

Promoting Independence, Self-Determination, Productivity, Integration, and Inclusion



Louisiana Developmental Disabilities Council



2014

Annual Report

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A Message from the Chairperson and the Executive Director

The Louisiana Developmental Disabilities Council is pleased to provide our Annual Report for Federal Fiscal Year 2014 featuring accomplishments of the Council in benefiting people with developmental disabilities throughout our state. Council advocacy, systems change, and capacity building activities resulted in improvements in the inclusion of individuals with developmental disabilities in Louisiana in all aspects of their lives, where they live, work, play and learn.

The Council and its partners continued to focus attention on protecting and restoring funding for home and community-based services in the state budget. The Council also advocated to enhance outcomes and inclusion of students with disabilities, to promote competitive, integrated employment, and to increase the capacity of early intervention providers and health care providers. As we work to translate values into policy the Council looks forward to continuing working with self-advocates and their families, community providers, and other agencies to improve the quality of life for individuals with developmental disabilities and their families.

Sam Beech
Chairperson

Sandee Winchell
Executive Director



Kay Marcel is a visionary who left her mark on Louisiana. Thanks to Kay's advocacy leadership, tens of thousands of Louisianans with developmental disabilities receive individualized supports that enable them to live and fully participate in inclusive communities. When Kay began her advocacy, individualized community and family supports were virtually non-existent in Louisiana. Through her selfless service Kay led the movement to transform Louisiana's service system, leaving people in control of the supports they need and a sea of advocates in yellow shirts to continue moving Louisiana forward.



Kay Marcel and Council leaders, past and present, at her farewell reception in January.

LOUISIANA BIDS FAREWELL TO KAY MARCEL

What a difference Kay made! A leader with vision of how the world should include people with developmental disabilities and the determination to make that vision a reality. Kay Marcel moved to Iowa leaving her legacy in Louisiana.



Kay embodied the essence of JFK's quote through an incredible thirty years of 'trying' her hand at advocacy. In her five terms as Council Chair Kay led the advocacy efforts resulting in hundreds of millions of dollars to fund supports and services that tens of thousands of people with developmental disabilities need to remain in their own homes and be contributing members of the community. Through grace, knowledge and determination she earned the respect of legislators, state government officials, advocates, and individuals and families.

Kay has been a role model in educating policy makers and mentoring, supporting and empowering parents and self-advocates to bring about change in policy and practice. While Kay created system changes she always found time to help people needing assistance in personal situations. Her legacy will prevail.



Our best wishes and heartfelt gratitude go with Kay as she embarks on this new stage of her life. Louisiana's loss is clearly Iowa's gain.

"One person can make a difference, and everyone should try." - JFK

FFY 2014 IN REVIEW

The Louisiana Developmental Disabilities Council, working with fellow advocates, progressed toward its mandate of advocacy, capacity building and systems change activities that result in self-determination, independence, productivity, integration and inclusion for people with developmental disabilities. In 2014, the Council's activities primarily focused on the areas of home and community-based services, inclusive education, health and competitive employment.

Through Partners in Policymaking, the Council provided advocacy training to individuals with developmental disabilities and parents of young children with developmental disabilities. Information and other support was provided through the Families Helping Families Regional Resource Centers. Through the Council's grassroots advocacy networks, Louisiana Citizens for Action Now (LaCAN) and Louisiana Together Educating All Children (LaTEACH), policy makers were educated and responded with increases to funding for individualized community and family supports and provided an alternative pathway for certain students with disabilities to graduate. In collaboration with the Advocacy Center the Council supported a pilot project to establish effective approaches and the need for an Ombudsman program for people in Supported Independent Living. Two training projects, one on mentoring supported employment providers and another providing Nurse Practitioner and Physician Assistant students and Physicians information on disabilities were developed in coordination with the Louisiana Health Sciences Center—Human Development Center.

LaCAN

Louisiana Citizens for Action Now (LaCAN) is the Council's statewide grassroots network of individuals, families and advocates who have worked together since 1988 advocating for a service system that supports individuals with disabilities to live in their own homes. LaCAN provides information and support to individuals wishing to effectively advocate for the expansion and improvement of individualized community and family support services for people with developmental disabilities and their families.

2,244 LaCAN members

1,431 Confirmed actions to policymakers

326 Participants at Legislative Roundtables



COMMUNITY SUPPORTS

The efforts of the Council and **LaCAN** members reaped significant benefits in 2014 for individuals with disabilities. The budget provided funding for waiver and other services that will assist well over a thousand individuals with developmental disabilities to live productive lives in their own homes and communities.

