

# DATA IN ACTION

Uses of data in maternal and child health to assess, achieve and communicate.

This guide contains examples from states health departments and non-profits on the active use of data. These examples were submitted and selected to represent ways to collect, communicate, and use data to achieve desired outcomes and influence policy. The guide is separated into four main sections:

## Data Collection:



The process of gathering information in a standardized manner that enables one to:

- Organize data
- Track processes & events
- Research, evaluate, & analyze

## Data Analysis:



The process of interpreting data to obtain meaningful context and inferences through the application of:

- Statistical techniques
- Deductive reasoning and critical thinking
- Criteria assessment of evidence & plausibility

## Data Communication:



The presentation and interpretation of data in an accurate, clear, and impactful manner via communication products such as:

- Written formats
- Oral presentations
- Visualizations
- Social media

## Data-informed Policy:



The use of evidence-based or research-informed data to inform and influence policy and policy-related interventions.

## State & non-profit examples of data-in-action:

### Data Collection:

- [Texas CYSHCN Survey](#)
- [Wisconsin PRAMS Partnership](#)
- [Alaska CUBS Survey](#)

### Data Analysis:

- [Mississippi PRAMS & Breastfeeding](#)
- [Massachusetts PRAMS & Race/Ethnicity](#)

### Data Communication:

- [Hands & Voices GBYS Program](#)
- [Louisiana BFH Presentation](#)
- [Nebraska DHHS Brochure](#)

### Data-informed Policy:

- [Delaware SIMC Impact](#)
- [Florida PQC & Hemorrhaging](#)



## Data Collection: Texas CYSHCN Survey

In 2015, the Title V Maternal and Child Health (TVMCH) or Maternal and Child Health Section (MCHS) of the Texas Department of State Health Services worked closely with epidemiologists to prepare the Title V Five-Year Needs Assessment. Data obtained during the needs assessment process informs statewide Maternal and Child Health (MCH) programming. While analyzing the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), the team identified the need for additional data in areas that the NS-CSHCN did not provide (i.e. care coordination). The program launched a state-specific Children and Youth with Special Health Care Needs (CYSHCN) Outreach Survey to obtain supplemental and timely data to inform programmatic decisions. Terminology in the Outreach Survey was tailored to the parent audience. For example, to clarify the term “respite”, questions posed, “Do you ever feel that you need a short-term break (respite) to help care for your child?” These types of clarifying terms were employed to increase respondent understanding of question content and improve data quality.

The [CYSHCN Outreach Survey](#) was launched in 2014 as part of the last Title V Five-Year Needs Assessment and is conducted every state fiscal year with funding from the federal Title V block grant and state-appropriated dollars.

The survey is made available in both English and Spanish, and targeted outreach is conducted to ensure representation of the Spanish-speaking CYSHCN population in Texas. During survey development, the TVMCH team reaches out to Texas Parent-to-Parent to receive parent input on the survey content and layout. To overcome the challenge of reaching out to families across the geographically large state of Texas, TVMCH distributes both online and print copies of the Outreach Survey. Title V partners and stakeholders assist in promoting the online survey, including statewide Medical Home and Transition Workgroup members, GovDelivery listserv subscribers, and community-based contractors who provide local support to CYSHCN. The team also prints over 2000 copies of the survey to mail to children on the state’s Children with Special Health Care Needs Services Program, which provides health care benefits to CYSHCN. Families are given many months to complete and return the Outreach Survey.

Data from the survey has propelled the creation of programming related to the transition from pediatric to adult health care. The 2015 CYSHCN Outreach Survey indicated that the average age of respondents’ children was 12 years old. However, many respondents indicated they had not prepared for their child’s transition to adulthood. In response, TVMCH is partnering with Easter Seals of Greater Houston to develop a tool to better prepare families for transition. The interactive website directly links families to individualized resource recommendations in a variety of topical areas. Additionally, TVMCH has partnered with the University of Texas at Austin School of Social Work to develop a graduate level curriculum to assist future health care providers in understanding the needs of transitioning youth with special health care needs.

To strengthen the needs assessment data, TVMCH holds discussion groups at local conferences for families of CYSHCN and health care professionals as needed. Challenges in

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implementing the annual Outreach Survey include staff time for data cleaning and analysis, and costs associated with printing, distributing, and promoting the survey.

The CYSHCN Outreach Survey has helped TVMCH identify gaps in parent/caregiver knowledge and has enabled the program to relay feedback from families to health care providers. Information gathered continues to drive programming that aims to improve the delivery of health care transition and medical home services and promote community integration for CYSHCN.

Submitted by: Rachel Jew, Texas Department of State Health Services in 2016





## Data Collection: Wisconsin PRAMS Partnership

In 2007, the Division of Public Health (DPH) of the Wisconsin Department of Health Services began participating in the [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#) to collect population-based data on maternal behaviors and experiences before, during, and shortly after pregnancy.

From the beginning, DPH stratified their PRAMS sample by race and ethnicity to examine Wisconsin's disparities in maternal and child health and birth outcomes. The survey administration was first conducted by mail, and then followed by a phone call if a mother did not respond by mail. Black mothers were more likely to go into the phone phase, making the approach of stratifying the sample by race more expensive than other approaches.

Unfortunately, the funds provided in the PRAMS grant were not always enough to cover the phone phase of the survey in full—even with some financial support from the Title V Block grant—hurting response rates for this important population group.

