsored the annual Oregon Conference on Direct Supports in Corvallis. Hundreds attended the conference in 2006 and 2007 to improve their skills and knowledge as direct support workers and expand their networks.

Want to join The Oregon Network, receive a copy of the DD Coalition legislative report? Visit the Oregon DD Coalition at www.oregonddcoalition.org.

WHAT **WE** DO



WORK WITH COALITIONS AND PARTNERS

Family Action Coalition Team (FACT):

About a dozen family advocacy organizations actively participate in FACT. It 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. It has provided support for family-initiated activities that target young children in Multnomah County and has collaborated with Oregon Family Voices to bring a Family-to-Family Health Care Information and Education Center to Oregon.

Want to know more about FACT?

Visit www.factoregon.org.

DD Supported Employment Task Force:

Oregon was once recognized as a national leader in the employment of people with developmental disabilities. For more than a decade, however, little was happening in Oregon to promote integrated employment. In late 2005, the Council and the Oregon Technical Assistance Corporation pulled together a group of employment advocates, which in 2006 became known as the DD Supported Employment Task Force. The task force was formed to focus state attention on improving employment outcomes for people with developmental disabilities. Since then, the Seniors and People with Disabilities Division hired staff dedicated to employment and joined the Supported Employment Learning Network (SELN), a network of 13 states that share best practices and receive state-specific technical assistance from project consultants. The DD Supported Employment Task Force advises the SELN project and the Competitive Employment Project (see page 7).

WHAT **WE** DO



PARTICIPATE ON STATE ADVISORY GROUPS

During the biennium, the Council had a leadership role on many disability policy and advisory groups at the state and national levels, including:

Staley Implementation Group (SIG):

The SIG advises the Seniors and People with Disabilities Division (SPD) on policy matters related to implementation of Support Services for Adults. With oversight from the SIG, significant policy changes and program improvements have been made, including the creation of two new Support Service Brokerages. The SIG also provides advise on the development of “Comp 300” services. The Staley lawsuit settlement agreement called for the creation of non-crisis comprehensive services for 300 individuals by 2011. About half those services have been developed since the agreement took affect.

Want more information about Supports Services for Adults? Log on to The Arc of

Oregon Web site at www.arcoregon.org, contact your Community Developmental Disabilities Program office or see the *Roadmap to Support Services* on our Web site.

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

ReBAR advises SPD on this major systems change project designed to build fairness and equity into Oregon’s provider rates system and build self-determination into comprehensive services through budgets based on individualized needs assessments. Implementation is scheduled to begin in 2009.

Competitive Employment Project (CEP)

Leadership Council: Oregon Vocational Rehabilitation Division received a four-year Medicaid Infrastructure Grant in 2005 to fund the Oregon Competitive Employment Project. The purpose of the project is to address systemic barriers to competitive employment for people with all types of

WHAT **WE** DO



PARTICIPATE ON STATE ADVISORY GROUPS

disabilities. In 2007, the project launched the Work Incentives Network (WIN) to assist individuals on Social Security benefits who want to work but are worried about what will happen to their benefits.

DD Quality Assurance Committee:

This committee advises the Seniors and People with Disabilities Division (SPD) on its system for assuring the quality of community services. The committee's focus is on improving and expanding the state QA system so it is more thorough and effective.

Fairview Community Housing Trust Fund Advisory Committee: 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 to individuals who do not receive state-licensed residential services. A variety of projects have been funded, including ramp construction, bathroom remodels and purchase of therapeutic equipment. In 2006-2007,

these funds helped more than 200 people become more independent and safe in their homes through home modifications and equipment purchases.

Want to apply for a Fairview Community Housing Trust Fund grant? Visit the SPD web at www.dhs.state.or.us/disabilities.

Health Services Commission: This commission provides advice on the Oregon Health Plan's prioritized list of covered services. The Council's representative on the commission educates commissioners about the impact that changes to the list would have on people with developmental disabilities. The list was reorganized in 2007.

Diversity Development Coordinating Council: This Council advises the Department of Human Services (DHS) on issues of cultural competency and diversity. In 2007 DHS began an aggressive roll-out of an "all staff" cultural competency training

WHAT **WE** DO



PARTICIPATE ON STATE ADVISORY GROUPS

designed by members of this group, including a representative from our Council. The design team received a DHS Director's Award. All 9,100 members of the DHS staff are scheduled to be trained by August 2008.

National Association of Councils on Developmental Disabilities (NACDD): NACDD is a national non-profit that supports the work of state DD Councils and

is the voice of Councils on federal policy issues. Our Council is represented on the board of directors and on the Public Policy Team.

Want timely information on national disability policy issues? Visit the NACDD Web site at www.nacdd.org and click on their Legislative Action Center.

