



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

A message from the Chair:

Full inclusion and equality for all! Who would disagree? In a perfect world, all would agree; but we don't live in a perfect world. The CT Council on Developmental Disabilities works toward making this basic belief and human right a reality.

This past year, the Council was very instrumental in promoting a positive image of people with developmental disabilities. The Council, working collaboratively with People First (a self-advocacy group) and other organizations across Connecticut, was part of a successful effort to legislatively change what was determined to be the offensive name, the Department of Mental Retardation. It was changed to the more dignified name, the Department of Developmental Services. This is a very important first step in showing all citizens of Connecticut that individuals with disabilities are valued and appreciated. The Council looks to the day when the mission of the newly named Department of Developmental Services includes all people with developmental disabilities.

The Council was very active in supporting legislation regarding restraints used on children in classrooms across Connecticut. A watered-down bill was passed, but the Council has made the commitment to advocate strengthening the restraint legislation so that it includes training and alternatives to the use of restraints.

The Council works hard to develop and implement public awareness and educational and informational articles, letters to the editor, and programs to promote public understanding of people with disabilities, their families and their issues.

In 2008, the Council will continue to increase awareness of the Council through their annual report, blog and website. The Council supports initiatives that promote independence, productivity, integration and inclusion in the community. We will be looking at leadership development for self-advocates, parents and professionals. CT Kids as Self Advocates and ADAPT of CT are youth self-advocate initiatives that we will be supporting. Legislatively, we plan to be pro-active and propose legislation, but also reactive to legislation.

The CT Council on Developmental Disabilities was at the forefront when we introduced Able Lives (we now own the trademark) in 2006. We are now taking the initiative again. We will be providing awards for high school, technical school and college robotics teams through a robotics competition. These students will be designing, building and demonstrating robots that assist people with developmental disabilities with household activities, chores, tasks and other activities of daily living.

Carolyn Cartland did a magnificent job in leading us to such a successful year in 2007. I was proud to sit next to her as Vice-Chair. She kept us on task, and moving forward. It is my hope that I can do as good a job as she did.

It is always hard to see Council members leave as their terms expire. We lost some very good, creative, active members this year. You will all be missed. We are very lucky to have such wonderful new faces on the Council, full of new ideas and energy. They bring a freshness and new way of looking at issues. Welcome to all of our new members.

We have an incredible amount of work to accomplish, but if we all do our share, we will get through it all very successfully. I thank you all for giving me and my Vice-Chair, Armand Legault, this opportunity to lead you forward in the exciting year ahead.

Cathy Adamczyk

Cathy Adamczyk
Chair

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

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 28 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.

IN 2007, THE COUNCIL FUNDED 8 INITIATIVES:

1. *Influencing Public Mass Transportation Policy*
2. *African Caribbean American Parent Support*
3. *Kids As Self-Advocates*
4. *"Able Lives" Multimedia Campaign on Inclusion*
5. *Social Role Valorization (values-based) Training*
6. *Disability Advocacy Collaborative*
7. *Robotics as Assistive Devices*
8. *ADAPT of Connecticut*

Contact Information:

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Renaming the Department of Mental Retardation to the Department of Developmental Services

SINCE 1978, THE COUNCIL, ALONG WITH MANY PEOPLE WITH DISABILITIES, THEIR FAMILIES, AND ADVOCATES TRIED TO RENAME THE DEPARTMENT OF MENTAL RETARDATION TO A MORE RESPECTFUL NAME.

Connecticut was one of the few states that had not changed their Department of Mental Retardation name. At a Council Meeting, members discussed and submitted the name of Department of Developmental Services!

Chad Sinanian, a Council Member, was very vocal about the urgent need for a name change of this department. He felt the words of 'mental retardation' were disrespectful and hurtful. In addition, he felt, that at this day and age, such a name for a state agency was most inappropriate. Mr. Sinanian had a lot of support from the People First of CT, a self-advocacy group of people with disabilities. Many members of People First, the CT Council on Developmental Disabilities, family members, advocates and concerned citizens attended hearings to speak in favor of a name change.

On May 30, 2007, Governor Rell signed the bill to rename the Department of Mental Retardation to the Department of Developmental Services. Thom McCann, a current Council Member and Carol Grabbe, a former Council Member, both received a signed copy of the bill from Governor Rell.

The new name of the Department of Developmental Services is a great step forward to recognizing the gifts and abilities of people with intellectual disabilities. However, the department still only serves people with intellectual disabilities. Perhaps someday this department will change its mission and serve all people with developmental disabilities.