Grassroots advocacy was conducted through hundreds of advocates participating in **Legislative Roundtables** and the **Disabilities Rights Rally**, conducting personal legislative visits, providing testimony at committee meetings, and sending letters to share personal stories with policy makers.

These advocacy efforts resulted in the legislature and the Governor prioritizing supports and services for people with developmental disabilities. The Governor's Executive Budget initially included funding to fill 1,000 vacant slots in the New Opportunities Waiver (NOW), Children's Choice Waiver, and Supports Waiver, and 200 additional NOW slots; however, it excluded restoration of funding for several state-funded programs that are critical to many of those on the waiver waiting list. The Legislature responded to advocates by restoring to the budget the funds for these important programs. The waiver services will bring much needed relief to 1,200 individuals who have been waiting years for these services and the state-funded programs will provide assistance to those who continue to wait.

The Council helped lead a coalition to educate voters on the negative impact to community-based services if a Constitutional Amendment providing budget protection for nursing homes and ICFs/DD passed. The amendment ultimately passed, putting community-based programs in jeopardy of taking a disproportionate share of future budget cuts.



LaCAN advocates testify in front of members of the Louisiana Senate Finance Committee.

Bailey's Law

Through leadership of a Partners in Policymaking graduate and advocacy from the Council, the medication administration training requirements for direct service workers employed directly by a waiver recipient (in self-direction) were changed through legislation. The law became known as Bailey's Law in honor of Bailey Caroline Durham.

COMMUNITY SUPPORTS (continued)

The Council continues to oversee the funding and performance of various programs included in the Community and Family Support System that are administered by the Department of Health and Hospitals and Local Governing Entities. As a result of Council advocacy, the amount of funds for Individual and Family Support services increased in three regions of the state to help bring equity across regions.

Nine **Families Helping Families (FHF) Regional Resource Centers** were supported by the Council to provide individuals with developmental disabilities and their families information and referral, peer-to-peer support, and education and training to improve their quality of life, enable them to understand their rights and learn how to advocate for themselves. This support from someone “who has been there” has proven invaluable to family members navigating an often complicated service system. As a result of advocacy efforts, FHF Centers received a restoration of funding that had been cut over the past several years. This restoration of funding provided FHF Centers adequate resources to offer much needed support to individuals with disabilities and their families.

24,551 People supported by FHF Centers

QUALITY ASSURANCE

The Council had several activities that prepared self-advocates and family members to advocate for systems change. **People First of Louisiana (PFL)**, the statewide self-advocacy organization, received funding to coordinate statewide advocacy activities. PFL Board members received trainings covering topics such as “How to Advocate With Your Legislator.” PFL provided seven trainings to self-advocates covering a variety of topics. PFL advocated for a several issues, including successful revision of terminology in Louisiana law to reflect people-first language.

The 2014 session of **Partners in Policymaking** provided graduates with the skills to affect systems change. Council-funded **stipends** through Families Helping Families Regional Resource Centers allowed individuals with developmental disabilities and family members the opportunity to participate in training conferences and other events.



The 2014 Partners in Policymaking graduates.

15 Partners in Policymaking graduates in 2014
3 self-advocates

67 Stipend awards

289 PFL members

327 PFL training participants

LaTEACH

Louisiana Together Educating All Children (LaTEACH), is the Council's statewide grassroots advocacy network created for the purpose of affecting systems change in education. LaTEACH provides information and support to members interested in promoting policies and practices that lead to appropriate, inclusive education for all students.

1,595 LaTEACH members

491 Confirmed actions to policy makers

59 Visits to legislators and BESE members

EDUCATION and EARLY INTERVENTION

LaTEACH Leaders and members frequently contacted State Legislators and State Board of Elementary and Secondary Education (BESE) members throughout the year on issues and policies considered to have a significant impact on students with developmental disabilities.

As a result of LaTEACH and other advocates' efforts, the Legislature unanimously supported Act 833 which created an alternative pathway for certain students with disabilities to be promoted to higher grades and graduate. This change in policy is a monumental shift for Louisiana and brings Louisiana in line with how many states recognize the role a student's Individualized Education Program (IEP) has in determining student requirements for grade level advancement and exiting with a high school diploma.

