Bureau of Family Health (BFH) is part of the Louisiana Department of Health’s Office of Public Health (OPH). The Bureau administers the state’s Title V Maternal and Child Health Block Grant program and works to promote the health of pregnant women, babies, children, teens and adults, and youth with special health care needs. The Bureau offers a variety of resources and services for Louisiana families, as well as programs and data to support healthcare, social service and public health professionals in their work.

Children’s Special Health Services (CSHS) program works to ensure that children and youth who have special health care needs (CYSHCN) in Louisiana have access to health care services designed to minimize their disabilities and maximize their probabilities of enjoying independent and self-sufficient lives.

- CSHS continues direct service clinics for CYSHCNs in regions 2 and 4-9 to meet specialty care needs in provider shortage areas. CSHS clinics are staffed by part-time physician sub-specialist, a full-time nurse, and parent liaison. CSHS parent liaisons are the parent of a child/young adult with a special health care need and work in tandem with the clinic staff to assist parents with coordination of care and linkage to community services. Additionally, parent liaisons provide emotional support, and help create family/professional collaboration within the clinic and beyond. Parent liaisons are also involved in outreach activities throughout the community, and attend mandatory quarterly trainings, to assure that the current information and services are available to families. In Regions 2, 4, and 6-9, the care team also includes a social worker, in Region 2 a nutritionist is on staff that provides support services for patients in other regions.

- OPH is implementing a new electronic medical record system in direct service clinics; go live date is scheduled for November 12th.

- CSHS continues sponsorship of care coordination (CC) services in six academic clinics through partnerships with Children’s Hospital New Orleans (CHNOLA), Daughters of Charity, NOELA Community Health Center, Lafayette -University Hospital and Clinics, and Tulane Lakeside Pediatrics. This project provides area families access to CC services and allows residents to gain personal experience with the medical home delivery model.

- The BFH Developmental Screening Initiative continues to develop our capacity to provide implementation training and support for practices that serve the birth to five population. This includes developing an online toolkit for providers with tailored supports, providing trainings to Early Childhood Educators on general development and developmental screening tools. For example, Head Start and Early Head Start educators were provided additional training on three developmental screening tools through the United Way of Acadiana. Training family medicine residents on the differences between developmental monitoring, surveillance, and screening. Last, a four session professional development series for early childhood educators in Abbeville School District, which addresses typical and atypical development as well as classroom-focused strategies and referral processes.
The Early Childhood Systems & Strategy Manager gave a talk on developmental screening and care coordination to the physician attendees of the Louisiana Academy of Family Physicians’ (LAFP) 72nd Annual Assembly & Exhibition in New Orleans. The information was well-received, and will hopefully boost developmental screening rates in family medicine practices, which historically screen at lower rates than pediatric practices.

CSHS rescheduled the Region 3 Resource Information Workshop (RIW) *Improving Early Identification and Access to Comprehensive Care for Children and Youth with Special Health Care Needs* (CYSHCN) due to planning logistics. The team is exploring spring 2020 event dates.

**CSHS Transportation Assistance Program** provides needed transportation assistance for families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS.

<table>
<thead>
<tr>
<th>Transportation Assistance Program</th>
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<tbody>
<tr>
<td>June-August 2019</td>
</tr>
<tr>
<td>19 families served</td>
</tr>
<tr>
<td>Stipend expenditures $5415.99</td>
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**CSHS Family Resource Center** (FRC) located on the campus of Children’s Hospital in New Orleans, connects Louisiana families with needed resources through outpatient clinics and the inpatient rehabilitation unit. The FRC also links families with their local Families Helping Families center for ongoing support.

