

Office of Public Health (OPH) Quarterly Report to the Developmental Disabilities Council
 Bureau of Family Health (BFH)
 January 5, 2023

Children’s Special Health Services (CSHS) works to ensure that children and youth with 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.

- [Children’s Special Healthcare Services](#) (CSHS) - Clinical Services offers direct care clinics for CYSHCNs in all regions, except 1 and 7, to meet specialty care needs in provider shortage areas. CSHS-Clinical Services (Genetics, Sickle Cell, and subspecialty clinics) transitioned to a hybrid appointment schedule. Decisions regarding in-person vs telehealth appointment visits are now being made at the Regional level depending upon staffing capacity, the infection positivity rate, and the ability to provide services safely.
- CSHS-Clinical Services Social Workers continue to provide behavioral health assessments to determine if families are in need of outpatient behavioral health referrals, as well as providing support and resources.
- CSHS-Clinical Services also provides nutritional services in Regions 2 and 6 and hopes to expand to other Regions as the need dictates.
- Any family of a child/youth with a special health need that requires peer support, system navigation, or resource linkage is referred to Families Helping Families network in their respective region or the Family Resource Center. CSHS-Clinical services also refers to other community-based organizations as appropriate.

The Family Resource Center (FRC) is a statewide virtual center designed to ensure CYSHCN, their families, and health care providers in Louisiana have access to resource and referral services. The [BFH-Family Resource Center](#) provides community referrals, health/education transition supports, and system navigation services. For resource and referral services contact the FRC team via phone (504) 896-1340 or email BFH-FamilyResourceCenter@la.gov, Monday-Friday 8 am-4pm.

FRC now provides outreach to families of children identified through the Louisiana Birth Defects Monitoring Network to assist in linking to appropriate medical, educational, public health and peer support resources available in their region.

Family Resource Center September-December 2022	
New Referrals	442
Total number of outreach efforts	513
Unduplicated clients with a completed Needs Assessment	176
Total number of resource information and linkages provided to clients	830

Families Helping Families (FHF) – BFH Project aims to build a coordinated and family-centric statewide CYSCHN resource and referral service system utilizing the collaborative partnership between BFH-Family Resource Center and FHF Networks. FHF networks are Louisiana’s statewide parent-to-parent support organization serving individuals with disabilities and children/youth with special health care needs and their families.

CSHS Transportation Assistance Program provides needed transportation assistance for eligible families to attend medical appointments/procedures. Families must seek transportation assistance through their MCO before requesting assistance through CSHS. Families may contact the Family Resource Center (BFH-FamilyResourceCenter@la.gov) or their local [Families Helping Families](#) Center for more information.

Transportation Assistance Program October 2022-November 2022	
3 stipends issued	Stipend expenditures \$519.17

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. By case definition, we include children diagnosed prior to their third birthday.

In December, LBDMN filed the 2022 annual report to the legislature which included data reports on surveillance findings, system performance assessment and improvements, and data to action initiatives.

2022 Findings

Of 176,643 children born between 2017 and 2019, 4,657 children were diagnosed with at least one birth defect, yielding an overall prevalence of 263.6 per 10,000 live births or 2.63%. According to the CDC the US average is about 3% of all babies born each year. Among Louisiana children with birth defects born in 2017-2019, cardiovascular system defects (about 63%) were the most common followed (in order of occurrence) by defects of the genitourinary, musculoskeletal, chromosomal, orofacial, central nervous, gastrointestinal, eye, and ear/face/neck systems.

2022 Performance Assessment and Improvements

LBDMN follows national standards and guidelines for birth defects surveillance. Using National Birth Defects Prevention Network (NBDPN) data quality assessments, Louisiana ranks among the nation’s top active surveillance programs in completeness, accuracy, and overall quality. From 2019 to 2022 assessments, LBDMN increased from Level 1 to Levels 2 and 3 in both data quality measures of timeliness. This means 95-99% of data from NBDPN’s lists of 19 *Core* and 33 *Recommended* birth defects are identified, collected, reviewed, and available for reporting

within two years of birth. LBDMN continues to identify and report qualifying birth defects diagnosed before three years of age.

This increase in timeliness is a direct result of efficiencies realized from performance improvement strategies adopted in 2020-2021. Strategies included code list revisions, automated case-finding, database updates, and expanded remote access to medical records for data collection thereby eliminating travel and enabling staffing reassignments for equitable caseloads.

2022 Data to Action Spotlight: Referral to Resources

Timely data enables LBDMN to move data to action in the form of meaningful referrals to resources for families. When babies are born with birth defects, families need help learning about complex systems of care and how to navigate those often fragmented systems. In 2022, LBDMN partnered with BFH's Family Resource Center (FRC) to conduct a pilot of one-on-one needs assessments with families of children born in 2020 with birth defects most likely to impact developmental outcomes.