LaTEACH advocated that funding for students with disabilities be based on need and equitable across traditional and charter school systems. While the current Minimum Foundation Program (Louisiana's education funding formula) continues to lack an equitable and fair distribution between traditional and charter schools related to students with disabilities, advocacy efforts have succeeded in educating legislators about the impact of the inequity. One positive change was the amount of dollars in the High Cost Fund pool doubled. This Fund covers costs related to students with extremely high-cost needs.

The **Early Intervention Primary Service Provider Training and Coaching Initiative** is a pilot project designed to transform the Early Intervention system to a transdisciplinary service delivery system. Through collaboration with national early intervention experts and with support from the state's Early Intervention program, EarlySteps, the Council-supported project provided train-the-trainer activities. The project continues to provide training and technical assistance in the Primary Service Provider model to current and future EarlySteps providers.



126 Children and families served by the pilot in 2014

DD Health Care Training Project Modules

Module Topics Include:

- ◆ Community Support
- ◆ The Medical Home
- ◆ Typical and Atypical Development
- ◆ Families
- ◆ EarlySteps
- ◆ Developmental Screening
- ◆ Navigation of the School System
- ◆ Interdisciplinary Evaluation for Autism Spectrum Disorders

HEALTH

The Council advocated for policies and practices which would ensure people with developmental disabilities have access to adequate health care services.

The **DD Health Care Training Project** through Louisiana's University Center for Excellence in Developmental Disabilities (UCEDD) began a two-year project to develop modules designed to increase awareness and understanding of individuals with developmental disabilities and their families among students in Nurse Practitioner and Physician Assistant schools and Physicians through web-based Continuing Medical Education units. The project also expanded a program to include a structured interview of a parent of a child who has complex challenges to inform Pediatric Residents of the child's intensive support needs.

EMPLOYMENT

The Council's **Employment Advocacy** was largely conducted through representation on a variety of boards and workgroups including the Office for Citizens with Developmental Disabilities (OCDD) Employment First Work Group, the Louisiana Rehabilitation Council (LRC), Louisiana APSE (Association for People in Support of Employment First), and the Work Pay\$ Coalition. The Council joined the LRC in advocating for increased state match dollars in order to draw down federal vocational rehabilitation dollars.

The Supported Employment Provider Mentoring Project provided Community Rehabilitation Providers with Capacity Enhancement Plans (CEP) developed to guide work with each participating agency. As part of the CEPs, Employment Support Professionals (ESPs) received training and mentoring and supported job seekers in achieving employment outcomes. Finally, the project collaborated with Louisiana APSE to arrange a Certified Employment Specialist Professional Exam in Louisiana.