In 2011, the Wisconsin Partnership Program of the University of Wisconsin School of Medicine and Public Health approached DPH with an interest in using PRAMS data for the Lifecourse Initiative for Healthy Families (LIHF). LIHF is a community-driven initiative to develop and implement strategies to reduce disparities in infant mortality between non-Hispanic black and white infants in Wisconsin.

Through the PRAMS/LIHF partnership, DPH conducts an enhanced oversample of non-Hispanic black mothers in four counties (Milwaukee, Racine, Kenosha, and Rock), which are home to 85% of non-Hispanic black live births and 89% of non-Hispanic black infant deaths in Wisconsin. The enhanced oversample was fully funded by the Wisconsin Partnership Program (WPP), which also funds LIHF within the University of Wisconsin School of Medicine and Public Health.

At the beginning of the partnership, LIHF formed a Communications and Public Awareness Workgroup, which included members of local community-based collaboratives, WPP program staff, and Wisconsin PRAMS and public health staff to develop ideas for outreach and methods to increase response rates. The workgroup generated many ideas; however, the PRAMS team often found it challenging to ensure that the ideas raised adhered to the PRAMS data collection protocol. Ultimately, the workgroup and PRAMS staff together decided that they would change the color of the survey and its supplemental materials to make it more eye-catching. DPH now sends the survey to non-Hispanic black mothers in a colorful purple envelope. Each survey also includes a \$5 cash incentive as an additional method to increase the response rates for non-Hispanic black mothers.

With the additional funding from the Wisconsin Partnership Program, the PRAMS/LIHF partnership was able to increase the number of African American women included in the PRAMS sample well beyond the original stratification. For the enhanced oversample, DPH sent a survey to every Black mother who gave birth within three of the four counties, and to one in six Black mothers in Milwaukee County. The additional funding for PRAMS from LIHF provided for complete phone follow up for all mothers who did not respond to the mailed survey, further increasing the response rate.

Since the start of this enhanced oversampling method, the Wisconsin PRAMS response rate for non-Hispanic black mothers has shown substantial improvement. Challenges in implementing

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the PRAMS oversample included a lag in time between data collection and data analysis and the high cost of the enhancement due to the cash incentive and the intensive phone phase after historically low participation via mail.

The Wisconsin PRAMS Black mothers oversample has been extremely beneficial for both Wisconsin Title V programming and community partners. Using PRAMS data with the enhanced oversample, Wisconsin DPH and LIHF can look at maternal and child health measures by race at a county-level for the counties that are oversampled, which is useful for evaluation of ongoing programming. Furthermore, the LIHF program office has used the data to launch a series of data briefs highlighting priority areas within LIHF communities. For example, maternal mental health has been identified as an important contributor to infant health outcomes. LIHF can now use PRAMS data to display mental health disparities and differences within the LIHF communities. Data from the enhanced oversample has also supported programming for folic acid and oral health, in addition to supplementing the Title V block grant work and Collaborative Improvement & Innovation Networks' (COIIN) efforts for infant mortality. As demonstrated by these examples, the Title V program and partners have access to a valuable dataset that enhances the ability to analyze MCH indicators by race and ethnicity in a way that is meaningful at both the state and local levels.



Submitted by: Angela M, Rohan, Wisconsin Department of Health in 2016



## Data Collection: Alaska CUBS Survey

Overall, CUBS continues to identify issues within the Alaskan young children population in a timely manner. Its multiple forms of data access have formed partnerships across the state's health department to tackle and prevent issues pertaining to mothers and children that are not usually defined as a "Maternal and Child Health (MCH)" problem.

Since the 1990's, the MCH Epidemiology Unit of the Section of Women's, Children's, and Family Health at the Alaska Division of Public Health has collected data on women who recently delivered a live birth through the [Alaska Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#). The primary purpose of PRAMS is to improve the health of mothers and infants by reducing infant mortality and low birth weight by collecting data on maternal attitudes and experiences before, during, and after pregnancy. Although PRAMS was successful in providing information about pregnant women and infants, a gap persisted in knowledge about the wellbeing of young children in Alaska. While the MCH Epidemiology Unit had access to data provided by the National Survey of Children's Health, the data was published infrequently, and Alaska's sample size was too small for Alaska epidemiologists to analyze by region. Thus, the [Alaska Childhood Understanding Behaviors Survey \(CUBS\)](#) was developed in 2006 as a follow-up survey to PRAMS to find out more information about the health and early childhood experiences of young children in Alaska.

Alaska PRAMS send surveys to 1 of every 6 mothers of newborns in Alaska, while CUBS sends a follow-up survey three years later to all mothers who completed the PRAMS survey who are still living in Alaska. The team has found that 18-20% of women who respond to PRAMS have left the state by time the child is three years old.

Since the implementation in 2008, CUBS is conducted on an ongoing basis with funding from the federal Title V block grant. To administer the survey, CUBS follows the same protocol as PRAMS. The team first mails the surveys to the mother. If there is no response after two survey mailings, the team will follow up with a phone survey. Prior to the sending out the CUBS pre-letter, extensive research is conducted to verify the mothers' current addresses. The team primarily relies on Alaska's Permanent Fund Dividend Database to retrieve current addresses since it something that every Alaska resident applies for annually. If an address is undeliverable, the team will refer to other state databases (i.e. Medicaid, WIC) for verification. The CUBS program has found this task to be very time-consuming and has had to expand staff time to ensure CUBS sustainability.