FRC staff contacted families to assess their need for health and social services including specialty medical care, early intervention services, insurance, advocacy, disability agencies, peer support, transportation, food, and housing security. In the pilot, FRC staff made contact with 54% of identified families (142/261) via phone calls, text messages, and postcards. Of these families, 93% identified at least one needed resource. FRC staff facilitated connections to the appropriate resources for these families. This speaks to the high need for assistance with resource navigation that exists into and beyond the first two years of life.

Since evaluation of the initial referral pilot in July 2022, LBDMN and FRC staff have completed a third cohort referrals, testing and tracking different methods to improve contact success rates. Children born in 2021 and 2022 will be contacted in 2023. This timing is critical to connect children to early intervention services within the first two years of life to improve health and developmental outcomes as well as the quality of life for those impacted by birth defects.

2022 Data to Action Spotlight: Birth Defects Prevention Case Review Model

The focus of 2021-2022 board activities was to move birth defects data to action through data analysis. LBDMN program staff worked through the advisory board to develop a birth defects prevention case review model. The purpose of structured on-going case review is to move LBDMN data to action by identifying preventable birth defects to make evidence-based recommendations for systems level changes to improve primary prevention and intervention efforts in Louisiana's maternal health system.

In October 2022, the case review model was tested using LBDMN 2017-2019 orofacial defects data. After suggesting minor adjustments to the case summary form, the advisory board adopted the following schedule to apply the prevention case review model to fourteen birth defects designated as Core by the National Birth Defects Prevention Network:

- 2023: Critical congenital heart defects
- 2024: Neural tube defects and Trisomy 21

- 2025: Abdominal wall and limb reduction defects

Upon completion of this cycle of case review, the advisory board will bring recommendations of the identified strategies to aid in advancing prevention efforts and interventions to increase health and developmental outcomes for children identified with birth defects in Louisiana.

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 enroll 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.

- LA EHDI held their first in-person Regional Collaborative since COVID-19 in October of 2022. Participants included stakeholders in Region 1 which yielded a diverse group of stakeholders that included parents, audiologists, early intervention providers, and support coordinators for Part C. The audience was fortunate to hear the unique experience of a parent, who is also a physician, on their family's experience during the identification, amplification and intervention process. The sharing of her perspective was educational, passionate and affirming to those in attendance. In addition, several organizations shared literature about their programs, and each were invited to speak on the support they offer children and parents. Among the contributing parties were Early Steps (Louisiana's Part C program), the Parent-Pupil Education Program (PPEP) (non-part C through the Louisiana School for the Deaf), and The Bright School. One of the primary challenges noted by those in attendance focused on communication breakdowns that occur with non-English speaking families, citing limited access to consistent, qualified interpretation and parent literature not available in Spanish. Our EHDI program informational materials that were created with parent feedback and are available for hospitals and diagnosing audiologists to use with families to promote understanding and offer guidance were well received. We plan to host a follow-up meeting with diagnosing audiologists across the state to further encourage dissemination. Breakout sessions at the conclusion of the Collaborative grouped the audience in 3 categories: early interventionists and parents, hospitals, and audiologists. These smaller groups permitted focused discussion on the progress demonstrated and improvement needed in Region 1.
- A telephone survey was conducted with 29 families whose children were enrolled in early intervention. The survey included questions about EarlySteps and Parent Pupil Education Program (PPEP) services, as well as Guide By Your Side (GBYS). Questions included information about timely contact, visit frequency, family-centered service provision, satisfaction, and bias. Family responses indicated overall satisfaction with early intervention and family-to-family support.
- To maximize the early intervention enrollment of children identified as deaf or hard of hearing, it is imperative that these children receive a diagnosis by 3 months of age. We began concerted efforts to increase the number of infants diagnosed by 3 months of age via a Hot Topics newsletter. We included current statewide 1-3-6 data so audiologists will understand the status of these goals in Louisiana, and we made them aware that the EHDI benchmarks will be shifting from 1-3-6 to 1-2-3 as goals are met. This newsletter has been updated

annually, with this year's newsletter displaying statistics from the 2020 birth cohort. Additionally, with this year's newsletter, statistics from the previous two birth cohorts were included so audiologists could visualize a side-by-side comparison of statewide progress.

Louisiana Hands & Voices is the lead family based organization for the LA EHDI program. Guide by Your Side (GBYS) is a program from LA 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.

