



**CONNECTICUT COUNCIL ON
DEVELOPMENTAL DISABILITIES**

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*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:

The Council had perhaps its busiest and most productive year ever as we influenced the larger community in a number of unique and powerful ways, advocated for people with disabilities and educated many on the importance of the inclusion of folks with disabilities into the lives of our communities.

Our biggest undertaking was to partner, along with other public and private funders, with CT Public Broadcasting to create a ten episode television series called "Able Lives." This Emmy winning series, which began in April 2006, focused on the lives of people with disabilities and their families, and the obstacles they face in attaining full inclusion in society. Co-hosted by people with disabilities, each episode addressed, in a "docu-zine" format (part documentary and part magazine style), specific issues such as family life, transportation, employment, education, recreation, technology, assistive devices and other topics. Feedback from the community has been outstanding, with folks sharing stories of systems change, social transformation, and personal healing. We look forward to a continued partnership with CPTV as we expand the theme of "Able Lives" across our state and the nation. Several DD Councils across the country are working to create similar efforts after hearing about the series at the October 2006 National Association of Councils on Developmental Disabilities meeting.

The Council was also extremely active this past year testifying and educating others on a number of important pieces of legislation. Most notably, we were instrumental in creating an open atmosphere of discussion about changing the name of the Department of Mental Retardation by establishing a blog for folks throughout the state to voice their opinions. We were very gratified when the Department recommended the name our Council suggested, the Department of Developmental Services, to the Governor. Along with testimony advocating for the elimination of the use of physical restraints in school systems, we have taken strong public positions on the inherent worth and dignity of every child and adult and the importance of treating everyone with respect.

During the past year, we provided grant monies to a number of organizations and projects throughout the state, designed to help more people with disabilities lead "able lives". We helped to fund the first ever state-wide Disability Convention, provided money to African Caribbean American parents for empowerment training of parents of children with disabilities, continued our support of Kids As Self Advocates to develop the next generation of leaders from the disability community, underwrote Social Role Valorization Implementation Project workshops, and worked with the University Center for Excellence to study the issues and obstacles which impact the availability of safe public transportation for people with disabilities in Connecticut.

The Council also partnered with the Office of the Child Advocate in initiating and participating in the effort to expand awareness of the issues associated with children with complex medical needs and helped to develop the first-ever Summit on this issue. We continue to work to educate others on the significant needs faced by children with disabilities and the policy recommendations that are needed.

We did all of this and more, and we did it while undergoing significant change and transition within the Council. Jousette Caro, our Chair, took a leave of absence to successfully complete a pregnancy (mother and twins are well and happy!). In her absence, we were ably led by our Vice-Chair, Cathy Adamczyk. Thanks to both of them, and to a very active and dedicated Council, for making this past year a great success.

To those whose terms have expired, thank you for all you did to contribute to our accomplishments, and to all of you who have been recently appointed, hold on to your hats! We still have a lot of good work to do. Let's do it together, shall we?

Carolyn Cartland

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 NINE INITIATIVES:

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

Contact Information:

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Where the council has been and where we are going . . .



70's SERVICE ENHANCEMENT

- Corporation for Independent Living – community-based group homes to close institutions
- Alternatives to benchwork – supported employment to close sheltered unemployment centers
- Interrobusts – “Exploring The Unknown With Enthusiasm”
- Change the name and mission of DMR



80's BEYOND COMMUNITY SERVICES

- Circles of Support and Building Bridges to Community: Asset Based Community Development
- Personal Futures Planning
- Social Role Valorization Training
- Inclusive Education
- Co-op Initiatives, Inc. and co-op housing



90's EMPOWERMENT

- Self-Advocacy
 - CT Union of Disability Action Groups
 - Centers for Independent Living - DNEC
 - CT Coalition of Citizens with Disabilities
- Parent Groups
 - Padres Abriendo Puertas
 - CT Coalition for Inclusive Education
 - CT Parent Advocacy Center

00's NEW MILLENNIUM LEADERSHIP

- Council, Council Members, Council Staff
- Kids As Self-Advocates
- Political Convention



AFCAMP



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

SOCIAL ROLE VALORIZATION/IMPLEMENTATION

PROJECT: The Council hosted three Social Role Valorization trainings to enable, maintain, and enhance valued social roles in society for people with disabilities. These trainings focused on contemporary concerns in the field of human service. Issues addressed included living with in-home services, inclusive education, and frailty in old age. Sixty-four people attended the Social Role Valorization training sessions.

