

## **ANNUAL REPORT 2010**

### **ADMIT EVERYONE**

Promoting the **FULL INCLUSION** of all people with disabilities.

*The Council on Developmental Disabilities is a Governor-appointed body of people with developmental disabilities, family members and professionals who work together to promote the **full inclusion** of all people with disabilities in community life.*

#### **Connecticut Council on Developmental Disabilities**

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## **WELCOMING LETTER**

As the Chair of the Council on Developmental Disabilities, and a parent of a daughter with developmental disabilities, I am pleased to write this welcome letter for our 2010 Annual Report. Throughout the year, the Council fostered systematic changes with our new and continuing initiatives that have resulted in promoting the full inclusion of people with disabilities.

I want to personally thank Council Members for their leadership and commitment during this past year. Members participated at Council Meetings, Committees and/or Task Forces where they contributed their knowledge and personal experiences about disability issues. In addition, they provided technical support by attending meetings about the initiatives. We said good-bye to retiring council members who had given insight and wisdom to the Council. Yet, we welcome new members who will strive to create inclusive places for people with developmental disabilities.

The Council said good-bye to a Disability Policy Specialist, Angela Klonoski, who made particular contributions about the use of Adversives, Restraints and Seclusion. We welcomed Margaret Cohan, who was a Council member and Chair for six years, as our new staff person.

On March 2, 2011 current and veteran Council Members and distinguished guests attended the Council's 40<sup>th</sup> Anniversary. They celebrated the many accomplishments that the Council has made toward promoting the full inclusion of people with developmental disabilities in the community. Also, they honored leaders who have advanced equal opportunities for people with disabilities.

Then later in March we said good-bye to the Council's Executive Director, Ed Preneta, who retired. Ed was a Council Member for two years before he became Executive Director of the CT Council on Developmental Disabilities. Over his long and dedicated service to the Council, Ed has been persistent in his support of inclusion. He has provided many Council

members opportunities for leadership roles in ground-breaking initiatives spearheaded and supported by the Council. On behalf of current and prior Council members, thank you Ed, we will certainly miss you.

In closing, the Council looks forward with enthusiasm to working on another prosperous year. The Council will work hard to create an impressive and innovative new Five Year State Plan and also work on the Reauthorization of the Developmental Disabilities Act.

Sincerely,

*Anita Tremarche*

Anita Tremarche

Chair

CT Council on Developmental Disabilities

# DEFINITION OF DEVELOPMENTAL DISABILITIES

Public Law 106–402

106th Congress

Oct. 30, 2000

Developmental Disabilities Assistance and Bill of Rights Act of 2000

Title I

Section 102

114 STAT. 1683 - 1684

(8) DEVELOPMENTAL  
DISABILITY.—

(A) IN GENERAL.—The term  
“developmental disability”

means a severe, chronic disability  
of an individual that—

(i) is attributable to a mental or  
physical impairment

or combination of mental and  
physical impairments;

(ii) is manifested before the  
individual attains age

22;

(iii) is likely to continue  
indefinitely;

(iv) results in substantial  
functional limitations

in 3 or more of the following areas  
of major life activity:

(I) Self-care.

(II) Receptive and expressive  
language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent  
living.

(VII) Economic self-sufficiency;  
and

(v) reflects the individual’s need  
for a combination

and sequence of special,  
interdisciplinary, or generic

services, individualized supports,  
or other forms of

assistance that are of lifelong or  
extended duration

and are individually planned and  
coordinated.

(B) INFANTS AND YOUNG  
CHILDREN.—An individual

from birth to age 9, inclusive, who  
has a substantial

developmental delay or specific  
congenital or acquired

condition, may be considered to  
have a developmental disability

without meeting 3 or more of the  
criteria described

in clauses (i) through (v) of  
subparagraph (A) if the individual,

without services and supports, has  
a high probability

of meeting those criteria later in  
life.

## MISSION

To promote the full inclusion of all people with disabilities in community life.