Throughout the years, CUBS has consistently collected high quality data about the health status and well-being of Alaskan young children. Since 2008, the annual response rate to CUBS ranges from 48%-65%. Once the data has been collected, the CUBS coordinator publishes topic-specific datasheets on the CUBS website, in addition to sending them via email to MCH stakeholders. The MCH Epidemiology Unit has also published data books focused on CUBS data; these data books are more comprehensive than datasheets since they include narratives along with graphs. In addition, CUBS data is available on the Alaska Department of Health and Social Services' Indicator-Based Information System (AK-IBIS). Anyone can access this searchable tool and examine cross tabulations, which has been particularly helpful for grant writers who need to reference data for specific regions or groups. Furthermore, CUBS data has

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been reported in two peer-reviewed articles, numerous state reports, and presentations at local and national conferences.

The open avenues to access CUBS data have helped with numerous public health efforts in Alaska, such as obesity prevention and child immunization. Since the initiation of CUBS, a member from the Alaska Obesity Prevention and Control Program (AOPCP) has been on the CUBS steering committee. This member has helped design specific questions about the child's height, weight, and food and drink consumption. Responses to these questions has helped AOPCP inform its stakeholders on the current state of childhood obesity in Alaska and inform programmatic decisions. In addition to this, CUBS data has been highly beneficial in understanding Alaska's childhood immunization rate. A few years ago, data from the National Immunization Survey revealed that the overall prevalence of young children who received the full immunization schedule was declining. Since CUBS is completely under state control, the CUBS team had the freedom to include questions about the reasons for vaccine hesitancy and, to later analyze the response by region. Moreover, CUBS data has been used to advocate for funding for asthma prevention and to inform a needs assessment examining school readiness among Alaska Native children in Anchorage.



Submitted by: Margaret Young, Alaska Division of Public Health in 2016



## Data Analysis: Mississippi PRAMS & Breastfeeding

For the past decade, Mississippi's prevalence for breastfeeding initiation and breastfeeding continuation for six months have remained lower than the Healthy People 2020 target (81.9%, and 60.6% respectively). This comparison prompted the MSDH to conduct a study to analyze trends in breastfeeding using data from the Mississippi Pregnancy Risk Assessment Monitoring System (PRAMS). Prior research had indicated that infant care practices such as breastfeeding are key factors in promoting infant health and preventing infant mortality. Since little information was known about breastfeeding in Mississippi, MSDH decided to analyze the following two questions from the PRAMS questionnaire between 2003-2011: "Did you ever breastfeed or pump breast milk to feed your new baby after delivery, even for a short period of time?" and "How many weeks or months did you breastfeed or pump milk to feed your baby?"

In 2015, Mississippi received [funding](#) from AMCHP to conduct a return of investment study on breastfeeding. This project encouraged MS PRAMS team to focus on breastfeeding more and assess breastfeeding initiation, continuation and exclusive breastfeeding, and, also, identify their barriers or promoting factors. Shortly after this project, MSDH started another project assessing exclusive breastfeeding in collaboration with AMCHP to promote data translation in MCH area. This project was not funded by AMCHP; however, we received technical assistance and training for data translation. Using what MSDH learned from these two projects, the MS PRAMS team began preparing data products focusing on the Mississippi's top MCH indicators such as breastfeeding and infant safe sleep.

MSDH analyzed PRAMS data from 2003-2011 with a large sample size (n=9,131). Within the study, the outcome variables included self-reported breastfeeding initiation and self-reported infant safe sleep position. To estimate the prevalence of breastfeeding and safe sleep position, MSDH used a combination of descriptive statistics and chi-square tests. To identify factors associated with breastfeeding, MSDH used logistic regression. The team compared results based on array of factors, such as race, education attainment, and unintended/intended pregnancy. SAS 9.4 survey procedures were used to account for the complex sample design and unequal selection probabilities.

MSDH found that although the average percent of breastfeeding initiation among Mississippi women was 51.2%, there was a large discrepancy within different factors such as race, age, marital status, and educational attainment. For example, the breastfeeding initiation percentage was highest among white mothers, those who aged 30 years and older, and those who had above a high school education, and married woman. Between 2003-2011, the proportion of breastfeeding initiation was constant and did not have any significant variations. For the safe sleep analysis, it was found that between 2003-2011, the percentage of infants placed in the supine position significantly increased from 64.5% to 62.7%. This trend was also seen within all subgroups.

MSDH encountered certain pitfalls other state departments should be aware if replicating a similar study. For example, calculating breastfeeding continuation using PRAMS was challenging for team due to the timeline of the PRAMS survey. Since PRAMS mothers are only eligible to answer the questionnaire as early as two months after birth, calculating the breastfeeding continuation percentage at three months was too early. In addition, many of

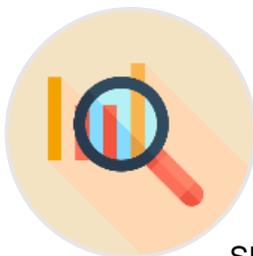
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mothers will have turned in their questionnaires before month three or six. To overcome this, MSDH decided to calculate breastfeeding continuation with a timing for at least eight weeks for the second question. Another limitation of the study was that at the time of the 2003-2011 Mississippi PRAMS, there were no questions that asked why the mother had discontinued breastfeeding (i.e. lack of milk). Thus, the study was unable to highlight such reasoning in the study. However, this has been corrected in phase seven version of the Mississippi PRAMS by including questions focused on breastfeeding discontinuation.