25 ESPs participated

436 ESP mentoring hours

14 Job seekers achieved outcomes

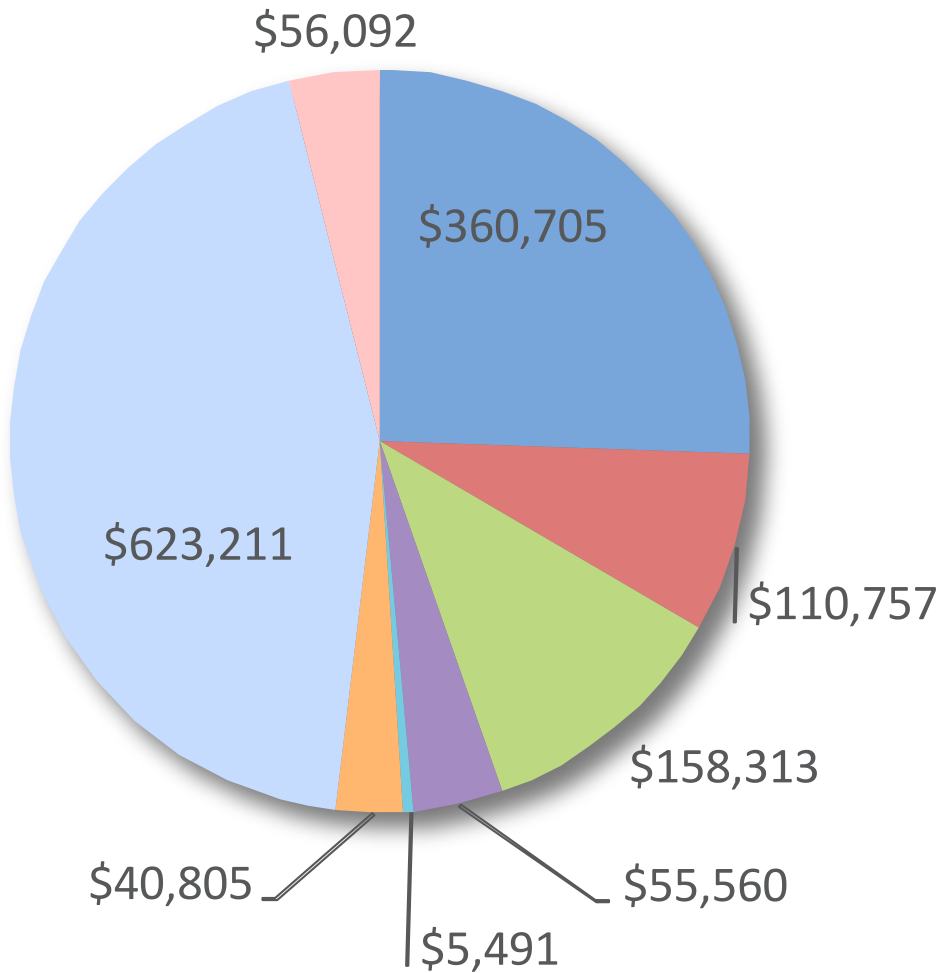
DEVELOPMENTAL DISABILITIES DEFINED

A developmental disability is a severe, chronic disability which is:

- ◆ Attributable to a mental or physical impairment or combination of mental and physical impairments;
- ◆ Manifested before the individual attains age 22;
- ◆ Likely to continue indefinitely; and
- ◆ 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, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth to age 9 who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without having functional limitations in three or more of the major life activities listed above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

FFY14 EXPENDITURES



Formal/Informal
Community Supports

Health

Education and Early
Intervention

Employment

Recreation

Child Care

Quality Assurance

General Management

About the Louisiana DD Council

To accomplish its work, the Council develops a state plan and conducts advocacy, systems change and capacity building activities. Our FFY 2014 plan addressed the following areas:

- ◆ Quality Assurance
- ◆ Community Supports
- ◆ Health
- ◆ Education/Early Intervention
- ◆ Employment
- ◆ Child Care

The Council addresses activities related to the Areas of Emphasis through two committees:

- ◆ Self-Determination/Community Inclusion/Housing
- ◆ Health/Education/Employment

VISION

We envision a system of services and supports in Louisiana which enable individuals with developmental disabilities to exercise self-determination, be independent, productive and integrated and included in all facets of community life.

MISSION

The Council's mission is to lead and promote advocacy, capacity building, and systemic change to improve the quality of life for individuals with developmental disabilities and their families.

MANDATE

The Council engages in **advocacy, systems change and capacity building** activities that contribute to a coordinated, individual and family-centered, individual and family-directed comprehensive system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

THE LOUISIANA DD COUNCIL

Sandra “Sam” Beech, Chairperson, Shreveport, Parent
Brenda Cosse’, Vice-Chairperson, Slidell, Parent
Sue Berry, Office of Public Health
Bonnie Buckelew, Winnfield, Parent
Donnica Conway, Autism Society of Greater New Orleans
Vickie Davis, Walker, Parent
April Dunn, Baton Rouge, Self-advocate
Kristopher Hebert, Broussard, Self-advocate
Michelle Hurst, Zachary, Parent
Raymond Jasper, Gray, Self-advocate
Mark Martin, Louisiana Rehabilitation Services
Terry McFillen, Lafayette, Parent
Margaret McGarity, Governor’s Office of Elderly Affairs
Paula Moreau, Baton Rouge, Parent
Lou Ann Owen, Bureau of Health Services Financing
Stephanie Patrick, Advocacy Center
Delery Rice, Metairie, Parent
Ellis Roussel, Governor’s Office of Disability Affairs
Stuart Simon, New Orleans, Self-advocate
Erin Smith, Springhill, Self-advocate
Donna Spears, Jennings, Self-advocate
Mark Thomas, Office for Citizens with Developmental Disabilities
Patsy White, Luling, Parent
Phil Wilson, Human Development Center
Jamie Wong, Department of Education

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Council Membership



The Louisiana Developmental Disabilities Council is comprised of twenty-eight people from across the state who are appointed by the Governor to develop and implement a five-year plan to address the needs of persons with developmental disabilities. Membership includes persons with developmental disabilities, parents, family members, advocates and representatives from public and private agencies.

COUNCIL STAFF

Sandee Winchell, Executive Director

Shawn Fleming, Deputy Director

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Keokah Sanders, Program Manager

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Brandi Lin Jones, Program Monitor

Sara Carr, Contracts Specialist

Paige Freeman, Executive Secretary

COST STATEMENT

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