# Connecticut Council On Developmental Disabilities

# 2012 ANNUAL REPORT



# **Connecticut Council on Developmental Disabilities**

**Our Mission:** 

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

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## Letter from the Chair, Bill Knight

As the Chair of the Council on Developmental Disabilities, and a person with a disability, I am pleased to write this welcome letter for our 2012 Annual Report.

This has been a year of growth for our Council. I want to personally thank Council members for their leadership and commitment. Members participated at Council meetings, committees and/or task forces where they contributed their knowledge and personal experiences about disability issues. This is an active and very talented Council who will make a lasting, positive impact on the lives of people with disabilities in our state.

In July 2012 Governor Dannel Malloy signed Executive Order Nineteen, officially creating the Council on Developmental Disabilities, and establishing the roles and responsibilities of the Council, as outlined in the Federal DD Act. In September, twenty-four members of the newly constituted council were appointed.

In 2012 the Council, in partnership with the University of CT Center on Disabilities and the CT Office of Protection and Advocacy for Persons with Disabilities, began teaching leadership and advocacy through a seven month course, Partners in Policymaking. This initiative will develop new leaders in the disability field who can carry the disability movement forward.

We look forward to making continued strides in improving the lives of people with disabilities in our state in the coming year.

Sincerely,

Bill Knight, Chair

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## **COUNCIL MEMBERS**

The Connecticut Council on Developmental Disabilities is a governorappointed 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 24 members. Sixty percent are either people with disabilities or parents of children with disabilities.

Emily Bickhardt, Self-Advocate Colchester

Chris Blake, representing SARAH-Tuxis East Haven

Thomas Boudreau, State Department of Education Hartford

John Curtin, Self-Advocate Bolton

Michelle Duprey, Self-Advocate New Haven

**Roslynn Hooks, representing Unified Theater** West Hartford

Jacqueline Jamison, Parent Hartford

Michelle Johnson, Self-Advocate Manchester

Mark Keenan, Department of Public Health, Title V Hartford

William Knight, Self-Advocate Torrington

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Alicia Kucharczyk, Bureau of Rehabilitation Services Hartford

Raymond Lasky, Parent Derby

Zuleika Martinez, Self-Advocate Bridgeport

Sabra Mayo, Parent Hartford

Shelagh McClure, Parent West Hartford

Meg McDermott, Self-Advocate Unionville

Sarah Rafala, Self-Advocate Windsor

Rabbi James Rosen, Parent West Hartford

**Bobby Shea, Parent** West Hartford

Brenda Stenglein, Parent Ashford

Christine Sullivan, UConn Center on Disabilities Farmington

Ada Suarez, Office of Protection and Advocacy Hartford

Jennifer Throwe, Department of Social Services, Aging Unit Hartford

Kathy Wolkner, Parent Farmington

### Members Whose Terms Ended During 2012

Fred Frank, Center for Disability Rights Stratford

Gabriela Freyre-Calish, UCONN Center on Disabilities Farmington

David King, Self-Advocate Bridgeport

Mary Ann Lombardi, Parent Wilton

Jennifer Lortie, Self-Advocate Lisbon

Laura Marcinauskis, Parent Shelton

Peter Morrissette, Self-Advocate East Hartford

Dwayne Paul, Parent Milford

Frank Reed, Self-Advocate Danbury

Monica Smyth, Abilis Stamford

Guy Sullivan, Parent Fairfield

## **Council Funded Initiatives**

Connecticut Legal Services, Medical Safeguards Project: The Council funded a third year of the Connecticut Legal Services Medical Safeguards Training Project. While continuing to implement some training with hospital staff, this year the project also focused on reaching people with developmental disabilities, family members and staff who care for them, in an effort to improve access to quality medical services for people with developmental disabilities. Between October 2011 and September 2012 CLS coordinated and conducted 20 presentations in 20 different forums. The project is staffed by two highly trained and knowledgeable attorneys, who are also a resource on other issues affecting people with developmental disabilities. In addition to the medical safeguards training, they executed two advanced directives on behalf of clients, with six more in process for the next reporting cycle. They have also served as consultants on placement and on other diverse matters such as immigration and probate matters. They represent approximately 35 individuals at Southbury Training School and 21 C.A.R.C. vs. Thorne class members, as well as other individuals regarding an array of issues. Thus, their ability to attract large numbers of individuals to their training is substantial, and they are well known and respected throughout the community. Modules developed include: Advanced Health Directives; Defining Capacity and Competency: Ensuring Informed Consents; Do Not Resuscitate Orders; Guardianship of an Adult with an Intellectual Disability in Connecticut; Overview of CT Legal Service, Inc.; Self Determination; The Self-Advocate's Guide to Guardianship in Connecticut; The Medical Safeguarding Project; and Your Choices-Your Life—You've Got the Power!

Western CT Association for Human Rights (WeCAHR), Aging In Place Demonstration Project : The goal of this initiative is to demonstrate the organization and delivery of services and supports to people with developmental disabilities who are aging and already living independently, or with individuals they have chosen, in their homes and communities. This project is modeled after the Beacon Hill Village aging in place model that includes people with developmental disabilities. The project has piloted the Discovery Survey Tool with individuals in the Danbury community and developed an advisory council to create Naturally Occurring Living Communities for individuals with developmental disabilities who wish to age in place in Danbury.