An Act Concerning Restraints and Seclusion in Public Schools

ON DECEMBER 13, 2006, THE OFFICE OF PROTECTION AND ADVOCACY HELD A HEARING ABOUT THE USE OF RESTRAINTS AND SECLUSIONS IN SCHOOLS. Angela Spino, one of the Disability Policy Specialist from the Council, gave her personal story of how her son was restrained at a school. She invited parents to attend the hearing and to present their stories. Families, legislators, attorneys, and educational consultants knew that Connecticut needed to pass a new law on this issue after they listened to stories about children who have been restrained and secluded in schools.

The DD Network sponsored a forum at the State Capitol on the Use of Restraints & Seclusion in schools. The Council invited Pat Amos from Pennsylvania and Dr. Chris Oliva from Queen's College in New York to present Positive Behavior Supports (PBS) as well as Positive Behavior Interventions Supports (PBIS). As a result of the forum, Senator Ed Meyer decided to sponsor the Restraints & Seclusion in Schools Bill. The Council collaborated with the Senator on the language for the bill.

Governor Rell signed the bill into law on July 3, 2007 and the law took effect October 1, 2007.



AFCAMP



CT KASA
CONNECTICUT
KIDS AS SELF ADVOCATES

ADAPT OF CONNECTICUT: ADAPT is a national organization that promotes living in the community.

AFRICAN CARIBBEAN AMERICAN PARENTS: Three years ago with the Council support, African Caribbean American Parents (AFCAMP) began a group called Parent Empowerment through Education, Training and Advocacy (PEETA) to organize African-American and Latino parents in Greater New Haven. The group educated, trained, and empowered parents that live in disenfranchised communities. In 2006, 206 parents and providers attended monthly workshops to learn about the various services for children with disabilities. PEETA trained 14 parents who became parent leaders and participated in trainings, conferences and legislative forums. In addition, PEETA provided information to community organizations and providers in an effort to raise their awareness about the needs of children with various disabilities.

CPTV ABLE LIVES . . . INCLUSION WORKS: "Able Lives," a ten-part documentary of how CT residents of all ages lead productive and meaningful lives, led to the development of "Inclusion Works." These episodes were presented in a one-minute report format providing weekly information on topics and issues that promote inclusive communities. Presented as reality-based content using satire, humor and wit to change perceptions about people living with disabilities, these reports focused on universal access as the platform for creating inclusive communities and showed that "what works for people with disabilities works for everybody; in other words, Inclusion Works!"

"Able Lives-Inclusion Works" left a large impression on self-advocates, families, legislators and the general public according to the broadcast industry. Able Lives became a trademark of the Council. In addition, the Council allowed the use of "Able Lives" by Connect-Ability, a CT Medicaid Infrastructure Grant.

DISABILITY ADVOCACY COLLABORATIVE: The Disability Advocacy Collaborative is a cross-disability self-advocacy organization that has been supported by the Council for the last three years. The Disability Advocacy Collaborative electronically sends a Bulletin and Calendar of Events to 1106 recipients. These monthly emails keep people informed about current events and about disabilities issues. The Disability Advocacy Collaborative assisted six regional networks that addressed local issues. In addition, the membership worked on state and national issues. The Collaborative hosted the national Road to Freedom Tour and training for youth activists.

CT KIDS AS SELF ADVOCATES: CT Kids as Self Advocates (CT-KASA) is a self-advocacy organization that is led and directed by youth with disabilities. They have employed two youth as the co-facilitators and three others as Youth Organizers. CT-KASA has 33 members who are between the ages of 13 and 25. Members made presentations at the CT Independent Living Conference, National KASA Conference, and at various transition conferences. At these conferences, they spoke on the importance of inclusion as well as the importance of self-advocacy. In addition, members



University of
Connecticut

were active on the CT Youth Leadership Project, State Rehabilitation Council, and at the National Leadership Conference.

SOCIAL ROLE VALORIZATION: Two Social Role Valorization (SRV) trainings were held to foster education and to heighten awareness of how people with disabilities are devalued or at risk of devaluation. The first workshop was called "Tube-feeding At Thirty Thousand Feet: De-Mystifying Assisted Nutrition/ Hydration And Other Life-Enhancing Decisions." Wolf Wolfensberger taught the second workshop that was called "What Happens To Vulnerable People In Times Of Disaster and Calamity, and How To Prepare For It In Advance." Fifty participants were presented with a strong foundation for positive change and leadership development at both workshops.