### **About The Council**

The Connecticut Council on Developmental Disabilities is a governor-appointed body of people with developmental disabilities, family members and professionals who work together to promote the full inclusion of all people with disabilities in community life. The Council has 29 members – 60 percent of whom are either people with disabilities or parents of children with disabilities.

The Council's focus is on people with disabilities that originate and manifest before the age of 22 and who are likely to require lifetime support. The Developmental Disabilities Act allows the Council to reach people regardless of their disability label.

The Council is a federal program that is entirely federally funded, based on a funding formula. It operates within state government as a state agency; however, the Council is not in state statutes and does not receive any state funds.

The Council's role is advocacy, capacity building and systems change. The Council is not a service provider and is prohibited from lobbying.

The CT Council has three staff members and an office located near the state Capitol in Hartford. At least 70 percent of the Council's funds are used for initiatives to promote independence, productivity, integration and inclusion in the community.

The Council has the following committees:

- Advocacy, Public Information and Education
- Legislation, Policy and Planning

- Membership and Support
- Proposal Review
- Executive

## What the Council Does

- Training
- Outreach
- Leadership Development and Learning Forums
- Technical Assistance to Policymakers and Legislative Committees
- Supporting and Educating Communities and Community Development
- Interagency Collaboration, Coordination and Convening Stakeholders
- Coordination with Related Councils, Committees, Programs and Partnerships with Government
- Barrier Elimination, Systems Design and Redesign
- Coalition Development and Citizen Participation
- Informing Policymakers and the Media
- Demonstrations of New Approaches to Services and Supports and Model Programs
- Influencing Public Opinion
- Nonpartisan Analysis and Research
- Supporting Advocacy
- Influencing Administrative Policy

## **ACCESSIBLE TRANSPORTATION**

The CT Council funded the Housatonic Area Regional Transit District (HART), Danbury, to demonstrate an on-demand wheelchair accessible system that enables people with developmental disabilities to get transportation to attend meetings and events of their choice in their community. The initiative is supported by the City of Danbury, the Housatonic Valley Council of Elected Officials and local provider agencies. 200 to 300 people with disabilities are being surveyed. Preliminary indications are for the establishment of an accessible taxi service with a voucher component, provided by existing taxi services, with most capital costs for accessible vehicles and half of operating costs of the service made available through the CT Department of Transportation's federal "New Freedom" funds.

## **AGING IN PLACE**

The CT Council funded the Western CT Association for Human Rights (WeCAHR), Danbury, to demonstrate the organization and delivery of services and supports to 55 people with developmental disabilities who are aging in their homes in their community. The initiative intends to avoid the institutionalization of these people for the rest of their lives. The regional demonstration is based on the Beacon Hill Village (Boston) aging-in-place in the community model. WeCAHR is the first and only Village-To-Village Network member in the country that includes people with developmental disabilities. In addition, WeCAHR collaborated with AgePlan, New York, to develop a survey instrument to measure peoples' interests and the connections they already have in their communities.

WeCAHR networked and attended a national conference with other "Aging In Place" villages. WeCAHR is the only "village" model that is inclusive of people with and without developmental disabilities.

## **COMMUNITY LIVING CONSULTANTS**

The CT Council funded CT Community Care, Inc, (CCCI), Bristol, to demonstrate self-directed support service options within CT's Money Follows the Person (MFP) program with 11 people with developmental disabilities moving from nursing facilities into the community on CT's Personal Care Assistance (PCA) Medicaid waiver. The service has been expanded beyond MFP to all 748 PCA Waiver participants. The intent is to make this service available in all of CT's Medicaid waiver packages.

## **ASSISTIVE TECHNOLOGY**

The CT Council funded Trinity College, Hartford, to host a RoboWaiter competition for college, high school student and independent engineers and to hold a symposium on service robots. The competition was to design, build and demonstrate robots that assist people with developmental disabilities with household activities, chores, tasks and other activities of daily living. 14 teams from around the United States, Canada, China, Israel and India registered to compete.

Two hundred people attended a symposium on contact robots and neuro-recovery by Dr. Neville Hogan, Sun Jae Professor of Mechanical Engineering, Professor of Brain and Cognitive Sciences, and Director of the Newman Laboratory for Biomechanics and Human Rehabilitation at MIT.