**State Education Resource Center, Parents With Cognitive Limitations:** The CT Council on Developmental Disabilities funded the State Board of Education, in partnership with the Department of Children and Families and the Parents with Cognitive Limitations Work Group. This multi-agency work group has been meeting for over ten years. This project is funded to train service providers to better support and meet the needs of parents with cognitive limitations.



**Partners in Policymaking 2012.** The Council, in partnership with the UCEDD and the Office of Protection and Advocacy, implemented Partners in Policymaking leadership training in 2012. This partnership venture utilized staff and resources from the Council and leveraged funds and support from our DD Network partners. Twenty-seven participants were selected for this program, including twelve self-advocates and fifteen parents. This intense leadership training program consisted of seven overnight sessions at a hotel. The content is based on a nationally recognized curriculum and included legislative advocacy, effective advocacy strategies, communication, disability policy, history, IDEA, assistive technology and strategies to run a meeting. All participants completed an advocacy project during the training.



**Candidates Forum, October 2012.** The Council, in Partnership with the University of CT UCEDD and the Office of Protection and Advocacy hosted a bi-partisan candidate's forum at Manchester Community College. The list of other co-sponsors included an array of disability and self-advocacy organizations: Advocacy Unlimited, African Caribbean American Parents of Children with Disabilities, American School for the Deaf, Americans with Disabilities Act Coalition of CT, Autism Spectrum Resource Center, Brain Injury Alliance of CT, Center for Disability Rights, Citizen's Coalition for Equal Access, Communitas, CT Association of the Deaf, CT Business Leadership Network, CT Legal Rights Project, Disabilities Network of Eastern CT, Disability Resource Center of Fairfield County, Hear Here Hartford, Independence Unlimited, Independence Northwest, Institute on Disability and Community Inclusion at Manchester Community College, National Federation of the Blind of CT, People First of CT, State Independent Living Council, The Arc CT, The CT Association of Personal Assistance, Inc., Western CT Association For Human Rights, Inc. The Keynote speaker for this event was John Kemp of New York, who spoke about employment and people with disabilities. Twelve of the fourteen candidates or their surrogates, including surrogates for both presidential candidates participated in this event. Over 140 people were in attendance.



## **Perspective from a Member of the CT Council on Developmental Disabilities**



## **Ray Lasky**

My name is Raymond Lasky. I live in Derby, Connecticut with my wife, Trudy and our son Nick. Nick has Cerebral Palsy, and Nick is the reason I am passionate about my advocacy work. Nick needs our voices, love and understanding.

My wife and I do our best to offer Nicholas the opportunities to learn and grow, so that he may succeed in life. I had no idea that our lives would include the many challenges we face each day. We are incredibly proud of Nick and work hard to make sure he will have a meaningful life in our community with friends and a job.

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In 2012 I enrolled in the Partners in Policymaking class. It was life changing! I graduated from the program in September, and that same month I was appointed by Governor Malloy to be a member of the CT Council on Developmental Disabilities

Since joining the Council I have become a member of the Advocacy, Public Information and Education Committee, and I have been busy setting up focus groups across the state to hear from others about issues affecting people with disabilities.

I am proud of my work on the Council, and feel that my leadership opportunities both on the Council and in my community are growing. I look forward to working with others to improve the lives of people with disabilities in our state.

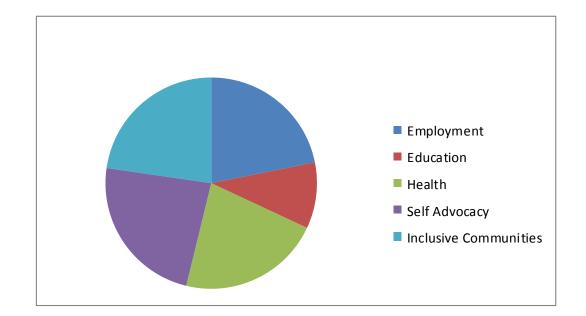


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The CT Council on Developmental Disabilities receives federal funds through the Administration on Intellectual and Developmental Disabilities. Each Council received funds, which are distributed among the states under a formula based on population, per capita income, unemployment rate, and Social Security disability statistics. Here is how the CT Council used their funds to support projects that will improve the lives of people with disabilities in our state.

### **2012 EXPENDITURES BY AREAS OF EMPHASIS**

Employment	\$ 60,000
Education	\$ 27,780
Health	\$ 60,000
Self Advocacy	\$ 64,492
Inclusive Communities	\$ 62,380





This report is dedicated to our dear friend and colleague, Peter Morrissette, who passed away in 2013. Peter was a Council member from 2006 to 2012 and served on several committees during his tenure. Friends will always remember Peter for his courage and determination as he advocated to change state and federal policy, and develop appropriate supports so that people with severe disabilities could live in the community. In addition, Peter was an avid Red Sox and Patriot fan. We will miss his witty sense of humor!!!