- In an effort to improve continuity of care, GBYS Parent Guides collaborate with PPEP Outreach teachers. This effort has led to increased communication between providers. Additionally, each Parent Guide is also meeting at least quarterly with the local PPEP teacher to discuss the status of family contacts and family support needs.
- LA H&V GBYS program also offers Deaf and hard of hearing guides to connect with families. Each of the DHH guides has a personal bio posted on social media platforms and the H&V website, which is linked to the LA EHDI website. Additionally, in an effort to promote awareness of, and access to DHH guides, they regularly participate in monthly Parent Chats, and family gatherings around the state. In October of 2022, one of the deaf guides presented "My Deaf Experience" during the Parent Chat.

The Louisiana Commission for the Deaf (LCD) functions as the principal state program that provides information and services to and for individuals who are Deaf, DeafBlind, or hard of hearing on behalf of the State of Louisiana.

LCD's Mission, Vision, and Values:

Mission- To engage, empower, and enrich the lives and opportunities of Louisiana Deaf, DeafBlind and hard of hearing individuals

Vision- A Louisiana that embraces the inclusion of a diverse deaf community through full access to information, communication, and opportunities

Values- Advocacy, Accountability, Equality, Accessibility, and Sustainability

More information on the LCD can be found [here](#)

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 certified 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.

MIECHV recently completed the HRSA Annual Performance Measures Report. This report is a requirement of federal grant funding and is an important opportunity to review data for the purpose of quality assurance. Improvements were noted across 63% of our performance measures and 58% of those improvements were significant, showing a greater than 10% improvement. Improvements were noted in the following measures:

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| 1. Preterm Birth | 7. Child Injury Rate |
| 2. Breastfeeding | 8. Parent-Child Interaction |
| 3. Depression Screen | 9. Literacy |
| 4. Well Child Visit | 10. Primary Caregiver Ed |
| 5. Postpartum Care | 11. Continuity of Insurance |
| 6. Tobacco Cessation | 12. IPV Referrals |

For more information about Louisiana MIECHV's NFP and PAT services, including how to get in touch with a home visitor near you, you can reach out to Susannah.Boudreaux@la.gov or 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> telephone line 1.800.251.BABY or visit the Partners for Family Health website at <https://partnersforfamilyhealth.org>.

Genetic Diseases Program operates a comprehensive statewide newborn heel stick screening (NBS) 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.

Louisiana Early Childhood Risk & Reach: 2021 Report. The Early Childhood Risk and Reach in Louisiana report is a tool designed to be used by all early childhood stakeholders, governmental and nongovernmental, to better inform policy and funding decisions that impact the distribution of critical resources. The [2021 Early Childhood Risk and Reach report](#) describes five categories of health challenges facing Louisiana kids and families: Economic Stability; Healthcare Access & Quality; Social & Family Context; Education Access & Quality; and Neighborhood & Built Environment. The report also describes the reach of key publicly-funded programs that address these risks and challenges. Data on program reach are overlaid onto maps of overall risk, which helps to illustrate which parishes may require additional services and investments to support children's health and well-being.

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.

The Statewide Young Child Wellness Collaborative (YCWC) is a cross-agency advisory council, the purpose of which is to provide leadership and inform priorities/strategic planning across the continuum of supports/services within Louisiana's Early Childhood System. The YCWC serves as the State-Level advisory team for the MIECHV program and Early Childhood Comprehensive Systems grant. The YCWC meets every other month on the second Tuesday of, the next convening is February 14, 2023 at 12 noon. The collaborative includes representation from BFH, EarlySteps, the Office of Behavioral Health (OBH), Medicaid, the Louisiana Department of Education (LDOE), the Louisiana Department of Child and Family Services (DCFS), LSU Human Development Center, the Louisiana Partnership for Children and Families, the Louisiana Policy Institute for Children, and the Louisiana chapter of the American Academy of Pediatrics. The YCWC is currently recruiting pediatric/perinatal health care providers and pregnant/parenting family leaders interested in participating and informing early childhood systems improvement. If you or someone you know may be interested in joining the collaborative, contact Patti.Barovechio@la.gov for more information.

The Bureau of Family Health's Developmental Screening Initiative hosts an evidence-based [Developmental Screening Toolkit](#) to help medical providers integrate developmental screening services into their day-to-day practice. The virtual toolkit uses a quality improvement framework, which allows providers to systematically improve the way health care is delivered to the families they serve. It contains step-by-step information contained in webpages, instructional videos, and downloadable worksheets. [Customized training and technical assistance](#) for implementation of developmental screening services is available at no cost to health provider practices through the Title V initiative. For information on the Developmental Screening Initiative and provider training requests, contact Dr. Tresa Northington at Tresa.Northington@la.gov.

BFH Adolescent School Health Program (ASHP) has 57 ASHP-certified School-Based Health Centers (SBHCs) across the state. These health centers are located in public and charter schools and offer comprehensive, primary, and preventive physical and mental health services for students enrolled in the school that houses the SBHC and surrounding schools. Information on the LDH Adolescent School Health Program website can be found [here](#).