



2004
Annual Report

CT COUNCIL ON DEVELOPEMENTAL DISABILITIES



Council Members

October 1, 2003 to September 30, 2004

OFFICERS

Eve Kessler, Chair
Jousette Caro, Vice Chair

PERSONS WITH DEVELOPMENTAL DISABILITIES

Steven Barnwell, New London
Jeffrey DePina, New London
Carol Grabbe, Middletown
Joy Minervini, Waterbury
Paul Seigel, New Haven
Chad Sinanian, Danbury
Jimmy Smith, Bridgeport

PARENTS

Jousette Caro, Hartford
Sheila Crocker, Bloomfield
Eve Kessler, Wilton
Barry Nova, Greenwich
(Resigned August 10, 2004)

STATE AGENCIES

Art Carey, Department of Education
Mary Beth Bruder, University Center for Excellence, UCHC
Pamela Giannini, Department of Social Services
Gretchen Knauff, Office of Protection and Advocacy
Richard Melchreit, Department of Public Health
(Resigned May 29, 2003)
Patti Clay, Bureau of Rehabilitation Services

PRIVATE AGENCIES

Carolyn Newcombe, Disabilities Network of Eastern Connecticut

STAFF TO THE COUNCIL

Edward T. Preneta, Director
Yvette Johnson, Disability Policy Specialist
Mary-Ann Langton, Disability Policy Specialist

WEBMASTER

Paul Hartleb

Message From the Chair

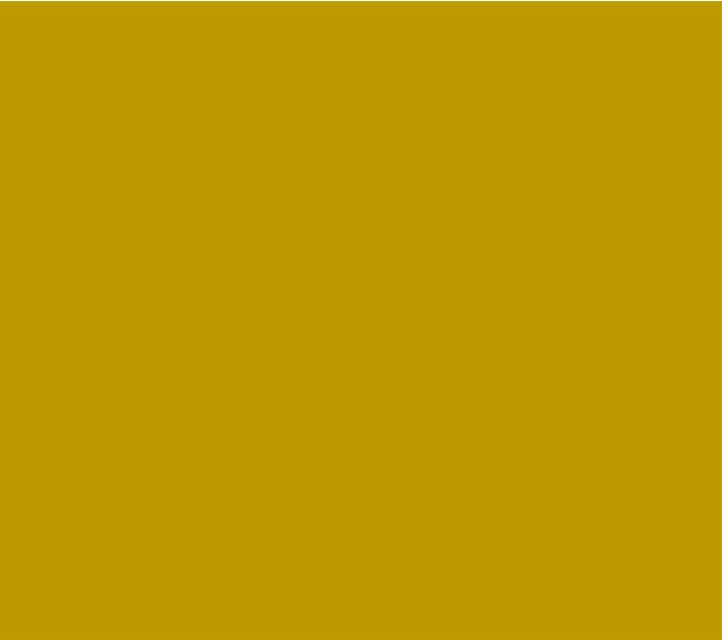
On behalf of the CT Council on Developmental Disabilities, I am pleased to present our 2004 Annual Report.

In many ways, 2004 was a year of transition to systems change. Some of the CT Council's initiatives started in 2001 will be sustained in the system in some other form and with some other support in 2005. One initiative started by the CT Council in 2002 will continue through 2005 and it is expected it will continue to be part of the system with other support in 2006 and beyond. Another initiative started by the Council in 2002, transitioned into the Council, attracted other support, and the CT Council is working to assist its transition to becoming an independent, free-standing entity within the system perhaps by 2006. Some new 2004 initiatives demonstrated that more systems change is needed. And some initiatives will simply require on-going CT Council support in order for the system to change.

Transition will continue in 2005. In the Summer of 2004, the CT Council published a request for proposal (RFP) for 2005 Grants and Mini-Grants and received a record response. The CT Council received seventy-two (72) full Grant applications and forty-nine (49) Mini-Grant applications totaling over \$4.2 million, which was nearly ten (10) times the amount of money the CT Council had for all grants and initiatives. The CT Council was pro-active about making decisions about systems change. You will see 2005 CT Council initiatives that (1) address all people with developmental disabilities not just a single disability, (2) demonstrate advocacy, capacity building and systems change rather than programs and services, (3) promote inclusion in the community rather than segregated activities and (4) are new and innovative approaches rather than existing and on-going activities.