CONDUCT PROJECTS, PROGRAMS AND TRAININGS

Inclusive Child Care Program: This program is a partnership between the Council, the Oregon Employment Department's Child Care Division and DHS. 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. The program also provides training to child care providers and builds capacity for inclusive child care by training local teams of trainers through the Partners in Inclusive Child Care Project. The program serves children through age seventeen with physical, developmental, mental, emotional, behavioral or medical disabilities. This biennium 118

WHAT **WE** DO



CONDUCT PROJECTS, PROGRAMS AND TRAININGS

children received subsidies through the program.

Want information about how to apply for a subsidy? Contact the Council and ask for the Inclusive Child Care Program.

Partners In Policymaking: The Council contracted with The Arc of Oregon to conduct an intensive training course for advocates with developmental disabilities and their families. 28 family members and self-advocates graduated in September 2006 after participating in eight monthly two-day trainings in Salem. Partners gain information and skills so they can become more effective advocates and change-agents in their communities and statewide. For the second time, PIP was offered in both English and Spanish; two Latino parents successfully completed the class in 2006.

Want an application for future PIP classes? Contact the Council or visit our Web site.

Provider Capacity Project: The Council, along with the Oregon Technical Assistance Corporation, received funds from the Seniors and People with Disabilities Division (SPD) to conduct a project that resulted in the publication of a white paper: *Building Oregon's Capacity to Serve Individuals with Complex Support Needs: Recommendations for Action*. The paper, which was based on stakeholder input and research on state and national best practice, made recommendations for short-term and long-term investments. SPD intends to fund projects in 2008 designed to implement some of the recommendations in the white paper.

Want a copy of the white paper? Contact the Council or visit www.ocdd.org.

Consumer Involvement Fund: The Council's Consumer Involvement Fund provided about \$24,000 in stipends for 173 self-advocates and family members to attend

WHAT **WE** DO



CONDUCT PROJECTS, PROGRAMS AND TRAININGS

in-state and out-of-state conferences and trainings. 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.

Person-Centered Employment Training: In 2006-2007 the Council received funds from the Oregon Vocational Rehabilitation Division's Competitive Employment Project (see page 7) to conduct five trainings for parents and youth with developmental disabilities who were interested in developing and implementing person-centered employment plans. These were followed by a train-the-trainer event to build capacity in communities to continue the trainings. Partner agencies also provided funds to create a person-centered employment planning video for trainers, which will be available in 2008.

Want a copy of the person-centered employment planning video?

Contact the Council at www.ocdd.org.

Oregon PTI Transition Conference: In 2006 the Council was a co-sponsor of the Oregon Parent Training and Information Center's Building Futures Conference on transition from high school to work and continuing education. More than 400 attended.

What to attend a transition conference?

Contact OrPTI at 503-581-8156 or www.orpti.org.

FACT Inclusion Conference: The Council collaborated with the Family Action Coalition Team (see page 5) on the first annual *All Born In* inclusion conference in 2007. This cross disability training provided tools, networking and inspiration for parents and professionals committed to inclusive education for children with disabilities.

WHAT **WE** DO



INCREASE PUBLIC AWARENESS

Developmental Disability Awareness Month: 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 policymakers and advocates, and an awareness poster is unveiled. The poster in 2006 encouraged parents to believe in the possibility of employment for their sons and daughters. In 2007, the poster promoted in-home supports for medically involved children. The posters were distributed throughout Oregon.

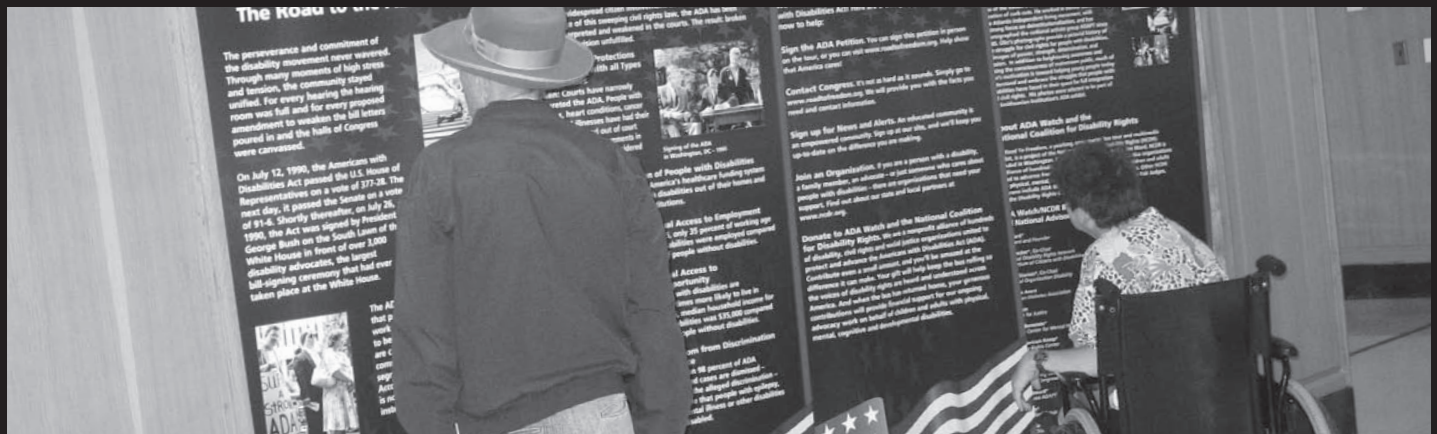
Want a poster? View or order posters through the Council's webpage at www.ocdd.org, or contact the Council.