Overall, this study was successful in highlighting the need for interventions focused on certain subgroups to increase both breastfeeding continuation and initiation across the state. Thus far, results from this study have been shared throughout other Mississippi State Department of Health (MSDH) programs such as Family Planning and Women, Infants, and Children (WIC). Furthermore, the analysis has been used to inform the Health & Resources Services Administration (HRSA) of the work being done to address National Performance 4: Breastfeeding in Mississippi for the state's Title V block grant application.



Submitted by: Mina Qobadi, Mississippi State Department of Health in 2016



## Data Analysis: Massachusetts PRAMS & Race/Ethnicity

Overall, this analysis revealed the disparities within Massachusetts' declining SUID rate. Moving forward, the state's safe sleep educational programs may need to include country- and culture-specific materials to effectively promote safe sleep practices, helping to reduce the disparity in SUID rates. In addition, some interventions will need to be targeted to the groups / communities with the lowest prevalence of supine sleep---particularly among Dominican, Salvadoran and Puerto Rican mothers.

Sudden Unexpected Infant Death (SUID) is the leading cause of deaths within Massachusetts infants aged 1-11 months. From the 2009-2013 [Massachusetts Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#), it appears that state's SUID rate has been steadily decreasing. However, the Massachusetts State Department of Health (MSDH) found that non-Hispanic black and Hispanic mothers reported lower prevalence of supine sleep compared with non-Hispanic white mothers. This is important since it has been reported that placing infants on their back to sleep can reduce the incidence of SUID. This has prompted the Bureau of Family Health and Nutrition to place safe sleep as one of the top priorities for the state's Collaborative Improvement & Innovation Networks (CoIINs). When the Injury Prevention and Control Program (IPCP) received a CDC grant to initiate a safe sleep campaign, the program contacted the Bureau of Family Health and Nutrition within the Massachusetts Department of Public Health (MDPH) for a possible partnership. In exchange for data support, IPCP would financially support MDPH's efforts for the campaign. Currently, the campaign is being funded with a grant from the Perinatal Quality Collaborative from the CDC's Division of Reproductive Health.

The primary objective of this safe sleep study was to determine if there are ethnic subgroup variations in the frequency of infant supine sleep position among Massachusetts mothers identifying as non-Hispanic Black and Hispanic who had a recent birth. To answer this, the bureau linked data from 2007-2013 MA PRAMS and birth certificates that were hospital-specific (n=9,762). Only data from PRAMS regarding the infant sleep position and maternal characteristics were analyzed. The following conditions were excluded from the analysis: infant died, infant not with mother, no race/ethnic data for mother, and no sleep position data. To avoid the risk of small or insignificant sample sizes, the bureau oversampled by race/ethnicity and the CDC weights the responses for population and non-response rates. Since safe sleep is not just one component, the group measured each component of safe sleep (i.e. clean crib, baby in supine position, presence of fluffy blanket).

The analysis process was conducted in four phases. First, the bureau collected information about safe sleep practices from different hospitals until May 2016, when they had ten hospitals reporting safe sleep practices. The second phase consisted of collecting the percentage of infants audited for safe sleep practices. This information was collected each month as part of the hospitals' quality improvement project. Next, the bureau looked at each hospital's safe sleep compliance (i.e. sleep position, presence of a fluffy blanket) over time by each month. The final phase entailed observing total compliance to safe sleep measures and monthly comparisons.

Once all the data was collected, the team used multivariate logistic regression in SAS to examine the adjusted relative risk of infant supine sleeping among the ethnic subcategories, while also controlling for maternal education, age, nativity, and marital status. The team

conducted a separate analysis for Hispanic and Non-Hispanic black women first. Then within the model, each ethnic subgroup was treated as an independent variable. Mothers who identified as non-Hispanic black (n=1,718) [Cape Verdean, Haitian, Caribbean Islander, Ghanaian, Nigerian, Ugandan, Kenyan, Somali, Ethiopian or other non-Hispanic black (mothers without further self-identification)] or Hispanic (n=1,940) [Puerto Rican, Dominican, Salvadoran, Guatemalan, Mexican, Honduran, Colombian, Cuban or other Hispanic] were included. One of the challenges the bureau encountered was the change in birth certificate coding of the ethnicity variable in 2011. Some of the finite subgrouping was not available early on, which caused a loss of power for some subgroups. This also caused certain subgroups to be omitted or combined into the “Other” category. However, the team tried not to collapse the subgroups due to the significant cultural variations.

