## Introduction

Since early 2019, the Iowa Department of Public Health's (IDPH) Bureau of Family Health (BFH) and the Oral Health Center (OHC), along with partners at the University of Iowa Division of Child and Community Health (DCCH) collaborated to conduct the five-year Needs Assessment (NA) for the FFY2021 Title V Maternal and Child Health Block Grant.

#### **Process**

# Goals, Framework, Methodology

The framework of conducting the Needs Assessment was developed based on literature review of methodologies from past Title V NA reviews, Iowa's previous NA process, comments from federal reviewers on previous NAs, and the guidance and resources provided by the Maternal and Child Health Bureau (MCHB) at Health Resources and Services Administration (HRSA).

The 2021 Title V Needs Assessment developed a vision and mission statements to guide the work.

#### Vision:

Families in Iowa are safe, healthy, and connected.

#### **Overall Mission:**

To ensure that mothers, infants, children and youth in Iowa, including children and youth with special health care needs, and their families have access to the resources needed to thrive in their communities.

#### **Health Equity Mission:**

To work to eliminate differences in health among ethnic, racial and other population groups who have low income or have historically had less access, power or privilege.

## **Leadership Team**

The Needs Assessment Leadership team was composed of IDPH Staff, DCCH staff and staff from the University of Kansas Center for Public Partnerships and Research (KU). IDPH staff included Population Domain Leads, Health Equity Advisory Committee Coordinators, Oral Health Leadership, State Title V Director, and Process Facilitator. DCCH staff included a Family Representative from the Family Navigator Network,, the Title V CYSHCN Program Manager and the CYSHCN Title V program coordinator.

# **Health Equity Advisory Committee**

The Health Equity (HE) Advisory Group advised the project overall and assisted with the recruitment of underrepresented populations. Advisory Committee members were recruited utilizing a variety of strategies including internet searches for organizations serving the target population, outreach through

community organizations including known organizations working with priority populations, Title V Agencies and networking through professional and personal relationships. Facilitators were recruited through Health Equity Advisory Committee members. Health Equity Participants were recruited by facilitators, utilizing a variety of strategies including social media, outreach through community organizations (including Title V Agencies), relationships/networking with facilitators and/or Health Equity Advisory Committee members.

#### Stakeholder Involvement

IDPH, DCCH and KU program leadership met to identify stakeholders to provide guidance and input throughout the needs assessment process. A network analysis was conducted by over 30 leaders to identify current stakeholders and needed stakeholders. After conducting the network analysis, an initial list was compiled for the overall for the identification of stakeholders for the 2021 Needs Assessment Work. Leadership teams then conducted a second round of consideration though a health equity lens to broaden the stakeholder base to include nontraditional partners. Stakeholders that were identified included individuals, community organizations, professional organizations, faith based groups, institutions of higher education, philanthropic organizations, advocacy groups, consumers, providers and governmental entities. In addition to stakeholders identified through this workgroup, Title V staff reviewed past needs assessment contributors and crosswalked to insure continuity. Stakeholders were then analyzed and sorted into data collection activities such as focus group and key informant conversation participants and survey respondents.

# **Quantitative and Qualitative Methods**

# **Data Snapshots**

Data Snapshots were created for each of the five population domains. Snapshots contain available data for all National and State Performance Measures. In addition to traditional data sets, disparity data was included if available. Emerging issues that were not currently an NPM or SPM were identified by staff and included in the discussion portion of the documents. The intent for these documents was to be a concise tool that stakeholders could use to discern current landscape and make recommendations for priority selections. Data Snapshots for each population domain can be found at: https://chsciowa.org/chsciowa.org/datasnapshots.

# **Qualitative Data Collection**

The Title V and MIECHV needs assessments have significant overlap in target populations, predominantly in the population domains of women/maternal, infant/perinatal, and child health. Coordinating qualitative data collection efforts for both needs assessments provided rich data from diverse voices enhancing both needs assessments. The Iowa Title V Needs Assessment aimed to collect data from participants in each of 6 Title V regions, participants representing each of the 5 population domains: Women's/Maternal Health, Infant/Perinatal Health, Child Health, Adolescent Health, and Children with Identified Special Health Care Needs, Title V recipients and Title V eligible non-recipients, and participants in each of 8 underrepresented groups: Fathers, People with Disabilities, LGBTQIA+,

Refugees/Immigrants, Native American/Alaskan Native, Asian/Pacific Islander, Hispanic/Latinx, and Black/African American.

Targets for participation were exceeded

Non Participant Input

While Focus Groups and Key Informant Conversations provided insight to the families that received Title V Services, it was important to engage potentially eligible individuals that did not receive services. A paper survey was sent through the mail to over 200 WIC recipients eligible for Title V services, but did not receive or refused Title V services. The paper survey contained the same 5 main questions used in Focus Groups and Key Informant Conversations, collected demographics, and a few questions related to not accessing available services and referrals. Over 30 responses were received.

