

ANNUAL REPORT 2008

ADMIT EVERYONE

Trying to promote the FULL INCLUSION of people with disabilities.

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

Connecticut Council on Developmental Disabilities

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Message from the Chair

The CT Council on Developmental Disabilities' mission is to promote the full inclusion of all people with disabilities in community life. The Council works toward making this basic belief and human right a reality for all. The Council recognizes the fact that it is essential to support our youth with information and provide them with leadership and advocacy training, because the youth with disabilities of today will be the advocacy leaders of tomorrow. The Council has supported CT Kids as Self Advocates and Youth ADAPT of CT, both youth advocacy initiatives. The Council also knows how important it is for parents of children with disabilities to be educated in advocacy and leadership training. We will be partnering with other like-minded organizations to sponsor a forty hour, six part parent leadership training/advocacy series. Our Council has also continued its partnership with CPTV to produce two tool kits—one on Special Education and the other on Inclusion. It is our hope that these toolkits are distributed throughout Connecticut to educate our citizens on these two very important topics.

The Council continues to sponsor presentations on Social Role Valorization, which means giving value to all people, including those with disabilities, who tend to be devalued in our society. In keeping with Connecticut's role as being very progressive, and on the cutting edge of sponsoring new and exciting initiatives, the DD Council continues their partnership with Trinity College to sponsor a robotics competition. Students from high schools, technical schools and colleges design, build and demonstrate robots that assist people with developmental disabilities with household activities, chores, tasks and other activities of daily living.

How much of a difference can the CT Council on Developmental Disabilities, which is only made up of thirty members, make in the State of Connecticut? Let me tell you how much of a difference a single person can make, and then you can just imagine the difference an organized group like the DD Council can make.

I thought I was "supposed to be" a top executive for a company in Greenwich. Everyone else seemed to be under the same impression. My little two-year-old son changed all of that. Michael was diagnosed with autism, a developmental disability. He changed my whole life. He made me a better person than I could have ever hoped.

How much difference could this one little boy make in helping me and those around him understand the needs of people with disabilities? I knew that I would have to spend more time with Michael than my other four children, teaching him everything he would need to know to survive in our confusing world. What I didn't expect was that as much as I taught him, he would teach me more...the most important things in life. He taught me patience, tolerance, acceptance, kindness, trust and unconditional love. He taught me that when it comes to the abilities of all people, especially those with disabilities, the worst thing you can do is to have preconceived expectations that put ceilings on what can be achieved.

Through supports provided by his family and community, Michael is fully included in community life. Michael is nineteen years old now. He is a full-time student, a member of the Valley YMCA and the Lower Naugatuck Valley Boys and Girls Club. He is an active member of his Church, and a champion swimmer on two teams—one with the Valley YMCA, and the other in our vacation community in Pennsylvania. In addition, Michael has been an employee of the Ansonia Library for over a year. He is a wonderful example of what it means to be an active and respected member of his community.

Michael has more of a social life than I do. He goes bowling, to the mall, the arcade, to movies, to the Ansonia Nature Center and to local restaurants on a regular basis. He is a familiar face to most, and known by many. It brings a smile to my face when people from the community come up to me and say, "Aren't you Michael's Mom?" Nothing brings greater pride and pleasure than to be able to say, "Yes I am!"

Wouldn't it be wonderful if all persons with disabilities were included in their communities like Michael? This is the goal that the CT Council on Developmental Disabilities is working hard to achieve. However, it takes a whole community to make this goal a reality.

Cathy Adameczyk

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 3 staff members and an office located near the state Capitol in Hartford. Approximately 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
- 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

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 2008, the CT Council received an allotment of \$695,612. The CT Council carried over \$11,823 of 2007 funds for use during 2008. The Council also generated \$20,344 in conference registrations. The Council's total 2008 budget was \$727,779. The Council leveraged \$171,006 in matching funds.

