In 2018 the Louisiana Developmental Disabilities Council (Council) initiated activities targeting goals in the 2017-2021 Five-Year Plan. This new plan recognizes the significant focus of the Council’s work in supporting advocacy and leadership development, along with goals targeting community supports, inclusive education, and competitive integrated individual employment for individuals with developmental disabilities. Key policies and practices impacted by the Council include transformation of the waiver system to make offers based on the needs of people with developmental disabilities rather than on a first-come, first-served basis; appropriation of funds to provide 650 mixed waiver opportunities to people with the most urgent needs; the creation and funding of a hi-needs rate to serve people with complex and challenging needs; increased provider rates for Individual and Family Support (IFS) night services for waiver recipients; retention of the New Opportunities Waiver (NOW) Fund and the Community and Family Support System (CFSS) Fund; and to require school systems to allow access of private behavior therapists upon parental request.

The Council stands poised to capitalize on partnerships with stakeholders, other organizations, and policymakers to ensure continued progress is made in developing and implementing a coordinated, consumer- and family-centered, and consumer 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, productive, and fully included in all facets of community life.
Community Supports

Faced with an astounding $1 Billion state budget deficit, the Council advocated through one regular and three special legislative sessions for a variety of policy changes designed to expand access to individual and family supports, reduce the state’s reliance on institutionalization, and increase the community’s capacity to serve those with the most challenging and complex needs. Successful advocacy efforts through FFY2018 include:

- Elimination of the home and community-based waiver waiting list for individuals with developmental disabilities through the implantation of a tiered-waiver system based on an individual’s urgency of need;
- Funding for additional mixed waiver slots for people with the most urgent need;
- Funding for an enhanced rate in the New Opportunities Waiver (NOW) for people with complex medical and/or behavioral needs;
- Funding to increase the Individual and Family Support (IFS) night rate in the NOW;
- Additional one time funding for the two Human Services Districts and Authorities with the lowest state funding per capita; and
- Full funding for the LA Department of Health (LDH) ensuring the protection of current services for individuals with developmental disabilities.

The Council also created two workgroups consisting of parents, self-advocates and other stakeholders from around the state who were charged with reviewing policies and procedures in the Flexible Family Fund, Individual and Family Support, and Consumer Care Resources programs to ensure practices were meeting the needs of individuals with disabilities and their families. Workgroup recommendations were adopted by LDH and will be implemented in FFY 2019.

One self-advocate and four parents served as mentors by sharing their experience with self-direction of waiver services and provided support to those interested in pursuing self-direction. The mentors completed thirty-six workshops reaching 171 individuals. Eighty-five percent of the participants were highly satisfied with the workshop overall. Sixty-five percent of the participants indicated they “agreed or strongly agreed” that the workshop convinced them to pursue self-direction.

The Complex Needs Training and Technical Assistance Partnership with the Office for Citizens with Developmental Disabilities (OCDD) worked with home and community-based providers to increase capacity and improve outcomes for the people they support through in-class training and provider- and individual-specific ongoing technical support. In 2018 of this multi-year program, six providers were initially engaged and actively participating. However, due to natural disasters and staffing challenges, two providers had to withdraw from the program. Results were still achieved in the forms of reduced critical incidents and emergency room visits/hospitalizations, and improvements in family relationships, community involvement, efforts in obtaining competitive employment, and independent living.
LaCAN (Louisiana Council’s Advocacy Network) helped the Council further its mission by advocating for effective policies and systems that support inclusion in home and community-based services, education and early intervention, and employment. Nearly 1,500 LaCAN members from around the state took more than 3,500 actions including participation in Legislative Roundtables, legislative visits, calls/emails to legislators, and legislative committee or education board meetings.

The Council provided information on issues important to individuals with developmental disabilities and their families through LaDDC News articles and posts to the Council’s Facebook page and Twitter account. The Council also supported nine Families Helping Families (FHF) Regional Resource Centers. The FHF centers assisted 23,000 individuals with disabilities and family members by providing information, referral, or other supports. During FFY 2018, the centers disseminated over 37,000 units of information and referrals, hosted over 260 trainings, and conducted 360 outreach activities to hospitals, pediatricians, and school districts. Five of the FHF Centers and People First of Louisiana participated in Council-funded Board of Directors trainings offered by the Louisiana Association of Nonprofit Organizations (LANO).