We have new administrations and budget deficits at both the federal and state level. More sweeping changes are expected. We are prepared to respond.

Jousette Caro
Chair



Introduction

The Council on Developmental Disabilities

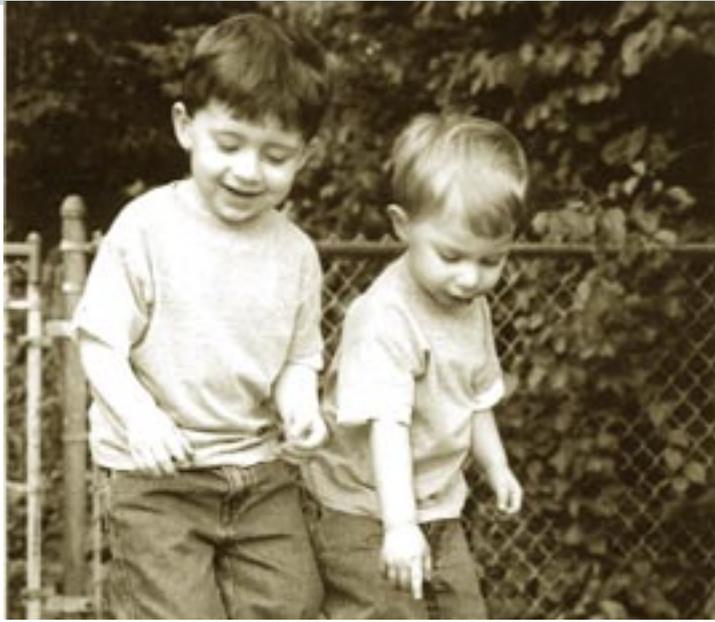
The Council on Developmental Disabilities is a Governor-appointed body of people with disabilities, family members and professionals who work together to promote the full inclusion of people with disabilities in community life. First established by Governor Thomas Meskill in 1971, the CT Council is currently authorized and funded by the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000. The CT Council receives a fixed amount of federal funds each year and maintains an office with 3 staff members. The CT Council engages in advocacy, capacity building and systems change activities on behalf of people with developmental disabilities, their families and their communities. The Council speaks out on issues; educates communities, policymakers and service providers; and funds initiatives designed to create opportunities for inclusion in community life, reduce dependence on government services and restore citizen control over programs.



People With Developmental Disabilities

Developmental disabilities are very severe disabilities that typically are lifelong in duration. The federal Developmental Disabilities Act defines a developmental disability as a severe, chronic disability that -

- is attributable to a mental or physical impairment or a combination of mental or physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language;
 - learning;
 - mobility;
 - self-direction;
 - capacity for independent living; and
 - economic self-sufficiency; and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that are of lifelong or extended duration and are individually planned and coordinated
- except that such term, when applied to infants and young children, means individuals from birth to age 9, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.



2004

Highlights

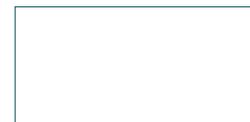
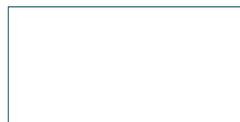
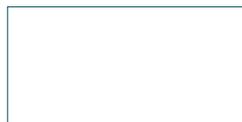
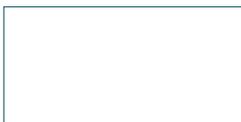
INCLUSIVE EDUCATION

In January 2002, the CT Council began supporting the University Center for Excellence (UCE) at the UCONN Health Center to provide training to parents in all of CT's school districts on how to use special education to improve its effectiveness for students

with disabilities, with a particular emphasis on inclusive philosophy, policies and practices. Over a 3 year period, the UCE, in partnership with 10 parent agencies, delivered a 10 hour course to 916 parents and educational professionals in 93 school districts. Parents reported feeling better equipped to advocate for their children and to actively participate in planning their children's education program. Educators reported having increased knowledge of special education laws and an improved ability to work collaboratively with families. Also, the Council's Chair, a parent and attorney, was trained by the Council of Parent Attorneys and Advocates (COPAA) in the Individuals with Disabilities Education Act (IDEA) and used that training to volunteer as a USE trainer and adviser to parents.