2008 Initiatives

Meaningful Employment

Council and Staff Initiated Activities \$42,579

Inclusive Education

Council and Staff Initiated Activities \$70,984

Connecticut Public Broadcasting – Toolkit \$14,500

Total \$85,484

Inclusive Housing

Council and Staff Initiated Activities \$42,579

Life Threatening Public Policy

Council and Staff Initiated Activities \$54,243

Social Role Valorization Implementation Project \$24,600

Total \$78,843

Self-Advocacy

Council and Staff Initiated Activities \$49,266

Disability Advocacy Collaborative \$2,006

CT Youth in ADAPT \$10,000

CT Kids As Self Advocates \$32,400

Total \$93,672

Interactive Robots

Trinity College \$8,500

Inclusive Communities

Council and Staff Initiated Activities \$42,579

Connecticut Public Broadcasting – Able Lives \$45,000

Connecticut Public Broadcasting – Toolkit \$14,500

Total \$102,079

Aging In Place In The Community

Council and Staff Initiated Activities \$16,843

Connecticut Public Broadcasting – Aging In Place \$21,000

Total \$37,843

Family Support

Connecticut Family Support Council \$14,992

Subtotal \$506,571

Administration - 5% of the federal formula grant goes
directly to the CT General Fund \$34,781

Council Office and staff \$154,260

Subtotal \$695,612

Carried over for use in 2009 \$32,167

Total \$727,779



2008 Grants

Able Lives and Toolkits



Able Lives is a ten-part television series that was produced by the Council on Developmental Disabilities in partnership with the CT Public Broadcasting Services (CTPBS). The series highlights how people with disabilities can be productive and contributing members of society. The series was very successful in reaching and educating the public about the contributions and accomplishments of people with developmental disabilities. Responses from the community have shown that many people changed their attitudes and hearts about the perception regarding the capabilities of people with disabilities after watching the Able Lives shows.

These Able Lives tapes are a powerful tool and need to reach the public and the policymakers. In 2008, a task force was formed of Council members and supported by staff, CT Public Broadcasting staff to develop Inclusive Education and Community Inclusion Toolkits. Each toolkit will have an Able Lives DVD along with additional information that enhances the community presentations. Able Lives videos from 2005 through 2007 were embedded in the power-point presentations. These “how to” toolkits were completed in early 2009 and will be used for a variety of training opportunities across the state.

CT Kids As Self Advocates

Starting in 2002, the Council on Developmentally Disabilities started a highly successful self-advocacy youth organization called CT Kids as Self Advocates (CT-KASA).

CT-KASA testified before state legislators. In addition, they raised funds for a Boundless Playground, and received the Youth Service Award from United Teen Connection. One youth credited CT KASA with helping him transition from high school to college.

The Council is pleased CT KASA will be supported for the next 3 years on an \$110,000 service integration subcontract with the Division of Maternal and Child Health in the CT Department of Public Health.

CT Youth In ADAPT

Through the Disability Resource Network, the CT Council on Developmentally Disabilities enabled youth with developmental disabilities to become activists locally, statewide and nationally. Youth learned about civil disobedience, demonstrations, protests and rallies as advocacy tools and put this knowledge to positive use locally. Four students met with their United States Representative in Washington, D.C., and received academic credits for learning about advocacy.

CT Youth of ADAPT were successful in writing letters to advocate on behalf of their desire to have the use of a public school gym for after school activities. In addition, they protested the inaccessibility of school cafeteria tables and the segregation of students with intellectual disabilities. The Council will call upon these youth to testify on Council supported legislation. We are pleased that the Governor appointed one of the youths to be on the Council.

Interactive Robotics

The Council on Developmental Disabilities is proud to be a pioneer in funding service robots initiative because this technology can significantly enhance the lives of people with disabilities.

In the “Hide and Seek Robots” competition in 2008, the goal of the robots was to locate a frightened, hiding child with intellectual disabilities in a simulated house fire. Out of 107 robots registered, 15 registered for the service robot competition, seven successfully competed and the three winners were from Connecticut, New Hampshire and Israel. In addition to the



competition, there was a symposium where Dr. Francois Michaud of the University of Sherbrooke, Quebec, Canada spoke on the “Interactive Robotics for Health Care and Technologies.”

The Council believes that by sponsoring the competition and symposium that these events have influenced the thinking of many college and high school students. The council members were pleased when the Odyssey Magazine, a child's science magazine, published a story about the “Hide and Seek Robots” competition.

