

Commonwealth Council on Developmental Disabilities CCDD



The Commonwealth Council's mission is to "Create systematic change in Kentucky that empowers individuals to achieve full citizenship and inclusion through education, capacity building and advocacy". The Council identifies and addresses pressing needs, including inequities in employment, education, transportation, health care and advocacy. In 2011, the Kentucky Council received \$1,273,000 in federal funding authorized under the Developmental Disabilities Act to support its work. More than 60% of Council members are people with developmental disabilities or family members.

Key facts

- Over 874K Kentuckians have an identified disability and it is estimated that over 200,000 people in Kentucky have a developmental disability (severe, lifelong disabilities such as cerebral palsy, autism, epilepsy, intellectual disabilities that manifest at birth or before age 22)
- The number of people with developmental disabilities living in state institutions in the U.S. has declined by 70% over the past three decades as Kentucky continued efforts to support individuals to live work and play in their own communities. However, many people with developmental disabilities remain on long waiting lists for services and benefits (2,189 in Kentucky)
- Access to integrated education continues to increase but there continues to be a need to support educators in this endeavor. Seclusion and restraint have also become an issue as students with more challenging personalities participate in 'typical' school settings.
- Kentuckian's health and well being ranks below the national average, this is also true for individuals with developmental disabilities. A statewide effort is ongoing to promote health and well-being, including access to health care and recreational opportunities.
- People with developmental disabilities have the highest unemployment rate of any group of Americans: up to 80% of people with developmental disabilities are not employed
- Many people with developmental disabilities remain on long waiting lists for services and benefits (2,189 in Kentucky)

The Council has worked diligently to ensure that any grant project utilizes existing community resources. Their belief that it is not necessary to create segregated programs has offered opportunities for collaboration with non-traditional partners and thus expanded the Council's network of associates.

Some Commonwealth Council accomplishments

1. As part of its post-secondary education goal, the KCDD created and supports the Post Secondary Inclusionary Partnership (PIP) contracted through the University Center for Excellence in Developmental Disabilities (UCEDD) at the University of Kentucky. This statewide program provided support to individuals with Developmental Disabilities who wished to pursue continued education after high school at

various universities across the state. PIP has been recognized nationally as a model program for its highly individualized and pragmatic approach to continuing INCLUSIVE education for students with disabilities. **As a result of this grant the University of Kentucky has been awarded a \$2.2 million grant from the US Department of Education Office of Postsecondary Education.** The Supported Higher Education Project (SHEP) will develop a comprehensive system of support for students with intellectual disabilities across the state, further enhancing and expanding the work of PIP for years to come. It is the mission of the KCDD to create change through visionary leadership. This project showcases the unique role the KCDD can have in creating incredible opportunities for people with disabilities even beyond our ability to fund.

2. In an effort to support aging care givers and the need to plan for the future of their children with developmental disabilities, the Council funded the ARC of Kentucky a grant called “The Future is Now”. This grant provides highly individualized support to families seeking to create plans to care for their loved

ones. Participants receive one-on-one assistance in creating wills, trusts, and/or plans based upon individual resources. This is often a difficult aspect of life for families to address but because the grantee has designed the program to be affirming and reassuring it has exceeded the targeted numbers to families to be served. The process involves all family members, including the individual with developmental disabilities. This is done to ensure that everyone is aware of choices and preferences for the future of all family members.

The success of this program is evidenced by the number of families that have participated, exceeding our targeted amount of 30 per year

but also by the fact that the program has brought together families of all ages and can be replicated throughout the state.



A family that participated the “Future is Now” project, discussing their plans for their daughter with an attorney.

3. The Commonwealth Council on DD contracted with Seven Counties Services, Inc., for The “Support Providing Employees Association of Kentuckiana” (SPEAK) project to provide encouragement to those who provide direct support to individuals with developmental disabilities in the community. These individuals often receive little acknowledgement and poor wages while performing vital service. In Kentucky, as in many places throughout the United States, high turnover and burnout of Direct Support Professional’s (DSP’s) is prevalent. It is obviously vitally important to the well being of our persons with developmental disabilities to have dedicated, professional and trained DSP’s. To accomplish this, SPEAK was created as an organization for DSP’s in which providers pay membership dues to participate. SPEAK in turn provides pre screening to applicants by offering an overview of the work the individuals will be doing, provides workshops, newsletters and other mechanism as a way to provide DSP’s an inclusive environment to come together and discuss issues pertaining to their profession.

The participating providers host an annual DSP banquet to celebrate and acknowledge the successes of DSP’s in Kentucky. **SPEAK activities have reduced turnover rates, improved**



DSP’s accepting awards at the annual SPEAK banquet for outstanding work in their field.



moral and enhanced the quality of care for the individuals they serve as referenced in an independent report from the Martin School of Public Policy at the University of Kentucky.