Additional FRC activities:
- Supports Botox, Spasticity, Neuromuscular, Spina Bifida, Down Syndrome, Muscular Dystrophy, Cerebral Palsy and Neurology Transition clinics.
- Youth liaison visits families receiving inpatient rehab services and provides information about the resource center and community/state resources that they may request.
- Provides resource information to physicians and Children’s Hospital Staff and is supporting a campus initiative to embed some resource information into the EHR.
- FRC parent liaison, Thuy Nguyen, serves on the CHNOLA Commission on Accreditation of Rehabilitation Facilities (CARF) providing the family perspective and resource information to inform the group’s work.
- FRC youth liaison, Steven Nguyen, participates in the Statewide Independent Living Council and serves in the role of vice chairman; sits on the Developmental Disabilities Council; and is a member of the Jefferson Parish Complete Streets Coalition.
- FRC staff met with regional Maternal Infant Early Childhood Home Visiting (MIECHV) staff to discuss opportunities for partnership and methods to collaborate in serving CYSHCN.
**Family Resource Center**
Resource Dissemination Activities June-August 2019

<table>
<thead>
<tr>
<th>Total Client Encounters</th>
<th>224</th>
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<tbody>
<tr>
<td>Identified Resource Needs</td>
<td>447</td>
</tr>
<tr>
<td>Resource Needs Met</td>
<td>433</td>
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**Louisiana Birth Defects Monitoring Network (LBDMN)** tracks the occurrence of over 70 structural, functional, and genetic birth defects in Louisiana residents. This work helps to identify environmental conditions, pharmaceutical side effects, or behavioral risk factors threatening Louisiana’s newborns.

- LBDMN is pleased to introduce Tracy Zehner, BSN, our new Data Collection Specialist in Regions 4 & 5. Filling this vacancy will enable us to complete the 2016 birth cohort in the upcoming quarter. By case definition, we include children diagnosed prior to their third birthday. Therefore, birth cohorts are closed in three and a half year cycles.
- We are eagerly awaiting a mid-September CDC announcement of a funding opportunity for Neonatal Abstinence Syndrome surveillance.
- LBDMN staff are participating in the MCH Regional Community Advisory and Action Teams across the state. CAATs are co-facilitated by the MCH Coordinators and Nurse Supervisors for the Home Visiting Teams. CAATs work at the community level to improve maternal and child health through the collaborative and coordinated effort of a diverse group of community leaders.
- Family Engagement: Julie Johnston, LBDMN program manager, also serves as Louisiana’s Title V Family Representative. Julie is mom to Zac, a 26 year old with medical complexity and developmental issues. The following are opportunities Julie has had to represent the CYSHCN family perspective at the system and/or program level:
  - LA Child Death Review: A cross-system workgroup is working to reduce child mortality thorough motor vehicle safety. Julie is facilitating a sub-workgroup particularly focused on proper seating equipment for CYSHCN.
  - Bureau of Family Health is developing a work plan to integrate CYSHCN standards of care into each of the Title V domains. The first stage in building an evaluation tool for the 5 year Needs Assessment from which the workplan will evolve. Julie serves in this work group to bring consideration of family perspectives and to incorporate the experiences of families who could benefit from or are accessing Title V services.
  - BFH selected Family Engagement and Leadership (FEL) as Title V State Performance Measure #5. The SPM5 workgroup is building a culture of valuing FEL as well as adopting processes across programs to integrate family involvement at different levels to institutionalize FEL within BFH and Louisiana Title V programs.
  - The Young Child Wellness Collaborative is a diverse cross-systems group facilitated by BFH focused on improving wellness in the early childhood period 0-5 in Louisiana. While Julie has served on this group for several years, recently a FEL subgroup was formed with representation from DOE, BFH, and the Governor’s Office of Women’s Affairs. It is focused incorporating a pipeline for
Family Leadership into the broader development of a seamless system for early childhood in Louisiana.