The concept of Robo-Waiter is becoming well known. Papers on assistive robotics were presented at the 2010 American Society for Engineering Education and the Federation of International Robot-soccer Association (FIRA) World Congress in Bangalore, India. Trinity students used RoboWaiter as a theme for promoting international peace and won a grant from the "Kathryn Wasserman Davis Project for Peace" to foster peace through robotics.

## **DISABILITY CONVENTION**

700 to 800 people participated at the 2010 Disability Convention and Exposition, sponsored by the Disability Advocacy Collaborative and supported in part by the CT Council. At the candidates' forum, the five candidates who ran for office in November 2010, including both candidates for Governor and Attorney General, as well as a candidate for Secretary of State, attended and shared their views on disability public policy. There were 81 exhibitors, including a "Focus on Employment" section that attracted 9 exhibitors. 15 people participated in mock interviews and 10 people sought help with resume writing. There was a visual arts display and entertainment, including entertainers with disabilities. The video "The 20<sup>th</sup> Anniversary of the ADA: Human Rights in Progress" was shown.

## **EDUCATION CONSULTANTS OF CT**

The CT Council funded Educational Consultants of CT, Canton, to train parents and professionals on using personal futures planning techniques to achieve quality transition plans with students with developmental disabilities. 89 participants signed up for 3 training sessions. 28 people (14 Teams) were accepted into Facilitator Training. 100% of the participants reported an increase in their level of competence on person centered planning and transition. A CT Council intern, who was a former Council member representing parents, is training parents on using special education law to achieve inclusion using the Council's Education and Community Inclusion Toolkits in 9 workshops expected to reach 200 parents. The Council is also working this intern to bring a Wrightslaw workshop on special education into CT during 2011 for a workshop for 200 parents and professionals.

## **AVERSIVE, RESTRAINTS AND SECLUSION**

The CT Council has been the leader with regard to opposition to the use of aversives, restraints and seclusion (ARS) in schools and systems change to support family focused positive behavioral interventions. The CT Council was successful with working with key members of the CT Congressional delegation in achieving

proposed federal legislation that rightly failed when education lobbyists inserted language that made the proposed legislation unacceptable to parents.

## **EMERGENCY PREPAREDNESS FOR PEOPLE WITH DISABILITIES**

The Council was a partner in educating First Responders and Community Emergency Rescue Teams (CERT) in the Capitol Region. Training was supported by the Capitol Region Emergency Planning Committee (CREPC).

Presentations were made to 300 Responders and CERT members to learn how to assist people with disabilities during and after a disaster. Responders may need to rescue the person quickly from an emergency but, when time permits, the committee stressed the importance of proper communication between emergency personnel and people with disabilities.

## **HEALTH**

The CT Council funded CT Legal Services, Middletown, to work with St. Mary's Hospital, Waterbury, and Charlotte-Hungerford Hospital, Torrington, regarding end of life planning, do not resuscitate (DNR) orders, advanced directives, guardianship, and other medical ethics and medicolegal issues regarding people with developmental disabilities entering emergency rooms. The intent of this initiative is to protect the lives of people with developmental disabilities in in-patient settings. Hospital emergency rooms can be the most dangerous encounter with the medical system and medical professionals for people with developmental disabilities, particularly people with intellectual disabilities and communication disabilities. CT Legal Services consults with the Social Role Valorization Implementation Project, Massachusetts. Also, CT Developmental Disabilities Network partners, the CT Council, the Office of Protection and Advocacy and the University Center for Excellence in Developmental Disabilities at the UCONN Health Center, held a forum in the Legislative Office Building on January 22, 2010, that averted state legislation enabling physician assisted suicide.

## **PARENTS WITH COGNITIVE DISABILITIES**

The CT Council funded the State Board of Education, in partnership with the Department of Children and Families and a Regional Educational Service Center, to support a Parents with Cognitive Limitations Work Group to train 38 Head Start workers and their partners on supporting parents who have cognitive limitations.