More who have benefited from the work of the Kentucky Council

The Commonwealth Council on DD has had many projects over the years that have impacted people throughout the state. The CCDD completed a 'Look Behind' study to measure sustainability of the Council's activities over the past 30 years. Several Council funded activities have become an integral part of organization's service offerings. Because the Council is in the unique position of taking a conceptual idea and making it a reality, the Council can offer support to creating systemic change through our efforts. Some examples of projects from the past and present include:

Health Modules Training (Physicians, medical students, nursing students, allied health students, dentists, dental students), **(modules being utilized internationally at medical schools)**

Project ASSET (Self run business opportunities) (Incorporated within OVR services)

Supported Living Investment (lead to the utilization of general fund dollars for self-directed funding opportunities)

Accessible parking (increased the fine for illegal parking and provided an awareness campaign)

Emergency management (supporting and educating first responders, individuals with developmental disabilities and their support network on emergency response and preparedness)

Best Buddies (an international outreach to teenagers and college students)

Kentucky Self Advocates for Freedom (An organization run by people with developmental disabilities active in advocacy, policy and systems change)

KYSAFF advocates attending meetings and trainings



Project Dream Big Brothers Big Sisters (Kids with disabilities)

Youth Advocacy Initiative (Kids with disabilities mainly with communicative disorders)

Recreational Involvement Fund (Encouraging persons with developmental disabilities and their families to utilize community recreational opportunities)

Project SAFE (Educating providers on support for individuals with developmental disabilities who are victims of abuse)

ROLES (employment and Community involvement for all people with disabilities)

Exceptional Family Magazine (provides informative articles and resources to individuals with developmental disabilities and their families as well as the community at large) (over 3000 copies distributed annually)

This publication picks up popularity with each passing year and with each new issue. To check out Exceptional Family online go to:

<http://www.lexingtonfamily.com/resources/exceptional-family>

or you may request copies through our office or by ordering on-line.



CCDD members are very involved with Public Policy within our state. Our Council believes that advocacy is an important part of true systems change. Here are a few things they worked on last year:

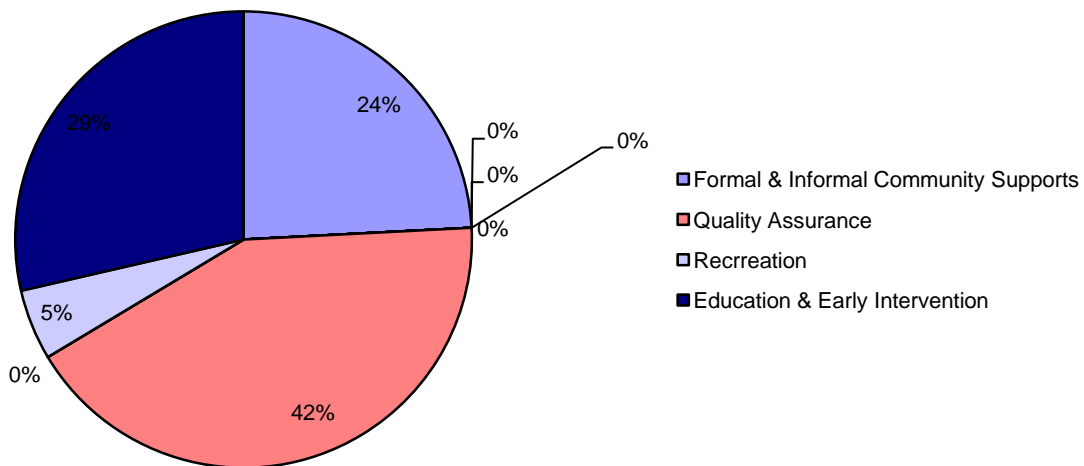
Legislative – followed 52 state bills, 11 of which were signed into law; advocated against Medicaid cuts; offered to assist Department of Insurance in drafting regulations following the passage of autism & insurance bill

Events & Awareness – hosted state legislative breakfast with 19 legislators in attendance; sponsored three 874 K disability days at state capitol; sponsored booth at National Legislative Conference; sent three people to National Summit on Disability Policy

Research & Planning – updated & finalized Public Policy Committee Work Plan; authorized Martin School of Public Policy to begin research on adult abuse registries (*as of this printing, that research is currently being used to educate state legislators on the need for an adult abuse registry bill*)

These are just a few of the KCDD's current projects. Other projects and reports can be found at www.ccdd.gov. Additionally, the Council participates in over 20 other committees, boards, activities that impact people with disabilities in a variety of venues.

Grant Expenditures for FFY 2011



Alternative copies of this report are made available by contacting our office at 877/ 367-5332 or by emailing Shelley.runkle@ky.gov

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For more information about our Council please visit our website

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