- Emergency Medical Services for Children program is funded by HRSA to expand the capacity of EMS agencies and hospital emergency departments to respond appropriately and effectively to pediatric medical emergencies. Each state EMS-C program is required to have a Family Advisory Network representative. Julie has been Louisiana’s FAN since 2014. In August, Julie presented on CYSHCN preparedness and transition planning at the annual grantees meeting in Arlington, VA. This resulted in two more opportunities:
  - An invitation to present to the federal partners of the Children's HHS Interagency Leadership on Disasters (CHILD) Working Group comprised of members from 18 HHS divisions. The CHILD Workgroup works across HHS to assess current capabilities and facilitate coordination at the program and response levels. The CHILD Working Group provides recommendations to enhance how the Department provides and facilitates care to address the disaster-related health and human services needs of children (birth through age 17) during and after disasters or public health emergencies.
  - To participate on the Pediatric Emergency Care Applied Research Network (PECARN) dissemination workgroup as a family representative. The workgroup is tasked with developing strategies and methods of knowledge dissemination and content to take the very high level information being produced by these researchers and be able to present that information in a way that is practical and useful across a range of personas including parents, physicians, the general public, child health advocates and various stakeholders.

**Genetic Diseases Program** operates a comprehensive statewide newborn heel stick screening program meeting national standards as well as ensuring access to genetic evaluation and counseling to residents of Louisiana. Currently the heel stick program screens for 28 genetic conditions. The Genetics Program also operates the Sickle Cell Disease (SCD) Program, which provides resources and information on how individuals diagnosed with sickle cell can receive assistance and care through the Sickle Cell Foundations and Clinics around the state.

- Genetics and Newborn Screening
  - September is National Newborn Screening Awareness Month.
  - The next Genetic Diseases Program Advisory Committee Meeting will be held at the end of October. The meeting will focus on the programmatic and fiscal impact of adding three new tests (Spinal Muscular Atrophy, Mucopolysaccharidosis Type-I, and Pompe) to the state newborn screening heel stick panel.

- Sickle Cell
  - September is National Sickle Cell Awareness Month. Look for activities occurring throughout each region of the state.
  - Staff participated in the Sickle Cell resource Fair at Our Lady of the Lake Regional Medical Center in Baton Rouge on August 30.
Several BFH staff members attended the fifth Annual NOLA Sickle Cell Anemia Red Run on September 7 at the City Park Festival Grounds.

Staff from the Genetics Program and the Family Resource Center attended the Pediatric Hematology/Oncology Health Fair at Children’s Hospital in New Orleans on September 7.

Chevron Oronite has invited staff to present and provide resources at their Sickle Cell Awareness event on September 23 at the Oak Point plant in Belle Chasse.

Staff from the Genetics Program and the Family Resource Center will participate in the third Annual Sickle Cell Resource Fair at Children’s Hospital in New Orleans on September 28.

**Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program (LHHCLPPP)** works toward the goal of eliminating childhood lead poisoning as a public health problem through initiatives to promote lead poisoning prevention and coordinate lead abatement projects for low-income families in high-risk areas of the state.

**Hearing Speech and Vision - Early Hearing Detection and Intervention (EHDI) Program** is a national initiative that supports the early identification of infants who are deaf or hard of hearing (D/HH). The goals of the program are to complete screening before 1 month of age, complete audiologic evaluation before 3 months of age, and enrollment in early intervention before 6 months of age. The program works to ensure all children who are deaf or hard of hearing are identified early and supported effectively in order to have the opportunities to develop the language skills they need to learn, grow and thrive.

- At the last update, Members of the EHDI Team had presented at the EarlySteps Regional Interagency Coordinating Council, (RICC) meetings in Regions 1, 3 and 6. Continued presentations have now taken place in Regions 2, 4, 5 and 8. Information was shared with Family Service Coordinators about hearing screening, diagnosis and language development. The presentations highlighted the opportunities available between the two programs to offer coordinated support to families who have not followed through with their child’s hearing screening or diagnostic testing. Information was also shared about the Hands and Voices/Guide By Your Side Program and the Parent Pupil Education Program, both of which offer support to families of children who are deaf or hard of hearing. Presentations will be held in remaining Regions in an effort to coordinate the service and supports of all programs for purpose of reducing the number of children who are lost to follow up in the EHDI system and ensuring that families are offered the maximum amount of support and services available to them.