The analysis revealed significant differences in infant supine sleep position within the ethnic groups. Among Hispanic subgroups, the prevalence of supine sleep ranged from 46.65% for Dominican mothers (95%CI: 41.8-51.4) to 77.7% for Mexican mothers (95% CI: 68.3-84.9). Among non-Hispanic black mothers, infant supine sleep position ranged from 56.9% (95% CI: 51.1—62.5%) for Haitian mothers to 80.54% (95% CI: 61.1—91.6) for Ethiopian mothers. Compared with other non-Hispanic black mothers (n=1,035), Haitians were significantly less likely to place their infant supine [aRR=0.81(95% CI: 0.68—0.96)], while Ethiopians were more likely to place their infant supine [aRR=1.36 (95% CI: 1.04—1.77)]. For the Hispanic mothers (n=1,035), Dominicans were significantly less likely to place their infant supine [aRR=0.69 (95% CI: 0.59—0.82)], while Cubans were more likely to place their infant supine [aRR=1.31 (95% CI: 1.00-1.70)].

One limitation to note with using PRAMS data is selection bias since it only includes mothers reachable by mail or phone for survey administration. Despite the significant findings on ethnic subgroup variation for sleep practices, the Bureau encountered certain pitfalls other state departments should be aware of if replicating a similar study. For example, the eligible infant population was specific to preterm births. Each hospital had a different requirement for the gestational age on which preterm infant can be placed in the supine position. Some hospitals said at least 32 weeks while others said 34 or 35 weeks. Thus, other states should consider defining the eligible age of the population earlier on to make the data more consistent. Another challenge was reaching a consensus with hospitals to receive data for the study. Initially, many hospitals feared that other hospitals would have access to data from their patient population. To overcome this, the bureau created a protocol to allow each hospital to participate under the regulation that data is only being collected for quality improvement purposes and, will not be shared with other hospitals.

Data from this study has driven a multitude of programs and new partnerships centered around safe sleep within Massachusetts. For example, there has been an increase in education around safe sleep, both in communities and hospital staff, and home visitation programs. Furthermore, the bureau is developing a statewide safe sleep protocol that can be modeled in all participating hospitals. In addition, this study has brought together non-traditional partners. Prior when MDPH approached clinicians about safe sleep, many considered it as a public health issue and not a

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clinical issue. By using the results from this study, MDPH has been able to build clinical partnerships at a level that was not done before and, took a public health issue and made it into a quality improvement project in the hospital.

Submitted by: Sarah Stone, Massachusetts State Department of Public Health in 2016





## Data Communication: Hands & Voices GBYS Program

Hands & Voices is a non-profit, parent-driven organization committed to supporting families who are raising children who are deaf or hard of hearing (D/HH). Within all its efforts, the organization remains non-biased about the communication modes or methodologies, as they believe that families can make the best choices for their child if they have access to good information and support. As an organization operated by Family Leaders, Hand & Voices has used data to not only communicate the stories of many of its members but also, to finetune the development of many of its programs to the needs of the target population.

Unlike many of its partners, Hands & Voices does not fall under the Title V block grant and therefore, receives most of its funding from HRSA or private organizations. The grant director often uses outside data sources (i.e. CDC, Census, peer-reviewed journals articles from the American Academy of Pediatrics) to communicate stories of families with D/HH children. Often, these family members have very compelling stories thus, when speaking to potential funders, data and statistics strengthen these narratives to show that their story is not a singular experience but rather part of a larger scale issue. Apart from these outside sources, Hands & Voices has utilized an internal source of data collection to communicate programmatic goals to each of their chapters.

[Guide By Your Side \(GBYS\)](#) is a parent-matching program, implemented in 21 H&V Chapters that gives unbiased support to families with children who are D/HH. The program matches an experienced trained parent or D/HH adult, known as “guides”, to a newly diagnosed family. Each year, the program disseminates a health assessment questionnaire to Chapter Board of Directors, who oversees the GBYS program. Once the questionnaires are completed, Hand & Voices’ Director of Programs compiles the responses into a format that helps each GBYS program develop goals based on the responses. For example, if one of the responses revealed that many thought there was a lack of diversity of life experience among the guides, the Director of Programs would communicate back this information and recommend that the GBYS program incorporate “increase diversity within the guides” as one of their annual goals. Although each GBYS program has the authority to choose their own goals, the Director of Programs follows up with each program annually to track their progress. Overall, this method of data collection and communication has helped Hands & Voices to increase leadership within the organization and support the organization’s quality improvement process for its intended population.

Although data has been useful in many of Hand & Voices’ programming, the organization has encountered certain barriers when working with data. One of the primary barriers is the consistent battling of information presented from different studies. There has been a myriad of articles that favor one mode of communication for D/HH children versus the other, rather than being inclusive of various modes. This has caused hindrances in conversations between Hands & Voices and some of its stakeholders about using data to display certain outcomes for D/HH children. Hands & Voices has overcome this by taking an objective approach, especially when writing grants, by utilizing data that is not solely based on one mode or methodology but instead, by presenting outcomes of all D/HH children regardless of the communication mode they use. For example, data that highlights language access or the incidence of children born D/HH has been helpful in encompassing families using different communication methodologies.

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In conclusion, Hands & Voices strives to use data when communicating to its stakeholders, in a way that does not exclude the health or social outcomes of D/HH children who use different modes of communication. This method has been successful for the organization as it recently established a cooperative agreement with the Health Resources and Services Administration (HRSA) for a three-year Family Leadership in Language and Learning program. Moving forward, Hand & Voices believes that Family Leaders need assistance from other non-profit organizations to have both a firm understanding of where data is located and solid training on how to use data. A possible solution could be a partnership between epidemiologists and Family Leaders to create narratives based on Family Leaders' experiences that is backed up by data. Hopefully, this would give life to the data and build empathy within both parties' target audiences.