TRINITY COLLEGE ROBOTICS – HIDE AND SEEK ROBOT: Council Members took the initiative to explore how robots can assist people with disabilities. Trinity College has hosted an International Fire Fighting Home Robot Contest for the last 15 years. David Ahlgren, Ph.D., a professor in the Trinity Engineering Department, was receptive to expanding this well-known robot competition to the field of disabilities. In endorsing this new event, Professor Ahlgren said that "the new contest division, Robot Hide and Seek, is a unique opportunity to demonstrate how robots can assist persons with disabilities. It is the first step that will help to educate the public and encourage roboticists to develop assistive robots."

The 2007 Robot Hide and Seek event presented a scenario where a child with autism or an intellectual disability is in a fire, panics, and hides in a burning house instead of trying to exit. The robot's job was to find the child and to indicate to the firefighters where he or she was hiding. Six robots entered the competition, and the best performance was accomplished by the robot Ribbit, designed by a team of Trinity undergraduates.

THE UNIVERSITY OF CONNECTICUT MASTER OF PUBLIC HEALTH PROGRAMS: Seventeen second-year Masters and Ph.D Public Health students completed a practicum on "The Challenges of Living with Disabilities in Connecticut." Students gained knowledge and developed a greater understanding about people with disabilities. In addition, students had the opportunity to attend workshops about policy advocacy and asset-based community.

UNIVERSITY OF CONNECTICUT CENTER SURVEY OF RESEARCH AND ANALYSIS: The University of Connecticut Center Survey of Research and Analysis (CSRA) conducted a statewide telephone survey in August and September to assess residents' attitudes and perceptions on various topics concerning people with developmental disabilities. Five hundred and one (501) residents were interviewed in this survey, and we are pleased to share the highlights with you!

The survey revealed that only 24% of the residents were aware of the law that permits restraints and seclusions to be used on children with disabilities in



public schools. After hearing about the law, 89% of the responders believe that schools should be required to document all uses of physical restraints and seclusions on the children. In addition, 83% of the residents reported that they wanted their children to be taught in the same classroom as children with developmental disabilities. Ninety-nine percent (99%) of the residents felt that it is the state's responsibility to fund programs to assist individuals with their career skills and to learn about jobs. At the same time, 94% of the residents believe that it is the state's responsibility to fund programs and that private industry should take some responsibility to employ people with disabilities.

In addition, 99% of the residents agreed that people with developmental disabilities should have access to public places while 97% agreed that there should be access to private spaces. However, 90% of the residents felt that people with disabilities should have access to places of worship.

PLAN FOR THE ACHIEVEMENT OF TRANSPORTATION COORDINATION IN HUMAN SERVICES:

The Plan for the Achievement of Transportation Coordination in Human Services (PATH) worked with providers to create a coordinated community transportation system for people with disabilities. Eight people with disabilities participated in 13 regional meetings to raise peoples' awareness about the need for inclusion of riders with disabilities when undertaking future transportation initiatives for Connecticut.

A transportation summit was held on July 26, 2007. During the event, 50 people learned about a successful accessible transportation model from Colorado!

In addition, the Council submitted comments on both the Reorganization of Connecticut Department of Transportation (ConnDOT) and the 2003-2040 Long-Range Plan for ConnDOT. In their comments, the Council advocated for a culture change that will result in inclusive, accessible, affordable and available public transportation systems that enhance the independence, freedom and inclusion for people with disabilities.



Policy Forums in Action

The CT Developmental Disabilities (DD) Network is made up of the sister agencies in the federal Developmental Disabilities Act: the Council on Developmental Disabilities, the Office of Protection and Advocacy and the University Center for Excellence in Developmental Disabilities at the University of Connecticut (UConn) Health Center.

THE CT DD NETWORK COLLABORATED ON THREE ISSUES IN 2007: (1) Support for Families with Children with Special Health Care Needs, (2) the Use of Restraints and Seclusion in Schools and (3) Accessible Public Mass Transportation. The CT DD Network sponsored policy forums on these issues for legislators at the Legislative Office Building and the State Capitol.

Keeping Kids At Home: Support for Families with Children with Special Health Care Needs was held in February and featured Julie and Katie Beckett, Family Voices USA, who spoke about the impact of the Katie Beckett waiver on children and families, Boston University's Catalyst Center on implementation of the federal Family Opportunity Act and a report on Children With Special Health Care Needs by the Office of the Child Advocate.