SELF-ADVOCACY

In 2002, the CT Council funded CT Family Voices to start-up the first state chapter of Kids As Self-Advocates (KASA). KASA is a national, grassroots network of youth with disabilities. The CT Council started KASA to address the need for new and young leaders. In 2003, the CT Council brought KASA in-house as a Council funded and staff supported initiative and the State Department of Education transferred \$10,000 for KASA to the CT Council. In 2004, KASA became a project of the CT Youth Leadership Project (CYLP). The CYLP awarded \$18,410 to the CT Council to support KASA. The CT Council provided additional funds and technical assistance. Two (2) KASA members were paid stipends to serve as organizers of KASA events and meetings. KASA grew to 36 members with 25 of these members participating regularly at monthly meetings. KASA made many presentations to school personnel on transition from public school and presented on self-advocacy at the national convention of the Arc United States in Boston, Massachusetts.



OLMSTEAD AND THE AMERICANS WITH DISABILITIES ACT

In response to the U.S. Supreme Court's Olmstead decision, in January 2000 the CT Council called and organized the CT Olmstead Coalition to influence CT's Olmstead Plan. The CT Council ran the CT Olmstead Coalition until the Fall of 2000. From 2001 through 2004, the Council funded the CT Association of Centers for Independent (CACIL) to support the activities of the CT Olmstead Coalition. Governor John Rowland asked the Department of Social Services to develop an Olmstead Plan and instructed the General Assembly's Long-Term Care Planning Committee to provide oversight and leadership. A Community Options Task Force was created to take the lead in the development of the Plan. Members of the CT Olmstead Coalition participated on the Task Force. After 2 years, the Task Force created a CT Olmstead Plan, also known as Connecticut's Community Options Plan, entitled "Choices Are For Everyone."

SOCIAL ROLE VALORIZATION

Action steps in CT's Olmstead Plan included acknowledgment that people with disabilities relying on paid support staff for 100% of their support will still leave them vulnerable and that it was crucial to develop strong new relationships with neighbors and members of the community. Steps also included developing and making available training programs for people who want to support people with disabilities. Training topics were to include values associated with independent living. In response, the Council made available Social Role Valorization (SRV) training. SRV trained people to enable, establish, enhance, maintain and defend valued social roles in society for people with disabilities.

CHILD CARE

Klingberg Family Centers explored integrating children with developmental disabilities with children who do not have disabilities into generic childcare services. The initiative revealed that a great deal more work needs to be done to increase the pool of available, qualified and experienced childcare providers capable of including and integrating children with developmental disabilities with children who do not have disabilities.



PERSONAL ASSISTANTS

The CT Association of Personal Assistants (CTAPA) was founded in 2001 by personal assistants for personal assistants with support from the CT Council. The Association's main focus has been to establish personal assistance as a viable career and to grow the number of people who become personal assistants. The ranks of personal assistants participating in the Association has grown to 84. The movement has become incorporated in Connecticut's Real Choice grant known as the Community Integrated Personal Assistance Supports and Services (C-PASS) grant. Through leadership by the University Center for Excellence, the C-PASS grant will continue the efforts begun by the Council.



CT LIFESPAN RESPITE COALITION

Following a small feasibility study grant in 2001, the CT Council supported the start-up and continuation of the CT Lifespan Respite Coalition (CLRC) through 2004. The Coalition's main focus has been to achieve passage of a respite bill through the CT General Assembly. Passage of legislation has failed in the last 2 sessions of the CT General Assembly but impetus for the legislation grows as Coalition membership grows. The Coalition has also put itself in position to capture federal funds under the proposed federal Lifespan Respite Care Act.



EMPLOYMENT

Easter Seal Rehabilitation Center of Greater Waterbury enabled non-disabled employers to mentor employees with developmental disabilities by paying stipends to employees to mentor co-workers with developmental disabilities and provide orientation, job training and on-going support. The initiative demonstrated that employers are willing and able to hire people with developmental disabilities but that our field still needs to develop and implement a commitment to meaningful work, in integrated settings, for equitable pay, in an atmosphere of job and support security, with the opportunity for relationships for all adults, regardless of type or severity of disability.