KIDS AS SELF-ADVOCATES: CT-KASA is a grass-roots organization made up of 20 youth who are between the ages of 13 to 21. The youth learn various skills on how to become effective self-advocates. They also learn about the different supports and services available that may assist them during their lifetime. New members are joining every month!

AFRICAN CARIBBEAN AMERICAN PARENTS:

AFCAMP began the Parent Empowerment through Education, Training, and Advocacy (PEETA) to empower, educate, and train parents from disenfranchised communities. Sixty parents were trained and eight new parent leaders emerged from PEETA.

DISABILITY ADVOCACY COLLABORATIVE: The Disability Advocacy Collaborative revitalized and strengthened a cross-disability movement made up of individuals and organizations. Eight-hundred people attended the Collaborative's first statewide convention. Eight political candidates spoke. An email newsletter is distributed to over 1,000 people and organizations on a monthly basis.

UNIVERSITY OF CT HEALTH CENTER, UNIVERSITY CENTER FOR EXCELLENCE – TRANSPORTATION –

UNITED WE RIDE: The University Center of Excellence held six workshops around the state under the federal "United We Ride" initiative to educate transportation users about existing services for people with disabilities. One-hundred and five people attended the workshops and eleven people participated in a train-the-trainers course on disability awareness and safety.

FAVARH



FAVARH: The Council and the Farmington Village Green and Library Association co-sponsored a presentation on Asset Based Community Development. Fifty community members were in attendance. There was also a presentation in Spanish to 25 parents from *Padras Abriendo Puertas*, an organization of Latino parents in Hartford. In addition to these presentations, the Council had an initiative with the Arc of Farmington Valley, Canton, to connect people with developmental disabilities into community life.

CPTV – ABLE LIVES: The Council and CPTV co-produced a series of ten half-hour television episodes called “Able Lives.” These episodes demonstrated various ways in which Connecticut residents of all ages with disabilities, can lead productive and meaningful lives in their communities. The Council worked collaboratively with many other partners who contributed to the success of the series.



Policy Forums in Action

The Council, in collaboration with its sister agencies, the Office of Protection and Advocacy and the University of CT Health Center’s University Center of Excellence, sponsored four Policy Forms. They were as follows:

Accessible Housing and Universal Design

was co-hosted by the General Assembly’s Select Committee on Housing and the CT Chapter of the American.

“Cash and Counseling” Medicaid Waiver

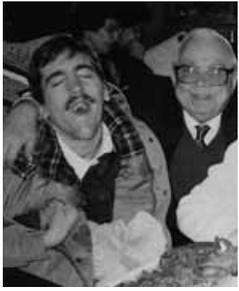
was held at the Legislative Office Building.

In-Home Supports for Children who are Medically Fragile/Technology Dependent

was co-hosted by the CT Family Support Council, the President Pro Tempore of the Senate, and the Speaker of the House.

Celebration of the 16th Anniversary of the Americans with Disabilities Act

was highlighted by the former Lieutenant Governor as the featured speaker. Awards were presented to people who have done successful work in the mental health field.



My name is Peter Morrisette and I am in my 40's. I grew up with my family. In the 1990's, I was accepted and moved into New Horizons. New Horizons is a congregate living facility for people with physical disabilities.

My mother became responsible for doing a number of tasks including hiring personal assistants and going grocery shopping for me. In addition, my mother and I went shopping, saw movies and attended other events. My mother's support was imperative because New Horizons provided me with only two hours of personal care assistance.

My mother developed Parkinson's Disease and she was no longer able to manage my care. I had a hard time moving from independent living to an institution. I learned that people often make decisions for me when I moved into the institution.

I am working with two counselors from Independence Unlimited, a center for independent living, on moving from the institution into the community. I have a circle of support that meets monthly where we discuss my goals.

In addition to helping me move into the community, my circle is trying to persuade the nursing facility to pay for a communication device. This device will enable me to express my thoughts.

I want to thank the State of CT for asking me to be a member on the CT Council on Developmental Disabilities. It is an honor to serve the disability community.



As a parent of a child with a developmental disability, my whole world changed when reality opened my eyes. When I first realized that something was different about my child, I was, of course, in denial and I found out that the

older he got the harder it was to try to hide the disability. Once reality hit and sunk in, I realized that my husband and I had to be our son's advocates until he could one day advocate for himself. We realized that we would have to gain as much knowledge about his disability as possible, so that we could help him to be as successful as he could possibly be. From the pediatrician, to Birth to Three, to Special Education our journey has not been an easy one. We have had to advocate strong and hard at times and then pick our battles at other times. Our son is now educated in a typical 4th grade class with his peers with supports & services, and continues to make progress. We are so proud of him and our motto is to "try hard and do your best" and we won't ask for anymore than that.