The Use of Restraints and Seclusion in Schools was held in March and featured Christopher Oliva, Queens College, City of New York, and Pat Amos, Alliance to Prevent Restraint, Aversives Interventions and Seclusion. Approximately 50 people including legislators or their aides attended this forum.

Catch The Spirit was the third annual Spirit of ADA Celebration co-sponsored by the CT DD Network. The celebration was held on July 26th, the 17th anniversary of the ADA. It featured an update from the CT Department of Transportation on coordination initiatives and honored advocates who had gone above and beyond to promote access to public mass transportation.





Fred Frank was an international executive headhunter who ranked eighth in the nation before he became disabled. Fred developed a rare bacterial infection that robbed him of his “motor skills”, such as, walking, talking,

breathing, and writing. He was told by social security that he would never work again and, “to go home” and to take the monthly income that would be sent to him. After eleven years, Fred regained his abilities and returned to the business world. Fred proved many people wrong because he now leads a very productive professional and social life.

Presently, Fred Frank is a Regional Disability Program Navigator (DPN) for the Career Resources in Fairfield County Connecticut. Fred’s duties are to work with businesses in the Fairfield County area while emphasizing the importance of work ethics for people with disabilities. Simultaneously, Fred will seek qualified people with disabilities to be employed in these job positions. Additional training is available to assist people with disabilities for a job.

Prior to his position as DPN, Fred was the Assistant Director at the Disability Resource Center of Fairfield County, CT (DRCFC). One of Fred’s roles as the Community Relations at DRCFC was to conduct Americans with Disabilities Act (ADA) trainings and sensitivity/awareness trainings for numerous organizations. In addition, he was the Vice-President of the Connecticut Association of Centers for Independent Living (CACIL).

When Fred is not at work, he is a volunteer on numerous boards and committees that are working toward improving the lives for people with disabilities. He is actively involved in Emergency Preparedness for People with Disabilities within his region.



Presently, Thom McCann works at Stop&Shop Supermarket and lives independently. He lives a productive life. His fight for independence, however, was not an easy one!

Thom lived with his father when he was young. Thom told his father that he wanted to move into a “group home” because he wanted to learn to become independent. However, Mr. McCann did not see why Thom should move out of the family house. In addition, he did not want Thom to think that he was putting him ‘away’ by allowing him to move, even though it was what Thom wanted in his quest for independence.

While Mr. McCann traveled to Germany, he permitted Thom to ‘test the waters’ and to stay in a group home. Mr. McCann saw that Thom was very happy in the group home, where he learned independent living skills. Thom lived there for one year. In 1988, Thom moved into an apartment. Thom was supported with both of these living situations by the Department of Developmental Services (DDS). Thom and his family are grateful for all the support they have received to make it possible for him to lead an independent, inclusive life in his community.

Thom has been a board member for People First of Connecticut. People First is an organization made up of people with disabilities who lead self-advocacy movement throughout the state on various issues that affect people with disabilities. This year, after advocating for many years, People First was instrumental in the success of getting the name of Department of Mental Retardation changed to a more respectful name, the Department of Developmental Services. Thom represented the self-advocates at the bill signing by Governor Rell.

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 2007, the CT Council received an allotment of \$675,805. The CT Council also carried over \$61,238 of 2006 funds for use during 2007. The Council's total 2007 budget was \$737,043. The Council leveraged \$138,743 in matching funds

2007 GRANTEES AND COUNCIL & STAFF INITIATED ACTIVITIES

ADAPT of Connecticut	\$ 1,000
African Caribbean American Parents (AFCAMP)	\$ 45,000
Connecticut Public Television (CPTV) – <i>Able Lives</i>	\$150,000
DD Network Forums – Restraints in Schools	\$ 775
Disability Advocacy Collaborative (including a workshop with youth activists)	\$ 46,500
FAVARH (expense carried over from 2006)	\$ 68
CT Kids As Self-Advocates (CT-KASA)	\$ 36,000
Social Role Valorization/Implementation Project (SRV) Staff Arranged Facility, Meals, Parking	\$ 10,500 \$ 3,774
Trinity College Robotics	\$ 7,500
University of CT Health Center, University Center for Excellence (UCE) Transportation – <i>United We Ride</i>	\$ 18,256
UConn Center for Public Health and Health Policy (policy advocacy and community building workshops)	\$ 3,000
Staff Arranged Facility, Meals, Parking	\$ 1,142
Asset Based Community Development Books	\$ 750
UConn Center for Survey Research and Analysis	\$ 18,500
	Subtotal: \$342,765
2007 Council and Staff Initiated Activities	\$ 145,188
	Subtotal: \$487,953
Administration – 5% of the federal formula grant goes directly to the CT General Fund	\$ 33,790
Council Office and Staff	\$209,362
	Subtotal: \$731,105
Carried Over for Use in 2008	\$ 5,938
	TOTAL: \$737,043



Emergency Preparedness Forum

Statewide trainings were conducted with regional planners and first responders about emergency preparedness and response for people with disabilities. These trainings addressed issues of registries, evacuation tips and techniques, shelter considerations, service animal tips, and other related issues. In addition to the presentations, participants had the opportunity to role-play different disaster scenarios which included people with disabilities.

