

Annual Report 2013

Connecticut Council on Developmental Disabilities



The Connecticut Council on
Developmental Disabilities

Council Mission

The Council Mission is to Promote the Full Inclusion of All People with Disabilities in Community Life.



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A Letter From Council 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 2013 Annual Report.

This has been a busy year for the Council. Once again, the Council supported Partners in Policymaking leadership and advocacy training, in partnership with the Office of Protection and Advocacy for Persons with Disabilities and the University of Connecticut Center for Excellence in Developmental Disabilities. Two Council members, including myself, were among the twenty-six graduates of the program in 2013.

The Council has worked hard to build collaborative partnerships to implement new initiatives. These include the formation of the CT Cross Disability Lifespan Alliance and Co-Sponsorship of the Women and Disabilities Conference, and Second Thoughts Connecticut, a group opposing physician assisted suicide proposals in the state.

Finally, the Council, in partnership with the CT Department of Developmental Services was awarded a Supporting Families Community of Practice grant through the Administration on Intellectual and Developmental Disabilities (AIDD) and The National Association of State Directors of Developmental Disabilities Services (NASDDDS). We are one of five states to receive this award.

The Council continues to build partnerships to promote the full inclusion of people with disabilities in communities across our state.

Sincerely,

Bill Knight, Chair





Perspective from a Council Member

Michelle Johnson

CT Council on Developmental Disabilities

My name is Michelle Johnson. I have Cerebral Palsy from birth which left me with the inability to walk, talk and use my left hand. I was born and raised in New Haven and attended ACES Village School in North Haven. In school, I enjoyed art and reading books about Martin Luther King, Jr. and the 1960's Civil Rights Movement. Whenever I read a book, I always wrote a book report about what I read. I thought I wanted to be a writer, but like all young people, I later changed my plans.

When I was 14 years old, I discovered that upon graduation I would be receiving a certificate of completion and not a high school diploma. This was when I began to advocate for myself. I wrote letters to the New Haven Superintendent of Schools and the director of my program at ACES asking that my work, that was the same as any other public school student, be recognized and I be given credits for the grades I earned. In 1992, I was the first student from my school to graduate and receive a high school diploma.

Upon graduation, I volunteered for three years in the office for the Special Olympics World Games held in 1995. That same year I moved to Virginia, and while there, I pursued a childhood passion and joined an art studio for artists with disabilities called the "Da Vinci Project." While I was developing my artistic abilities in drawing, painting and photography, I worked for an employment agency for people with disabilities as the writer and editor of their quarterly newsletter. In 2002, I relocated to Maryland where I continued to grow artistically. I became a part of "Art Enables-Art Work Outside the Beltway," another studio for artists with disabilities based in Washington, D.C. I also began a business plan to start my own business, Right On Art, producing and selling my artwork on note cards.

In 2008, I moved back home to Connecticut, settling in the town of Manchester, where I have had the opportunity to make many new friends who led me to the Connecticut Council on Developmental Disabilities. I am now serving my second term on the Council, and I am the Vice-Chair of the Membership Committee. This January, I was accepted into the Partners in Policymaking Program 2014. I am learning a lot from the program and having fun at the same time.



Council Funded Initiatives

Connecticut Legal Services Medical Safeguards Project

The Council funded a third and final year of the Connecticut Legal Services (CLS) 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 and 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.

State Education Resource Center Parents with Cognitive Limitations

The CT Council on Developmental Disabilities funded the State Department of Education, in partnership with the Department of Children and Families and the Parents with Cognitive Limitations Work Group to implement training that better identifies and supports parents who have intellectual disabilities. This multi-agency work group has been meeting for over ten years. In 2013 the Council funds supported the annual conference of the Association for Successful Parenting in Mystic, CT. This two-day event focused on the successes and challenges facing parents who have intellectual disabilities and featured national and regional speakers. It was attended by over 150 people from across the country.



A Place to Live that I Can Call H.O.M.E.