The Council’s robotics contest will be dramatically changed for this spring’s competition. Formerly it was entitled the “Hide and Seek” robotics contest, now it will be called the “Robo-Waiter” robotics contest. What had been pictured before for the “Hide and Seek” competition was that a small autistic child, caught in a house fire, runs and hides in fear of the flames. Each robot’s challenge was to find the child and signal to caregivers where he or she is. The new the “Robo-Waiter” competition shows two people sitting at a table, one of them in a wheelchair. Here the challenge for each robot will be to go to a refrigerator (an imagined “refrigerator,” signified by a shelf), take a plate of food over to the table, so the two people sitting there can eat. The “Robo-Waiter” concept points to the idea that perhaps someday larger robots, built for utilitarian purposes, will be available to people with disabilities who find it difficult to do such things as carrying food from place to place. “It will be interesting to see how the robots do with this new form of competitive challenge,” said Joyce Baker, a Council Member.

Staff Projects

Aging-In-Place-In-The-Community

Have you thought about aging-in place? The CT Developmental Disabilities Network made up of the Council on Developmental Disabilities, Office for Protection and Advocacy and the University Center of Excellence in Developmental Disabilities held an Aging-In-Place Symposium on October 30, 2008. Approximately 100 parents, people with disabilities and providers gathered at the Crown Hotel in Cromwell to brainstorm ways for people with disabilities to age-in-place.

Jim McGaughey from the Office of Protection and Advocacy charged the participants to develop a vision that will influence state legislators and programs on the importance of aging in place for people with disabilities. Before participants began to share their vision, they heard about the aging demographics presented by Dr. Robinson from UCONN Center of Aging. There was a panel of self-advocates, parents and a professional who shared stories about aging-in-place and the importance to age in the community with many connections of family and friends.

During lunch, participants watched the a premiere of a show called Local Lens that was produced by CT Council on Developmental Disabilities in partnership with the CT Public Broadcasting. This show focused on older adults with disabilities who have productive and meaningful lives in the community. In addition, the show featured older caregivers who discussed their hopes for their older adults with disabilities when they are no longer able to assist them.

The participants went to work within their diverse small groups to create a vision for the future for our elders with disabilities and action plan to make the vision realty. Many wonderful ideas were shared that will guide the planning committee to the next steps in 2009.

Emergency Preparedness For Disasters

Have you ever thought about what you would do if there were a man-made or natural disaster in CT? The Council on Developmental Disabilities is pleased to share their accomplishments with Emergency Preparedness for People with Disabilities in 2008.

Mary Ann Langton, a Disability Policy Specialist at the Council, along with other advocates with disabilities and a few state agencies, gave presentations on Emergency Preparedness for People with Disabilities. This team gave presentations to over 300 fire responders, emergency personnel and interested community members within Greater Hartford. The purpose of this training was to create better understanding so that responders would be more sensitivity to the needs of people with disabilities. As a result, responders would be more knowledgeable and be better prepared to assist them during an emergency situations.

These two hours presentations consisted of information about how to respond and assist people with various disabilities during emergency situations. The highlight of these presentations was when some of the participants volunteered to role-play scenarios with the speakers. From their comments, we learned that some of the volunteers had never interacted with a person with a disability. They did not know how to manually move a power wheelchair. They did not know how to interact and respond to the needs of people with disabilities.

In addition, the speakers participated in some towns' drills to see if they were inclusive of all people. By participating in these drills, suggestions were made about assisting people with disabilities.

Inclusive Education

Angela Spino, a Disability Policy Specialist for the Council on Developmental Disabilities, is a parent with a son with a disability. She learned first-hand, as well as from other parents, that there was less oversight and reporting in CT on the use of aversives, restraints and seclusions in schools than in adult settings and in prisons. The Council decided to focus on a comprehensive approach to safeguarding students with disabilities from such treatment,

The Council collaborated with several individuals and organizations to write, publish and distribute an Individual Education Plan (IEP) guide and Special Education Made Easy (SEME) guide for parents. Approximately 1,000 English IEP and SEME guides were printed. In addition, the council had about 300 IEP and SEME guides translated into Spanish, printed and distributed. These written documents are in English and Spanish, which can be downloaded from the Council's website at www.ct.gov/ctcdd.