Oregon Perspectives: In 2007 the Council launched a new publication, *Oregon Perspectives*. Each edition of the magazine is focused on a particular developmental disability issue. The intent of the publication is to increase public awareness on those issues through the multiple perspectives and success stories of Oregonians around the state. The magazine is published three times a year and is free.

Want to read or subscribe to Oregon Perspectives? Visit www.ocdd.org, join the Oregon Network 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

- \$513,500 was leveraged for employment programs.
- 796 people were trained in person-centered employment.
- 11 employment policies/programs were created and/or improved.

EDUCATION AND EARLY INTERVENTION

- \$26,000,000 was leveraged for education programs.
- 809 people were trained in inclusive education.
- 247 students transitioned from school to community or work.

HOUSING

- \$6,282,464 was leveraged for housing.
- 217 individuals have homes of their choice due to Council efforts.
- 4 housing policies/programs were created and/or improved.

HEALTH

- 10,000 people have needed health care services through Council efforts.
- 5 health care policies/programs were created and/or improved.

CHILD CARE

- \$740,178 was leveraged for inclusive child care programs.
- 197 children were placed in inclusive child care settings through Council efforts.
- 217 child care policies/programs were created and/or improved.
- 194 people were trained in inclusive child care.

TRANSPORTATION

- 4 transportation policies/programs were created and/or improved.

HIGHLIGHTS OF COUNCIL ACCOMPLISHMENTS



QUALITY ASSURANCE AND SELF-DETERMINATION

- \$103 million was leveraged for quality assurance programs.
- 1368 people benefited from quality assurance efforts of the Council.
- 25 quality assurance policies/programs were created and/or improved.
- 1585 people were trained in quality assurance.
- 870 people were active in systems advocacy about quality assurance.
- 1052 people were trained in leadership, self advocacy and self determination.
- 137 entities participated in partnerships or coalitions created or sustained as a result of Council efforts.

PUBLIC EDUCATION AND AWARENESS

- 287 public policymakers were educated by the Council about issues related to Council initiatives.
- 2254 copies of products were distributed to policymakers about issues related to Council initiatives.
- An estimated 2 million members of the

public were reached through a report aired on CNN and on the CNN Web site about the documentary film "Where's Molly?" An estimated 100 million in 39 countries were reached through a Reader's Digest feature story on the same subject.

THROUGH OUR WORK WITH THE COALITION AND OTHERS, SEVERAL SIGNIFICANT PIECES OF LEGISLATION PASSED DURING THE 2007 LEGISLATIVE SESSION, INCLUDING:

- **Medicaid Waiver for Medically-Involved Children:** The state received approval to apply for and implement a Medicaid waiver program that offers in-home supports for children who require significant levels of medical support. The program will provide options other than nursing homes and foster care for families of these children.
- **Restoration of OHP Vision and Dental Benefits:** Reductions to the Oregon Health Plan (OHP) were repealed. Vision and dental benefits were restored

HIGHLIGHTS OF COUNCIL ACCOMPLISHMENTS



to approximately 10,000 people with developmental disabilities.

- **Equity in Health Benefit Plans:**

Limits were placed on the ability of health benefit plans to treat children under the age of 18 with specific disabilities differently than children without disabilities.

- **Increased Provider Rates:** \$20 million was included in the state budget to

increase provider rates – less than the \$60 million requested by providers and advocates but a significant victory nonetheless. This is an ongoing effort to stabilize the provider workforce.

- **Modified Diploma:** A statewide modified diploma will be created and school districts will be required to allow students receiving modified diplomas and alternative certificates to participate in graduation ceremonies.

INCOME AND EXPENDITURES

2006 *(10/1/05-9/30/06)*

Carryover Funds from Federal Fiscal Year (FFY) 2005	\$126,391
Other Funds	\$8,507
Administration on Developmental Disabilities (ADD) Grant	\$770,233
Expenses	\$801,791

2007 *(10/01/06-9/30/07)*

Carryover Funds from FFY	\$103,340
Other Funds	\$7,860
ADD Grant	\$768,227
Expenses	\$770,872

CONTACT US



OREGON COUNCIL ON DEVELOPMENTAL DISABILITIES

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This publication is available in alternative formats upon request. DD Awareness event pictures
courtesy of Claudean Schaeffer.

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