The Council funded the University of Connecticut Center for Excellence in Developmental Disabilities to develop a manual and training on accessing housing options for people with disabilities in Connecticut. The manual and training focus on all aspects of finding and accessing housing. This manual was developed in both hard and electronic versions, and was disseminated through an array of trainings across the state. http://www.uconnucedd.org/projects/finding_housing_in_CT/

Emergency Medical Services

The Council funded New Britain Emergency Medical Services to improve the readiness of municipalities and people with disabilities to respond in emergency situations, to develop community planning councils that effectively engage consumers in planning emergency response, and to implement training in an array of organizations and communities across the state.

Emergency Preparedness Training

The Council funded the University of Connecticut Center for Excellence in Developmental Disabilities to develop and implement an emergency preparedness training curriculum for municipalities, first responders, community emergency response teams and people with disabilities. The theme of this project is that 'fair is what every person needs' and that there is great value to being creative and thinking outside of the box.



Partners in Policymaking 2013

The Council, in partnership with the University of CT Center for Excellence in Developmental Disabilities (UCEDD) and the Office of Protection and Advocacy, implemented Partners in Policymaking leadership training in 2013. This program provides intense leadership training to parents of children with disabilities and self-advocates, and is based on a national curriculum. 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.

The Council published a booklet featuring the graduates and their projects. The booklets were disseminated to providers, policymakers and agencies so that others in the state could easily identify and connect with the graduates to offer them access to leadership opportunities.



Partners Participants at the Legislative Office Building

Building a Strong Disability Alliance

The Council has supported a coalition of disability groups, providers, parents and self-advocates developing the Connecticut Cross Disability Lifespan Alliance. The mission of the Alliance is to sustain a cross disability coalition that collaborates and communicates with one voice for the inclusion and participation of all people with disabilities in their communities. Their vision is that Connecticut will be a state in which all people with disabilities can look at their lives and say, "Life is good" because their communities respect, engage and value all of their members. The Alliance meets every other month at Manchester Community College.



Supporting Families Community of Practice

The Connecticut Council on Developmental Disabilities, in partnership with the Connecticut Department of Developmental Services (DDS), is one of five state teams to receive a national grant to participate in a five-year *Community of Practice* study. This project focuses on creating a learning environment for intense exploration into policy, practices, trends and barriers for individuals with intellectual disability. The *Community of Practice* process will help ensure that Connecticut resources are used efficiently and effectively to meet the needs of all families who have children with a disability across the lifespan. The Administration on Intellectual and Developmental Disabilities (AIDD) has funded the grant through the National Association of State Directors of Developmental Disabilities Services (NASDDDS). The purpose of the grant is to identify and implement policies and practices that will serve as a national framework for states to use to support individuals and their families across the lifespan. The *Community of Practice* is designed to include ideas, innovations and recommendations not only from the states identified but from the broader community. There are ten active committees in Connecticut that are meeting to address various aspects of supporting families.



Council Members

Chair

William Knight, Torrington
Self-Advocate

Vice-chair

Kathy Wolkner, Farmington
Family Member

Self-Advocates

John Curtin
Bolton

Michelle Duprey
New Haven

Michelle Johnson
Manchester

Zuleika Martinez
Bridgeport

Meg McDermott
Unionville

Antonio Orriola,
New Britain

Sarah Rafala,
Windsor

Family Members

Jacqueline Jamison
Hartford

Sabra Mayo
Hartford

Shelagh McClure
West Hartford

Rabbi James Rosen
West Hartford

Bob Shea
West Hartford

Brenda Stenglein
Ashford

Non-Profit Agencies Serving People with Developmental Disabilities

Chris Blake
SARAH-Tuxis
East Haven

Joyce Lewis
Key Human Services
Wethersfield

Federally Mandated Representatives of State Agencies

Thomas Boudreau, State
Department of Education,
Hartford

Mark Keenan,
Department of Public
Health, Title V
Hartford

Alicia Kucharczyk,
Bureau of Rehabilitation
Services, Hartford

Melissa Morton,
Department on Aging,
Hartford

Ada Suarez
Office of Protection and
Advocacy, Hartford

Christine Sullivan
UConn Center for
Excellence in
Developmental
Disabilities, Farmington

Robin Wood
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