- At last update, the LAEHDI program reported on developing a toolkit and conversation guide that supports physicians of young patients who have been diagnosed as deaf or hard of hearing. The toolkit now also includes a family information one-pager for families of children who have been newly identified as deaf or hard of hearing. The toolkit is currently being piloted with newly identified children who are deaf or hard of hearing to support physicians in leading informed and positive discussions with families – focusing on the abilities of the child regardless of the diagnosis. The toolkit guides physicians and
families to ensure that the child is receiving the recommended intervention services and are active participants in their child’s language and communication development.

**Louisiana Guide By Your Side (GBYS)** is the lead family based organization for the LA EHDI program. GBYS is a program from Hands and Voices (H&V) that provides support and unbiased information from trained Parent Guides to families of newly identified children who are deaf or hard of hearing.

- National Hands and Voices entered a cooperative agreement with the Health Resources and Services administration (HRSA) back in 2017. Under that partnership, a new program has developed called the Hands and Voices Family Leadership in Language and Learning (FL3). The goal of FL3 is to ensure that EHDI programs, supported by federal funding in the United States, use research-based concepts known to support families, parents and caregivers of deaf or hard of hearing babies, toddlers and young children identifies through newborn hearing screening. Parent Guides and D/HH Guides from Louisiana GBYS have been able to take advantage of the variety of trainings, webinars and other learning opportunities offered within the FL3 program. Trainings taken to date have ranged in topic from Language, Literacy and Social Involvement to Family Leadership and Support.

**BFH Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program** is a no-cost, voluntary program that supports the health and well-being of families with young children. MIECHV implements two evidence-based models, Nurse-Family Partnership (NFP) and Parents as Teachers (PAT). MIECHV pairs families looking for additional support and mentoring with specially trained registered nurses or parent educators who partner with families and provide personal home visits.

NFP and PAT services:
- Health and developmental screenings for children, promoting early identification of developmental delays.
- Assistance with goal setting and life skills development.
- Parenting guidance on a variety of topics.
- Connections to available resources, including early intervention and early childhood special education services.
- Coordinated care and support once families are connected to needed services.

*Nurse Family Partnership (NFP)*:
- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible first-time moms and families from pregnancy until the child’s second birthday.
- NFP serves moms living in all parishes except Caldwell, East Carroll, Madison, Tensas, Union, and West Carroll.
Parents as Teachers (PAT):
- Services and supports are provided to Medicaid-, WIC-, SNAP-, TANF-, and/or SSI-eligible expectant or parenting families from pregnancy until the child enters kindergarten.
- PAT serves families living in Northern Louisiana and the New Orleans area.

For more information about Louisiana MIECHV’s NFP and PAT services, including how to get in touch with a home visitor near you, please call the Partners for Family Health toll free telephone line at 1.800.251.BABY or visit the Partners for Family Health website at https://partnersforfamilyhealth.org.

Statewide Young Child Wellness Collaborative (YCWC) is a cross-agency advisory council, the purpose of which is to provide leadership and informed recommendations to drive shared priority setting and strategic planning across the continuum of supports and services within Louisiana’s Early Childhood System. The YCWC serves as the State-Level Advisory Team for the MIECHV program, the Early Childhood Comprehensive Systems CoIIN, and formerly for the SAMHSA-funded Project LAUNCH grant. The YCWC includes representation from BFH, EarlySteps, the Office of Behavioral Health (OBH), Louisiana Department of Education (LDOE), and Department of Child and Family Services (DCFS).

- YCWC Workgroups:
  - Family Engagement & Leadership
  - Early and Accurate Identification
  - Early Childhood Data System Integration
- For more information about the YCWC contact Fiona.Ritchey@la.gov.

Adolescent School Health Program (ASHP) manages 62 School-Based Health Centers around the state, which are health centers in public and charter schools that offer comprehensive, primary and preventive physical and mental health services for students onsite. ASHP establishes and monitors health centers’ compliance with standards, policies, and guidelines for school health center operation, provides technical assistance and coordinates and encourages collaboration with other agencies and potential funding sources. School-Based Health Centers support academic achievement by working with students in a safe and confidential manner to address emotional and health barriers that hinder academic success. For more information about the ASHP, contact Faith.Boudreaux@la.gov.