Submitted by: Molly Martze, Hands & Voices in 2016



## Data Communication: Louisiana BFH Presentation

Louisiana's Title V program through the Office of Public Health (OPH) - Bureau of Family Health (BFH) received technical assistance from AMCHP in 2015-2016 to create a communication product around one of the new national maternal and child health (MCH) life course metric indicators. As a result of the technical assistance, BFH created a presentation with the goals to both raise awareness of life course within the Louisiana Department of Health (LDH) and to introduce the concept of the place-based indicator, concentrated disadvantage, while highlighting Louisiana MCH data. BFH initially wanted to develop an issue brief on concentrated disadvantage in Louisiana, but chose instead to develop a presentation for their colleagues in LDH, to make sure those in leadership were knowledgeable and prepared to discuss life course and concentrated disadvantage before these concepts were communicated to outside audiences such as policymakers and funders.

The presentation used life course metric as a framework to discuss why place matters to health and to introduce the audience to concentrated disadvantage as a place-based health indicator. [Concentrated disadvantage \(CD\)](#) is a measure designed to go beyond measuring poverty or socioeconomic position. It captures the synergistic effects of economic and social factors that cluster geographically to create disadvantaged neighborhoods. This indicator is calculated from five census tract variables related to income, household structure, employment, poverty, and age to create a numerical index that represents the economic strength of a community. Concentrated disadvantage is relevant to the life course because neighborhoods with a high concentrated disadvantage index (low economic strength) experience an impact on the health trajectories of residents in ways that go beyond simple biology. They also feel the impact through social determinants of health such as reduced access to services, employment opportunities, safe neighborhoods, and nutritious foods. Living in areas of high concentrated disadvantage is linked with multiple outcomes that impact health, including verbal ability in children, high school graduation rates, teen pregnancy, overall health, risk taking behaviors, and life expectancy.

To communicate their message that it is important to support and engage with residents living in communities of high concentrated disadvantage to improve MCH outcomes, BFH used a combination of a life course framework, storytelling, targeted audience messaging, and continuous review and revisions to their presentation based on audience and partner feedback. The development of the presentation was funded from the AMCHP Technical Assistance.

BFH chose to start their presentation by introducing the life course framework using low-jargon definitions and visualizations. A clear explanation of life course allows the presenter to use that framework to discuss health equity and why where you live matters to your health at any age. The presentation did not discuss concentrated disadvantage data by simply listing census tracts and index numbers; rather the data was framed by telling the story of two infants, born at the same hospital and living only a few blocks away from one another. Through no fault of either infant, one lives in an area of low concentrated disadvantage, while the other lives in an area of high concentrated disadvantage. The story incorporates data on the comparative risk of life long MCH health outcomes for each baby and other babies living in Louisiana, and how the risk of those outcomes differ based on where they live. The presentation also includes quotes gathered

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during Louisiana's Title V needs assessment process from real women living in areas of high concentrated disadvantage about their economic struggles and trying to take care of their family's health. Presenters discussed ongoing successes for BFH in providing support to disadvantaged communities and, as a "call-to-action," what LDH could do additionally to reduce the effects of living in areas of high concentrated disadvantage and strengthen environments in which Louisiana children grow. The presentation's "call-to-action" included addressing concentrated disadvantage in funding and policy decisions, engaging with non-traditional partners, and sharing the information presented with partners.

BFH sought constructive feedback from several groups in the course of developing the communications product. Key contributors included the People's Institute for Survival and Beyond (PISAB) as well as audiences within LDH. PISAB recommended including historical drivers of inequity in the presentation and including images depicting a diverse variety of individuals in the slides. Internal LDH test audiences found some wording was polarizing, such as "female-headed households," a variable in the concentrated disadvantage index. This feedback prompted edits to wording on slides around the variables used to calculate the index, to avoid potential negative reactions or placing blame on the people in these communities.

The presentation was given over 20 times in 2016 to community groups, public health colleagues, BFH contractors, city council members, and students at Tulane University. The slides and script are regularly reviewed to ensure the content remains current and effective based on continuous feedback from audiences. A success stemming from this work came in 2016 when material from this presentation helped BFH secure a grant from the Robert Wood Johnson Foundation to work packaging social determinants of health and concentrated disadvantage data in communication materials for conversations about community, economics, and health with large employers in Louisiana. This work is currently ongoing but is an example of the "call-to-action" at the end of the presentation coming to fruition within LDH.

Moving forward, BFH hopes to create different versions of the presentation (especially a shorter 5-15-minute version) so it can reach more audience. They face the challenge of keeping up with the data as new data consistently comes in. Currently, the teams have new MCH indicators they can run in the areas of high CD however, since the CD data are based on the census, that will not change for another few years, but MCH should still be included. Another challenge the team has faced is looking at life expectancy and other health issues across the life course at this level; BRFSS does not go down to the census tract level. This makes it difficult to assess the risk for chronic diseases as easily as we can the MCH outcomes. The story of the babies needs to translate to the adults those babies will become. BFH hopes that individuals will stop blaming adults for their health circumstances and be willing to fund initiatives that could make a difference in areas that are not covered within OPH (i.e. housing, childcare availability, transportation, neighborhood development, etc.).