The Council successfully hosted a conference, “Raising Expectations: Employment for ALL” in November of 2017. The event was attended by 182 people including self-advocates, family members, service providers and other professionals. Attendees heard from two national speakers, Allan Bergman and Dr. Steven Hunt, on strategies, processes, and policies that are effective in supporting individuals with the most intense support needs to obtain and maintain competitive integrated employment. The conference also featured a panel of state agency representatives sharing information about employment services available in addition to a panel of parents and self-advocates sharing their employment experiences.

Twelve participants, including three fathers, graduated from the 2018 Partners in Policymaking® class in June 2018. Participants were active in systems change advocacy by attending and testifying at Legislative Committee hearings and responding to LaCAN Action Alerts. Partners’ graduates serve on numerous state and regional councils, boards, and committees.
Education

The Council successfully advocated for:
- students with disabilities to have access to quality, individualized programs in inclusive environments,
- transparency in outcomes through the release of public reporting of statewide statistics in enrollment and discipline,
- the prevention of the use of force against students in schools and laws allowing individual school employees to remove students from campus.

The Council expressed concerns over the need for:
- the release of compliance monitoring findings, investigations, and corrective actions;
- school performance calculations of alternative schools to be based on the same level of students as in neighborhood schools;
- the Board of Elementary and Secondary Education (BESE) to consider not extending or renewing charter school contracts for any charter school in violation of legal requirement regarding minimum enrollment rates of students with disabilities; the Louisiana Department of Education (LDOE) to provide a statewide plan for assisting schools in implementing behavior plans which are positive, proactive, evidence-based, and data driven;
- LDOE to provide information related to monitoring data, reports, citations, and corrective actions related to findings summarized in the Alternative Education Workgroup Report of October 2017 and information of how parents of students with disabilities sent to alternative sites have access to information necessary for them to effectively advocate on behalf of their children’s rights.

Employment

Council staff advocated for the certification of Employment Support Professionals (ESPs) during Louisiana Rehabilitation Council (LRC) meetings. As a result of this advocacy, the LRC requested Louisiana Rehabilitation Services (LRS) to determine a method for increasing certification requirements of LRS vendors who provide employment supports to individuals with the most significant needs. The DD Council provided funding for five ESPs to receive technical assistance from the LSU-Human Development Center and registration costs to pass CESP exams.

To build the capacity of employment support providers in Customized Employment, the Council sponsored multiple initiatives statewide.
- An overview meeting was conducted with LRS employment support vendors, Regional Managers, state and regional staff, and Local Governing Entities’ DD Directors.
- LRS vendors interested in providing Customized Employment services participated in Discovery Gateway Trainings and a Certification mentoring process conducted by Marc Gold & Associates.
- Single-day training sessions offered in West Monroe and Bossier City were conducted by Dr. Steven Hunt, of Briggs & Associates, on Customized Employment.

The Council successfully advocated for the establishment of an Employment First Workgroup by Governor John Bel Edwards to align policies across agencies and programs to promote inclusive, individualized, competitive employment. After five meetings, a subcommittee was formed to finalize the report and plan for making improvements to the system of employment services. Governor Edwards issued Executive Order (18-08) directing state agencies to implement strategies to “attract, engage, and advance people with disabilities” and created the State as a Model Employer Task Force within the Governor’s Office of Disability Affairs. This was a recommendation by the Employment First Workgroup.
Financial Report

The Council received $1.4 million in federal funds through the Developmental Disabilities Assistance and Bill of Rights Act. Each Developmental Disabilities Council is required to spend a minimum of 70% of its funds on advocacy, systems change, and capacity building activities that promote the independence, self-determination, productivity, integration and inclusion of individuals with developmental disabilities.

- 93.6% of the Council’s funds went to programmatic activities in 2018.
- Program funds were expended in the areas of Community Support, Education, Employment, and Advocacy and Leadership Development.

In addition to federal funds, the Council also receives state funds for the operation and administration of a network of nine Families Helping Families Regional Resource Centers that provide information and referral, education and training, and peer support to individuals with disabilities and their families from people who have been there.