## **INTERSHIPS INTO THE ADULT WORLD**

The Council failed to establish internships for youth with developmental disabilities who were transitioning into the adult world of work. Subsequent discussions were led by a CT Council member with connections with a financial services company, and a CT Council member representing a not for profit provider agency, on internship programs for students with developmental disabilities involving the CT Council, CT's Bureau of Rehabilitation Services, CT's Medicaid Infrastructure Grant, and CT's Department of Developmental Services. An internship program may be in place later during 2011.

## **VISITABLE HOUSING**

The CT Council funded Independence Unlimited (IU), Hartford, to encourage the development of visitable homes with home builders, architects and policymakers. The intent of this initiative is to create housing stock that is easily modified so that people with developmental disabilities have more options about where they can live and so that there is more accessible housing in general. Public Act 10-56, An Act Concerning Visitable Housing, was signed into law on May 18, 2010 to encourage development of visitable housing in the state. Advocacy is still needed with Department of Economic Development on implementation of the law. IU participated in a Home Builders Show and a Home Show to promote visitable homes. In addition, the CT Homebuilders Association published an article on visitability in their magazine.

## **COMMITTEES**

## **ADVOCACY, PUBLIC INFORMATION AND EDUCATION**

The Advocacy, Public Information and Education (APIE) Committee is working with First Experience Communications (FEC), Glastonbury, to develop a Marketing and Public Relations Plan on one or more issues of concern to people with developmental disabilities and their families.

## **LEGISLATION, POLICY AND PLANNING COMMITTEE**

The Committee was particularly active in collaborating with the Sexual Assault Crisis Center on legislation concerning sexual assault of people with developmental disabilities. In 2008, a man who was accused of sexually assaulting a woman with developmental disabilities was found guilty. The verdict was overturned by the CT State's Court of Appeals on the basis that the victim could not be considered physically helpless by the current definition of law. Although the victim can hardly move any part of her body, she hypothetically possessed the ability to communicate "no" if not verbally, then behaviorally. According to CT law, a 'physically helpless' person is defined as an individual who is 'unconscious or for any other reason is physically unable to communicate unwillingness to an act.' [53a-65(6)]. Legislation to clarify and strengthen the definition of "physically helpless" died in the House. The Committee will try to raise a better bill again in 2011 again.

## **A PERSPECTIVE FROM A COUNCIL MEMBER**

My name is Bill Knight. I was appointed to the CT Council on Developmental Disabilities as a self-advocate in October 2008. Since joining the Council, I have become Chair of the Legislative Planning and Policy Committee, and I serve on the Executive Committee and the Transition Team. This Transition Team will hire a new Executive Director for the Council.

For the last thirty years, I have chaired disability rights movements on local and state-wide organizations. These organizations, along with others, have led to the passage of state and federal legislation that enhances the quality of life for

people with disabilities. One of my proudest moments as a self-advocate was attending the signing of the Americans with Disabilities Act on July 26, 1990.

I am serving as the Northwest Connecticut Regional Coordinator for the Disability Advocacy Collaborative. I'm proud of the accomplishments that I have been part of the disability rights movement.

**HOW THE DD DOLLARS WERE SPENT**

The CT Council on Developmental Disabilities operates entirely with federal developmental disabilities funds, which are distributed among the states under a formula based on population, per capita income, unemployment rate, and Social Security disability statistics. In 2010, the CT Council received an allotment of \$725,688. The CT Council carried over \$187,074 of 2009 funds for use during 2010. Additionally, the Council generated \$7,075 in conference registrations. The Council's total 2010 budget was \$919,837. The Council leveraged \$167,741 in matching funds.