## **Focus Groups**

In tota, lowa conducted 7 MIECHV and 15 Title V focus groups, 9 Title V interviews, and 25 Key Informant Conversations. The intention was to conduct at least one Key Informant Conversation with each underrepresented population for each population domain. The advantages were that staff could gather targeted information from families and from each population domain to sample. This precision limited our ability to look in-depth to compare across specific underrepresented populations, because each underrepresented population was asked different question sets beyond the general Title V questions. However; this approach allowed underrepresented voices to be incorporated into each of the Title V population domains examined in the Needs Assessment.

## **Key Informant Conversations**

Key informant conversations with 1-5 participants for underrepresented populations

Trained community champions as facilitators; also acted as recruiters

Conducted either in-person or through teleconferencing based participant needs

Conducted in MIECHV counties and other communities of interest to Iowa Title V

Other than spoken English languages:

Spanish, Karen, Tigrinya, Vietnamese, Marshallese and Captioning

## **Participation Summary**

158 focus group/ key informant interviews participants

55 targeted Health Equity Voices (35%)

59% of the sample was urban

41% of the sample was rural

12 counties and the Meskwaki Settlement

## **Stakeholder Survey**

A survey was conducted to seek input about the greatest health needs and challenges for lowa's families, with a focus on the following populations: women/maternal, infants, children, adolescents, and children and youth with special health care needs. A brief video was created to describe the intent and background for the survey. Each population group included a set of questions relating to different national and state priorities. General data about each of the priority areas was embedded into the survey. Consideration of respondents' professional, personal, and community experience was used to answer survey questions. For additional information population groups, a link to a data snapshot was embedded within the survey. Themes for each group were also available by link within the survey about what people from impacted communities have shared through this process.

The survey had one section for each population group: Women/Maternal, Perinatal/Infant, Children, Adolescents, and Children and Youth with Special Health Care Needs. There was an option to answer questions for one or more of these groups. Participants were asked to rank the importance of issues within each population group.

Total Participants 487
Population Group Responses
Women/ Maternal Health 172
Child Health 172
Perinatal/Infant Health 127
Adolescent Health 116
CYSHCN 110

Capacity Assessment Local Capacity IDPH

Leadership from local agencies were brought together to reflect on local capacity to address the identified measures. Measures were narrowed to 3 measures for each population domain. Narrowed measures were identified by being ranked high in both importance and priority in the Stakeholder Survey. Local leaders were asked to discern what the local capacity was to address the narrowed measures and to identify specific activities that could move the needle to address the needs. Participants rotated through Population Domains and participated in discussion and study. There were separate discussion groups for both Rural and Urban agencies for each Population Domain as needs vary. Participants worked through a Solvability and Control Matrix to see where they could make the most local impact. Data Snapshots, Thematic Summaries from Focus Groups/ Key Informant Conversations,

compilations of research informed practices specific to the domain were used to guide discussion. Members of the Health Equity Advisory Committee were on site for consultation during small group work.

#### State Level Capacity

Lead state staff for each Population Domain conducted a similar exercise for their respective domain from a State perspective. In addition to Data Snapshots, Thematic Summaries, and compilations of research informed practice feedback gathered from the Local Capacity Assessment was considered. For each population domain (Infant/Perinatal, Women/Maternal, Child and Adolescent) staff reviewed each priority based on Need and Capacity.

For Need, they identified whether or not there was need for lowa's Title V program to take on work in this measure. Each measure was ranked as either Low, Medium or High.

Low Need: Another bureau or program within IDPH or state agency is addressing the issue, Title V is already a partner or could be a partner in the work, but don't see Title V as the leader in the work. Medium Need: There is work happening in the state, but not a clear leader. Title V could take on the leadership role, but may be better for others to.

High Need: There is no coordination of the work in the state, or lacks clear vision of the work. Title V is positioned to be the convener/leader of the work.

For Capacity, the group identified the capacity of Iowa's Title V program to move the needle on the NPM, SPM or emerging issue. The group discussed strategies the state Title V program could perform and ranked them in capacity of Low, Medium, or High.

Low Capacity: Iowa's Title V program could not identify strategies to address the priority. Medium Capacity: Iowa's Title V program identified a small number or weak strategies to address the priority.

High Capacity: There were multiple evidence-based strategies the state Title V program could identify to address the priority.

#### **Data Sources**

Data from national surveys, such as the National Survey of Children's Health and state-level data, including the Behavioral Risk Factor Surveillance System, as well as internal data sources such as Iowa's Vital Records, the Barriers to Prenatal Care Survey, and the state's MCH data systems, were reviewed.

## **Finalization of Needs and Development of Action Plan**

State Title V staff reviewed the results of the prioritization survey and identified top priority needs for lowa. The team then selected 6 of 15 MCHB defined NPMs. The team examined the results and the data to address any unmet needs this has resulted in the development of 7 SPMs. Population domain leadership then worked with the subject matter experts within the department to develop the state action plan.