After serving one term on the Connecticut Council on Developmental Disabilities and currently serving my second, my eyes have been opened even more to the future for my son. I have found it quite rewarding to serve on the Connecticut Council on Developmental Disabilities with all of the other parents, self-advocates, and agencies realizing that we all have to work together. I have realized how the life of individuals with developmental disabilities are affected on a day to day basis. As a member of the Connecticut Council on Developmental Disabilities, I want to help to make a positive difference in not only my son's life but also in the lives of other individuals with disabilities. While they are too young to advocate for themselves, we must advocate for them while helping them to one day be self-advocates, as well as advocates for others.



When I was less than ten, attempts were made to either write with a pencil or type, but with little success. In school I could make marks with a pencil on a piece of paper. But nothing very legible came from this. And after I wrote two or three words, I was exhausted. In therapy I could type perhaps a sentence in an hour. I'd make a lot of mistakes, though, and my mind would wander.

As I typed, I rested my wrist on a board attached to the front of the typewriter and stretched out my fingers. This steadied my hand and gave me better finger control. My therapist decided I wasn't reaching the third row of keys well. She told me to type using only the first two rows of keys, which severely limited the choice of words I could write.

When I was thirteen, I was introduced to something called a keyguard. This is a piece of equipment with holes a person can type through, fastened over a typewriter (now a computer) keyboard. I tried typing on an electric typewriter with a keyguard in place, and I was typing!!!! And at a fairly reasonable rate of speed.

I could rest my hand on any part of the surface of the keyguard and type from there. I could use the whole keyboard, not just the first two rows of keys.

One important problem remained, though. With many years of not being able to write, my spelling was terrible. I remember agonizing over even simple words.

Taking Latin helped immensely. In my Latin homework, I had to practice breaking English words into parts and finding Latin derivations there. My spelling soon became much better. I was on a roll!!!!



As parents of a 10-year-old daughter with developmental disabilities, my wife Christine and I have worked on a daily basis to create an inclusive environment for our daughter, Lydia. We have watched her grow as a person because she has made friends through her school, local Park and Recreation programs, summer camps and church. Our belief is that Lydia can have the opportunity to perform to her maximum potential when she is surrounded by typical peers and mentors, and these opportunities have succeeded far beyond our expectations.

Lydia is well known within our community by children and their parents who always stop to say "hi" and to ask her about her day. What is amazing to me is they help to facilitate conversations with her and treat her as a person. The community has acted with great respect towards Lydia who has truly become an active young lady of society.

Nevertheless, Lydia would not be connected to the community unless our family believed in the concept of inclusion. Peter, our son, Christine and I play a role with building bridges for Lydia.

Having the opportunity to work with the Connecticut Council on Developmental Disabilities has allowed me to grow and to extend my philosophy of fostering inclusion for people with disabilities. Meeting other parents and self advocates never ceases to amaze me as to where our State could go with respect to all individuals. I look forward to the time I spend with the fellow Council members and their families.

HOW THE CTCDD 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 2006, the CT Council received an allotment of \$677,542. The CT Council also carried over \$42,672 of 2005 funds for use during 2006. The Council's total 2006 budget was \$720,214. The Council leveraged \$414,977 in matching funds

2006 GRANTEES

ADAPT of Connecticut	\$ 1,000
Social Role Valorization/Implementation Project (SRV)	\$ 8,000
Staff Arranged Facility, Meals, Parking	\$ 3,972
Kids As Self-Advocates (KASA)	\$ 40,000
African Caribbean American Parents (AFCAMP)	\$ 47,214
Disability Advocacy Collaborative	\$ 50,000
University of CT Health Center, University Center for Excellence (UCE)	
Transportation – <i>United We Ride</i>	\$ 50,000
FAVARH	\$ 58,875
Connecticut Public Television (CPTV) – <i>Able Lives</i>	\$ 75,000
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Subtotal:	\$334,061

2006 COUNCIL & STAFF INITIATED ACTIVITIES

Publications (Mouth Magazine, SRV Journal)	\$ 128
Asset Based Community Development Meetings	\$ 400
Public Policy Technical Assistance Workshop:	
National Association of Councils on Developmental Disabilities	\$ 1,096
UConn Center for Survey Research and Analysis	\$ 15,000
Staff Program Activities	\$122,527
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Subtotal:	\$139,151
Administration – 5% of the federal formula grant goes directly to the CT General Fund	\$ 33,877
Council Office and Staff	\$181,299
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Subtotal:	\$215,176
Carried Over for Use in 2007	\$ 31,826
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TOTAL:	\$720,214