Submitted by: Rebecca Majdoch, Louisiana Department of Health in 2016





## Data Communication: Nebraska DHHS Brochure

The “Building a Healthy Community” brochure was designed as a resource for conversations about how a neighborhood can impact the health of its residents and how community partnerships can address concentrated disadvantage in their community. The brochure focused on concentrated disadvantage as it captures the synergistic effects of economic and social factors that cluster geographically.

Prior research has identified high concentrated disadvantage areas as being associated with high rates of high school dropout, teen pregnancy, infant mortality rate, and adolescent delinquency, and decreased overall health. Concentrated disadvantage was calculated using five variables from the 2009-2013 American Community Survey for all census tracts in Nebraska (5 tracts were removed because they did not include households) including the percent of individuals living below the poverty line, the percent of individuals receiving public assistance, the percent of families that are female-headed households, the percent of adults unemployed, and the percent of the population that is under the age of 18. Standardized z-scores were calculated for each census tract by variable and then summed for each census tract to create a tract-specific concentrated disadvantage score. The range of scores was split into low, medium low, medium high, and high quartiles. These quartiles were then mapped using geographic information system (GIS) software.

To understand how concentrated disadvantage was related to an individual’s health Nebraska Department of Health and Human Services explored its relationship with the teen birth rate. NEHHS assigned each teen birth that occurred from 2009-2013 a concentrated disadvantage score based on where the mother lived when she gave birth and then, calculated the teen birth rate in each of the four quartiles. With that data, NEHHS developed a four page, consumer-oriented brochure and an interactive PDF counterpart.

The group that developed the “Building a Healthy Community” brochure began working on the project in September 2014 after being selected to participate in AMCHP’s life course indicators technical assistance project. The group was comprised of mostly NE DHHS staff but included three community partners. NEHHS met roughly twice a month and often had subgroups meet to help fine tune parts of our project. Subgroups focused on topics like data, deciding who the audience was, and identifying the best way to communicate the data to the audience. Within AMCHP’s technical assistance project Nebraska was one of the first states to calculate and use concentrated disadvantage as a robust measure of the health of a community. Discussions within the technical assistance project enhanced understanding of concentrated disadvantage and our excitement about mapping it in Nebraska. The “Building a Healthy Community” brochure was given final approval in July 2016. Prior to final approval NDDHHS was able to pilot its use within the state and revise their brochure after receiving feedback from four target organizations that serve communities impacted by high concentrated disadvantage.

Concentrated disadvantage is a very academic term and rarely used in public health work. One of our main challenges in the development of the “Building a Healthy Community” brochure was figuring out how to communicate the information about concentrated disadvantage without losing the interest or understanding of our audience. NEHHS attempted to overcome this with the use of graphics that supported and built on the text of the brochure. They explained how a

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neighborhood could impact health using tips and language from “A New Way to Talk About the Social Determinants of Health” from the Robert Wood Johnson Foundation (2010). To increase the utility of the brochure for our communities, NEHHS included a fillable insert so that communities could note local partners to approach for collaboration.

After the “Building a Healthy Community” brochure was finalized, NEHHS posted it online and mailed it out to all local health departments, federally qualified health centers, and community action agencies in Nebraska. Included with the “Building a Healthy Community” brochure was a cover letter introducing them to the brochure, explaining its development, and encouraging them to review the brochure and use it within their communities. To date, NEHHS has received positive feedback about the brochure and one local health department has requested larger maps of their service area (which were provided) and commented that the maps have already been useful in presentations with local businesses and program staff. The local health department director said, “It is a GREAT tool when talking with business partners and community leaders who often do not SEE poverty in their area!”

Submitted by: Jessica Seberger, Nebraska Department of Health and Human Services in 2016





## Data to Policy: Delaware State Infant Mortality Collaborative Impacts

Between 2004-2006, the Centers for Disease Control and Prevention (CDC), the Association of Maternal & Child Health Programs (AMCHP), and the National March of Dimes partnered on a multiyear project that supported five multidisciplinary state teams interested and able to address their high rates of infant mortality. [The State Infant Mortality Collaborative \(SIMC\)](#) was established in response to the 2002 increase in the infant mortality rate (IMR), as well as persistent racial and ethnic disparities in infant mortality rates. The five state teams that participated in the SIMC – Delaware, Hawaii, Louisiana, Missouri and North Carolina – were selected based on their increasing, stagnant or high infant mortality rates. The membership of each team was comprised of key stakeholders and included the Title V MCH director or designee, scientists and maternal and child health (MCH) epidemiologists or other scientific representative, policy/program decision makers, and community partners. The project focused on the practical application of MCH epidemiology to discern the underlying factors responsible for high rates of infant death and to identify opportunities for intervention. The goal of the SIMC was to assist state public health agencies in investigating their increasing, persistent or high infant mortality rates. With many states experiencing increases for several years, this collaborative also brought national experts together to work with the teams.

For two years, the different state teams explored probable reasons behind the current infant mortality trends. Each state worked alongside national experts to develop tools and resources that were eventually compiled into the [State Infant Mortality \(SIM\) Toolkit](#). Within the toolkit, SIMC identified the following three domains/pathways a state could follow to determine the contributing factors to infant death: data reporting, cause and timing of infant death, and maturity and weight at birth/maturity and birth weight-specific mortality. By starting with data reporting, a state team could determine if inconsistencies within data reporting significantly contributed to the state's IMR prior to analyzing other causes. If this was the case, then the state could take the necessary action to correct the inconsistency.