DD NETWORK

The Connecticut Developmental Disabilities Network (DD Network) was established to provide leadership for implementation of the federal Developmental Disabilities Assistance and Bill of Rights Act. The DD Network included the CT Council on Developmental Disabilities, the Office of Protection and Advocacy and the University of Connecticut's A.J. Pappanikou Center for Excellence in Developmental Disabilities. These three organizations have a common goal and purpose: the protection and full integration of individuals with developmental and other disabilities into society in a manner that is consistent with the unique strengths, resources, abilities and capabilities of each individual and his or her family.

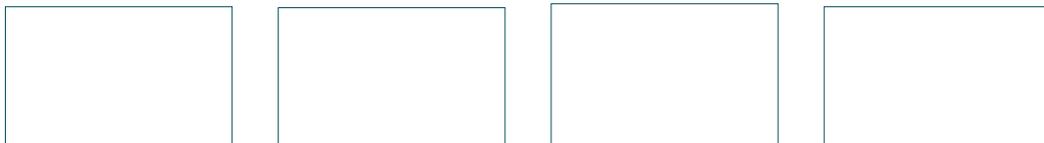


The DD Network held a conference on the 14th anniversary of the ADA in the Legislative Office Building of the State Capitol on accessible voting. The conference included discussion by both legislators and people with developmental disabilities on the barriers to voting. In the concourse between the Legislative Office Building and the State Capitol, ten (10) vendors demonstrated new voting technologies designed to remove barriers to voting for persons with disabilities.

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 2004, the CT Council received an allotment of \$690,715. The CT Council also carried over \$60,849 of 2002 and 2003 funds for use during 2004. The Council's total 2004 budget was \$751,564. In addition, in July 2004 the Council accepted a grant of \$18,410 from the Connecticut Youth Leadership Project (CYLP) for Kids As Self-Advocates (KASA). Including funds from CYLP, the Council leveraged \$112,723 in matching funds.

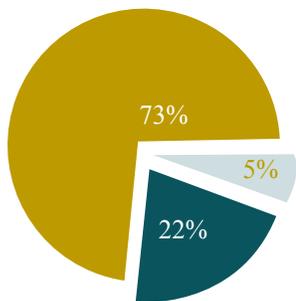
Grantees

Klingberg Family Centers	\$5,337
CT Kids As Self-Advocates (KASA)	\$7,782
Social Role Valorization/Implementation Project (SRV)	\$15,000
Communitas, Inc. for the CT Association of Personal Assistants (CTAPA)	\$25,000
Easter Seal Rehabilitation Center of Greater Waterbury	\$35,624
CT Association of Centers for Independent Living (CACIL) for the CT Olmstead Coalition	\$36,979
CT Lifespan Respite Coalition (CLRC)	\$42,977
University of CT Health Center, University Center for Excellence (UCE)	
Understanding Special Education (USE)	\$80,000
DD Network, Annual Report, Publications	<u>\$7,925</u>
Subtotal	\$256,624



Council and Staff

Publications	\$63
Ad hoc Council Member Support Committee	\$585
Social Role Valorization Training	\$1,080
Council of Parent Advocates and Attorneys	\$1,729
Staff Activities:	
CT Chapter of Kids As Self-Advocates	
DD Network	
Department of Education's Continuous Improvement Partnership Team	
CT's Multicultural Early Childhood Team	
Long Term Care Advisory Commission	
Real Choice Model Communities and Nursing Facility Transition Grants	
Department of Social Services' Council for Persons with Disabilities	
Testified on bills before the CT General Assembly and served as Project Officers to Council grantees	<u>\$111,504</u>
Subtotal	\$114,961
Administration - 5% of the federal formula grant goes directly to the CT General Fund	\$34,536
Council Office and staff	<u>\$168,756</u>
Subtotal	\$203,292
Carried over for use in 2005	<u>\$176,687</u>
Total	\$751,564



■ Systems Change, Advocacy and Capacity Building	\$548,272
■ Council Administration	\$168,756
■ CT General Fund	<u>\$34,536</u>
	\$751,564