Emergency Preparedness Forum

The council has collaborated with its sister organizations regarding emergency preparedness. Following Hurricanes Katrina and Rita, the Developmental Disabilities (DD) Network knew that educating and informing emergency planners, first responders, service providers and people with disabilities about disaster preparedness was imperative. It also needed to address services and support that needed to be implemented in our state to promote the inclusion of people with disabilities. Connecticut residents with disabilities wanted to learn how to survive during a disaster. In addition, they wanted to know what they could expect from the town officials and the state government.

In 2005, the DD Network hosted a conference titled, "Lessons Learned: Forum on Disaster Preparedness for People with Disabilities." This past year, the DD Network created a curriculum that focused on disaster preparedness. It also identified other issues that first responders needed to consider when assisting people with disabilities. This curriculum centered around issues such as registries, evacuation tips/ techniques, and shelter considerations. People with disabilities and advocates were the presenters, and additional trainings will occur throughout 2007.

The Council has the following committees:

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

Officers

Jousette Caro, *Chair*
(Term ended September 12, 2006)

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

Cathy Adamczyk, *Vice Chair*

Persons with Developmental Disabilities

Joyce Baker, *Wethersfield*

Steven Barnwell, *New London*

Richard Burney, *Unionville*

Carolyn Cartland, *Bloomfield*

Jamie Graham, *Bloomfield*

Jay Lang, *Fairfield*

Armand Legault, *Newington*

Jennifer Lortie, *Griswold*

Thomas McCann, *Manchester*

Peter Morrissette, *East Hartford*

Paul Seigel, *New Haven*

Chad Sinanian, *Danbury*

Parents

Cathy Adamczyk, *Ansonia*

William Broadbridge, *Cheshire*

Jousette Caro, *Hartford*

Patricia Carrin, *Canton*

Jennifer Carroll, *Glastonbury*

Sheila Crocker, *Bloomfield*

John Flanders, *Cromwell*

Nancy Taylor, *Canton*

Anita Tremarche, *Manchester*

Patricia Vidal, *North Haven*



State Agencies

Art Carey, *Department of Education*
(Retired September 6, 2006)

Patricia Anderson, *Department of Education*
(Appointed September 6, 2006)

Lawrence Carlson, *Department of Social Services*

Mary Eberle, *University Center for Excellence, UCHC*
(Changed Representation September 6, 2006)

Julia Rusert, *University Center for Excellence, UCHC*
(Appointed September 6, 2006)

Carol Grabbe, *Department of Mental Retardation*
(Retired November 21, 2005)

Kathryn duPree, *Department of Mental Retardation*
(Appointed November 21, 2005)

Gretchen Knauff, *Office of Protection and Advocacy*
(Retired December 27, 2005)

Patricia Tyler, *Office of Protection and Advocacy*
(Appointed December 27, 2005)

Martha Okafor, *Department of Public Health*
(Resigned September 29, 2005)

Lisa Davis, *Department of Public Health*
(Appointed December 27, 2005)

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)

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*



The Council looks forward to the following grants in 2007 that will promote advocacy, capacity building, and systems change in Connecticut.

2007 INITIATIVES

Asset Based Community Development and Effective Advocacy UCONN Center for Public Health and Health Policy, East Hartford	\$ 3,000
ADAPT of Connecticut	\$ 1,000
Influencing Public Mass Transportation Policy University Center for Excellence, UCHC, Farmington	\$ 41,381
<i>Able Lives</i> Multimedia Campaign on Inclusion Connecticut Public Television (CPTV), Hartford (2 years)	\$145,000
Self-Advocacy, Self-Determination and Parent Support Kids As Self-Advocates, Office of Protection and Advocacy, Hartford	\$ 36,000
African Caribbean American Parents, Hartford and New Haven	\$ 45,000
Disability Advocacy Collaborative, Manchester	\$ 45,000
Value Based Training Social Role Valorization Implementation Project	\$ 10,500
Robotics As Assistive Devices Trinity College, Department of Engineering, Robotics Competition	\$ 7,500

TOTAL: \$333,381



*“Do not follow where the path may lead.
Go, instead, where there is no path and leave a trail.”*

RALPH WALDO EMERSON