Delaware was one of the states that developed new hospital policies due to their participation in SIMC and the SIM Toolkit. Beginning with data from 1990's, the state's SIMC team found inconsistent data reporting on the IMR. By examining quality, completeness, and timeliness of the hospital records, the SIMC team could clarify definitions and reporting requirements for fetal death, which improved communication among the hospital staff. Further issues identified through participation in the SIMC, such as the misclassification of infant and fetal deaths, revealed that the state's live-born infants were higher than what was previously reported between 1993-2002. In conclusion, Delaware's participation in SIMC allowed the state to continue efforts in improving quality control of infant death reporting and changing hospital protocol, including flagging records with missing or unknown birth weight and, flagging records of infants weighing less than 750g for follow up to confirm live birth at the time of reporting. Data resulting from SIMC caused the Delaware Division of Public Health to report infant death data to the public online through statistical micro-reports. This has been utilized by public health partners for their own reports and analyses to support both new programs and policy development.

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Overall, the SIM Toolkit provides a standardized method to examine both increasing and static infant mortality rates that could be replicable in other states to allow for comparison. By deciphering between misclassifications and new causes of infant mortality, the SIM Toolkit stands as a resource other states can use to analyze IMR trends.

As a result of participating in the SIMC, four of the five states initiated new projects, while three states reported changes in legislation requiring Level III hospitals to provide neonatal obstetric care. The collaborative process resulted in immediate benefits in participating states, such as justifying expansion of analytic resources, strengthening broad-based partnerships, and highlighting opportunities to implement known best practices. However, the long-term impacts of such collaboratives are rarely explored due to funding and capacity limitations for certain states.



Submitted by: Caroline Stampfel, Association of Maternal and Child Health Programs in 2016



## Data-informed Policy: Florida PQC on Hemorrhaging

In 2010, The Florida Perinatal Quality Collaborative (FPQC) was founded by William M. Sappenfield, MD, MPH and John S. Curran, MD with a seed grant from the March of Dimes. Since then, FPQC is fully funded by the state's Title V block grant. The collaborative aims to advance perinatal health care quality and patient safety for all of Florida's mothers and infants through collaboration of all FPQC stakeholders in array of different initiatives. The Obstetric Hemorrhage Initiative is one of many successful initiatives spearheaded by FPQC that has helped combat Florida's increasing pregnancy-related mortality. Data from the Florida's Pregnancy Associated Mortality Review (PAMR) committee revealed that hemorrhage was one of the top three causes of maternal deaths in Florida; it accounted for 15% of deaths between 2005-2009. In order to address this issue, the Florida Department of Health contracted with FPQC to assemble a group of maternal health, public health, and other quality improvement leaders to collaborate on a Maternal Mortality Prevention Initiative. This workgroup agreed that hemorrhage is the state's most preventable mortality issue and should be given the highest priority due to the amount of action that could be easily implemented within hospitals. Thus, the workgroup enacted a multihospital collaborative of 35 hospitals (31 in Florida and 4 in North Carolina) to implement process changes regarding to hemorrhages.

Each hospital was asked to spend 18 months implementing the FPQC's recommended changes and 6 months institutionalizing them within their facilities, starting from July 2013 to April 2015. Since FPQC observed that a strictly education-based approach was not effective in persuading hospitals and physicians to change their practice, they decided to enact a series of actions to help each hospital implement the recommended changes. By using the American Congress of Obstetricians and Gynecologists' (ACOG) parameters under readiness, recognition, and response, FPQC provided each pilot hospital with a range of resources such as technical assistance from an advisory team, an implementation guide, and a hemorrhage management toolkit. To monitor the outcomes of the initiative, the FPQC staff quantified blood loss for vaginal deliveries by recommending the hospital measure blood loss using visual percent saturation, by weight, and by collection in graduated containers. All measurements were added to the patient's OB Hemorrhage Chart. To gain an estimate of the hospitals' progress, each hospital was asked to audit 30 charts per month: 10 cesarean delivery and 20 vaginal delivery charts. The hospital would then send FPQC monthly aggregate reports for data collection and subsequent analysis. By allowing each hospital to have access to their own baseline data, hospitals were more receptive to implement changes to their systems.

At the end of 18 months, FPQC found significant changes in hemorrhage admission protocol among the 35 pilot hospitals. The chart audit indicated that initiative-wide, approximately 79% of women were being assessed for risk of hemorrhage upon admission, up from 14% of women at baseline. In addition, the percent of vaginal deliveries in which blood loss was quantified increased from 4% to approximately 62% for all reporting hospitals. By the end of the initiative, each participating hospital educated 100% of their clinical staff on training and active

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management of the third stage of labor and 71% of their obstetricians/midwives on obstetric hemorrhage.

Overall, FPQC has been influential in encouraging hospitals to change practice to improve health outcomes for mothers and infants. FPQC hopes to inspire other hospitals both within and outside of Florida to make an actionable change within their healthcare system. Thus, all their toolkits, webinars, and other resources are available for public use on the collaborative's [website](#).

Submitted by: William Sappenfield, Florida Perinatal Quality Collaborative in 2016