Ms. Spino gave presentations, technical assistance and training on the guides to four parent groups. A hundred, forty-two parents attended these meetings. In addition, Ms. Spino attended Planning and Placement Team (PPT) meetings with parents where the use of aversives and restraints were being used in the classroom.

Ms. Spino along with the Council, University of Connecticut Center of Excellent in Developmental Disabilities and many advocates collaborated and organized a conference on Positive Behavioral Supports and

Interventions (PBS) called “Positive Approaches to Challenging Behaviors.” This event was held at the Crowne Plaza in Cromwell. Over 400 educators and human service professionals attended the conference while many others were on the waiting list. Members from the Council assisted with the registrations on the day of the conference.

In Ms. Spino represented the Council on the Board of Directors of TASH/New England. TASH has changed its definition to be inclusive but has still used the same acronym. When TASH was started in 1974, it was called the American Association for the Education of the Severely / Profoundly Handicapped and went by the acronym: AAESPH. In 1980, the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to The Association for Persons with Severe Handicaps in 1983 but the acronym continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized, however, to stop using the full name of the organization since it did not reflect current values and directions.

In addition, Ms. Spino represented the National Association of Councils on Developmental Disabilities on the National TASH/Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS) Councils. She presented a workshop about the use of aversives, restraints and seclusion at the 2008 National Association of Councils on Developmental Disabilities Conference (NACDD) with the national TASH President.

Medical Task Force

The Council on Developmental Disabilities heard many horror stories from people with disabilities about their treatments while being in the hospital. There seems to be a lack of understanding and sensitivity among the medical professionals. Mary-Ann Langton, Disability Policy Specialist, knew from her own experiences of being woman with a disability about the need to foster more awareness and education to the medical profession.

The Council held a brainstorming meeting on April 19, 2008 where people with disabilities, parents and personnel from the Department of Social Services met to discuss medical difficulties and ideas that could guide the Council with implementing a plan to address this issue. The general thread from the gathering was to bring about education that would raise the sensitivity, respect and understanding to all areas of the medical profession.

A small task force met to discuss how to begin addressing the problems. The Department of Public Health became interested with assisting the task force with their mission. A few meetings have been held to develop a presentation so the medical professionals would feel more comfortable with serving people with disabilities.

Council Members

October 1, 2007 to September 30, 2008

Officers

Cathy Adamczyk, Chair

Armand Legault, Vice Chair

Persons with Developmental Disabilities

Joyce Baker, Wethersfield

Richard Burney, Unionville

(Resigned October 9, 2007)

Carolyn Cartland, Bloomfield

(Resigned April 29, 2008)

Leo Germain, Manchester

Jamie Graham, Bloomfield

Armand Legault, Newington

Jennifer Lortie, Griswold

Thomas McCann, Manchester

Peter Morrissette, East Hartford

Rajiv Root, Fairfield

(Resigned May 11, 2008)

Paul Seigel, New Haven

Chad Sinanian, Danbury

Parents

Cathy Adamczyk, Ansonia

William Broadbridge, Cheshire

(Resigned May 8, 2008)

Jousette Caro, Hartford

Patricia Carrin, Canton

Sheila Crocker, Bloomfield

Mary Eberle, Bloomfield
John Flanders, Cromwell
Nancy Taylor, Canton
Anita Tremarche, Manchester
Patricia Vidal, North Haven
(Resigned December 21, 2007)

State Agencies

Patricia Anderson, Department of Education
Lawrence Carlson, Department of Social Services
Gabriela Freyre-Calish, University Center for Excellence in Developmental
Disabilities, UCHC
Kathryn duPree, Department of Developmental Services
Patricia Tyler, Office of Protection and Advocacy
Lisa Davis, Department of Public Health

Private Agencies

Frederick Frank, Career Resources, Bridgeport

Staff To The Council

Edward T. Preneta, Director
Angela Spino, Disability Policy Specialist
Mary-Ann Langton, Disability Policy Specialist

Webmaster

Matthew Smith, Litchfield County Computer, Woodbury