**2010/2011 INITIATIVES**

***Meaningful Employment***

Council and Staff Initiated Activities	\$35,445
Internships for students (2011)	\$6,264
	Total \$41,709

***Inclusive Education***

Council and Staff Initiated Activities	\$35,445
Educational Consultants of Connecticut	\$40,000

APRAIS/TASH Participation	\$84
Special Education Workshop	\$389
Wrightslaw Participation	\$175
Connecticut Parent Advocacy Center (2011)	\$15,000
LD Transition Institute (2011)	\$3,000
	Total \$94,093

***Inclusive Housing***

Council and Staff Initiated Activities	\$35,445
Independence Unlimited	\$31,000
	Total \$66,445

***Health***

Council and Staff Initiated Activities	\$35,445
Connecticut Legal Services	\$40,000
	Total \$75,445

***Transportation***

Council and Staff Initiated Activities	\$35,445
Housatonic Area Regional Transit District	\$15,000
	Total \$50,445

***Self-Advocacy***

Council and Staff Initiated Activities	\$35,551
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Disability Resource Network – Powerfest	\$11,237
Participate in People 1st of Connecticut	\$163
Disability Advocacy Collaborative - 2010 Convention	\$5,000

Total \$51,951

***Promoting Issues in the Field of Disabilities***

Council Retreat on Priorities	\$1,037
National Association Conference	\$1,196
Webmaster	\$1,395
Council Office	\$1,947
Digitizing Senator Weicker’s Papers	\$3,000
First Experience Communications	\$45,000

Total \$53,575

***Inclusive Communities***

Council and Staff Initiated Activities	\$36,648
Connecticut Business Leadership Network – ADA/504	\$600
Connecticut Community Care, Inc.	\$103,497
Social Role Valorization Training	\$3,359
State Department of Education – Parents with Cognitive Limitations	\$6,000

Western Connecticut Association for Human Rights	\$40,000
Americans with Disabilities Act Coalition of Connecticut	\$5,000
Trinity College – “Robo Waiter“	\$12,000
	Total \$207,104
<b><i>General Management</i></b>	\$109,185
	Subtotal \$638,661
<b><i>Carried over for use during 2011</i></b>	\$281,176
	Grand Total \$919,837

<b>COUNCIL MEMBERS</b>
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October 1, 2009 to September 30, 2010

**Officers**

Armand Legault, Chair

*(Resigned January 23, 2010)*

Anita Tremarche, Vice Chair

*(Assumed Interim Chair January 23, 2010*

*Elected Chair September 14, 2010)*

Frank Reed, Vice Chair

*(Elected Interim Vice Chair March 9, 2010*

*Elected Vice Chair September 14, 2010)*

**Persons with Developmental Disabilities**

Joyce Baker, Wethersfield

Stephen Belske, Bloomfield

Frank Reed, Danbury

Leo Germain, Manchester

*(Resigned October 5, 2009)*

John Curtin, Bolton

*(Appointed August 30, 2010)*

Armand Legault, Newington

Jennifer Lortie, Griswold

David King, Bridgeport

Bill Knight, Torrington

Zuleika Martinez, Bridgeport

Thomas McCann, Manchester

*(Retired September 30, 2010)*

Peter Morrissette, East Hartford

Sarah Rafala, Windsor

**Parents**

Darlene Borre, West Hartford

*(Appointed September 3, 2010)*

Stacey D'Angelo, Shelton

*(Appointed September 30, 2010)*

Hayley Kelley, Winsted

Maryann Lombardi, Wilton

Sabra Mayo, Hartford

Dwayne Paul, Milford

Al Piehl, Avon

Leslie Prior, Tolland

Guy Sullivan, Fairfield

*(Appointed September 3, 2010)*

Nancy Taylor, Canton

*(Retired September 30, 2010)*

Anita Tremarche, Manchester

### **State Agencies**

Gabriela Freyre-Calish, University Center for Excellence in  
Developmental Disabilities,

Lawrence Carlson, Department of Social Services

Kathryn duPree, Department of Developmental Services

Mark Keenan, Department of Public Health

Perri Mudica, Department of Education

Patricia Tyler, Office of Protection and Advocacy

**Private Agencies**

Frederick Frank, Career Resources, Bridgeport

Monica Smyth, Abilis

**Staff to The Council**

Edward T. Preneta, Director

Angela Klonoski, Disability Policy Specialist

*(Resigned May 5, 2010)*

Mary-Ann Langton, Disability Policy Specialist

Margaret Cohan, Disability Policy Specialist

**Webmaster**

Matthew Smith, Litchfield County Computer, Woodbury