In addition, workshops were offered to people with disabilities so they would know how to prepare for a disaster. People learned how they could foster greater awareness about emergency preparedness in their communities and how to sign up for registries.

We were pleased to collaborate with our sister agencies and other disability organizations on this vital issue. Trainings planned for 2008 will include a wide variety of people who have extensive experience responding to disasters of any type.

The Council has the following committees:

- **ADVOCACY & LEGISLATION COMMITTEE**
 - **EXECUTIVE COMMITTEE**
 - **GRANTS COMMITTEE**
- **MEMBERSHIP COMMITTEE**
- **PLANNING COMMITTEE**
- **PUBLIC INFORMATION & EDUCATION COMMITTEE**

Officers

Carolyn Cartland, *Chair*
(Elected September 12, 2006)

Cathy Adamczyk, *Vice Chair*

Persons with Developmental Disabilities

Joyce Baker, *Wethersfield*

Richard Burney, *Unionville*

Carolyn Cartland, *Bloomfield*

Leo Germain, *Manchester*

Jamie Graham, *Bloomfield*

Armand Legault, *Newington*

Jennifer Lortie, *Griswold*

Thomas McCann, *Manchester*

Peter Morrissette, *East Hartford*

Rajiv Root, *Fairfield*
(appointed September 28, 2007)

Paul Seigel, *New Haven*

Chad Sinanian, *Danbury*

Parents

Cathy Adamczyk, *Ansonia*

William Broadbridge, *Cheshire*

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*



State Agencies

Patricia Anderson, *Department of Education*

Lawrence Carlson, *Department of Social Services*

Julia Rusert, *University Center for Excellence, UCHC*

Kathryn duPree, *Department of Mental Retardation*
(DMR was renamed Department of Developmental Services October 1, 2007)

Patricia Tyler, *Office of Protection and Advocacy*

Lisa Davis, *Department of Public Health*

Staff to the Council

Edward T. Preneta, *Director*

Angela Spino, *Disability Policy Specialist*

Mary-Ann Langton, *Disability Policy Specialist*

Webmaster

Judi Sohn, *Mom At Home Design, New Jersey*

Private Agencies

Carolyn Newcombe,
Disabilities Network of Eastern Connecticut
(Retired September 8, 2006)

Frederick Frank,
Disability Resource Center of Fairfield County
(Appointed September 8, 2006)



The Council looks forward to the following grants in 2008 that will promote advocacy, capacity building, and systems change in Connecticut.

2008 INITIATIVES

TO PUBLISH AND DISTRIBUTE two Cliff Note-like guides to help parents navigate through the development of an Individual Education Plan (IEP) with their local education agency	\$ 2,200
TO SUPPORT grassroots parent organizing	\$ 42,185
TO SUPPORT a part-time staff person for the CT Family Support Council	\$ 33,315
TO SUPPORT the Disability Advocacy Collaborative's 2008 Disability Convention and Expo in Hartford	\$ 5,000
TO CONTINUE a Robot Hide and Seek competitive robotics event at the Fire Fighting Home Robot Contest at Trinity College, Hartford, CT	\$ 8,500
TO SUPPORT the Disability Resource Network, Ansonia, to enable youth leaders with developmental disabilities to participate in activist activities locally, statewide and nationally	\$ 10,000
TO SUPPORT CT Kids As Self Advocates (CT-KASA), a grassroots self-advocacy organization for adolescents and young adults between the ages of 13 and 24	\$ 32,400
TO SUPPORT a "Life Threatening Public Policy" series of 15 workshops targeting hospital patient advocates and ethics committees	\$ 36,725
TO WORK with Connecticut Public Television (CPTV) to redesign the CT Council's 2006 "Able Lives" television series on inclusion in the community into a "how to" toolkit for distribution to policymakers, parent and self-advocacy groups, educators and schools, libraries, business decision-makers and community leaders	\$ 70,000

TOTAL: \$170,325



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