# **MCH Population Findings**

# **Maternal Health (MH)**

The health of women of childbearing age and access to consistent medical care continues to be a problem in Iowa. The rate of women receiving preventive medical care has decreased from 71.2% in

2013 to 67% in 2017. This decline may be attributed to changes in screening recommendations for breast exams and pap smears. Additionally, it was reported that nearly one-third of pregnancies in lowa were unplanned in 2017. With this information in mind, it it is important to note the racial disparity between mothers who identify as Non-Hispanic Black seek 1st trimester prenatal care at a substantially lower rate (64.6%) than mothers who identify as Non-Hispanic White (77.2%) who received medicaid benefits during pregnancy. This same disparity holds true for preventive dental care during pregnancy in women who receive Medicaid benefits during pregnancy. Mothers who identify as Non-Hispanic Black, had a dental visit in pregnancy at a significantly lower rate (41%) than mothers who identify as Non-Hispanic White (58.5%). Another impactful health concern among women of reproductive age to note is the significantly higher rate of maternal smoking during pregnancy who received Medicaid benefits during pregnancy (24.3%) and the rates among women who have different payer sources; 4.3% for women with private insurance, 6.2% for women with other public health insurance and 5.1% for women who are uninsured.

Comprehensively, the racial and ethnic disparities in accessing care and health outcomes are significant in all areas identified. Iowa's maternal mortality rate rose by 55% from 14.7 deaths per 100,000 live births in 2007 to 22.8 in 2015. Nationally, women who identify as Non-Hispanic Black are roughly 4 times more likely to die from pregnancy related causes than women in all other categories. Data gathered from interviews and surveys obtained during the 2019 needs assessment, reflected the national data. Interviews and surveys revealed barriers to obtaining care including language barriers (including difficulty scheduling appointments), other communication issues such as building trust, feeling judgement because of number and spacing of children as well as problems with insurance and payment.

According to Iowa vital statistics data in 2018, 11.6% of newborns in Iowa were born to mothers who smoked cigarettes compared to 6.5% nationally. These newborns were 1.7 times more likely to be low birth weight (<2500 g) and 34% more likely to be born preterm (<37 weeks).

Three performance measures were selected for the Maternal/Women population domain:

- National Performance Measure 13-A: Percent of women who had a preventive dental visit during pregnancy
- National Performance Measure 14-A: Percent of women who smoke during pregnancy
- State Performance Measure 1: The number of pregnancy-related deaths for every 100,000 live births

These performance measures were selected by IDPH MCAH program staff and incorporated quantitative and qualitative data as well as an assessment of state and local capacity to impact each measure.

NPM 13-A was selected in response to Iowa's continued need of dental services for women and pregnant women in the state. This priority need was not included in the stakeholder survey due to the current high need for oral health services/lack of access/etc.

NPM 14-A was selected in response to a much higher rate of maternal smoking (11.6%) compared to the national rate (6.5%). Maternal smoking was ranked highly both as a top priority (58%) and as extremely important (84%) by respondents to the stakeholder survey. During the capacity assessment conducted in October of 2019, local agencies indicated they have high capacity to address maternal smoking, and state-level capacity to address this need is high as well.

The development of SPM 1 is strongly supported by Iowa's maternal mortality rates and maternal morbidity rates outlined above. Additionally, it was ranked highest in terms of priority (77%) and importance (93%) by survey respondents, and state and local capacity to address factors that impact maternal mortality and morbidity is very high.

## **Programmatic Approaches**

### Efforts to be Continued

Local Title V agencies continue to link pregnant women to a medical home for obstetrical care, promoting access to health insurance for women following the postpartum period, and providing postpartum follow up support to low income women.

Oral health care is integrated into Title V program activities throughout the state. Iowa's Title V funded agencies are able to provide oral health services to clients, including establishing a dental home for women.

## Areas of Opportunity for New Activities

The IDPH maternal health team recognizes the barriers and increasing health disparities reported in both the data and the needs assessment surveys and interviews and strives to work with Title V agencies across the state to meet the needs of Iowa's women. Collaborative work with child health and oral health are planned to address program-wide health equity needs.

Planned activities specifically for reducing maternal smoking rates, for this project period include providing motivational interviewing training to all Title V direct service providers, and ensuring women receiving enhanced health education from a local Title V MH agency receive education to specifically address tobacco cessation.

New activities to address maternal mortality include state-level initiatives in collaboration with the HRSA Maternal Health Innovation grant program, and local work through Title V MH agencies. State-level initiatives will include developing an Iowa Maternal Quality Care Collaborative (IMQCC), utilizing the Centers for Disease Control and Prevention Levels of Maternal Care Assessment Tool (LOCATe) to verify neonatal and maternal hospital levels, and participation in Iowa's annual Maternal Mortality Review Committee (MMRC). Local work to address maternal mortality will include ensuring Title V MH staff receive training on health equity. Agencies providing direct services must provide individualized health education specific to recommendations from the MMRC and ensure postpartum follow up for all clients.

## **Infant and Perinatal Health**

The areas of breastfeeding initiation and continuation through 6 months of life, the importance of safe sleep environments, and access to appropriate care for infants born preterm continue to top the list of important health factors for infants in Iowa. Breastfeeding, or feeding of breast milk to infants is one of the most important things a mother can do to provide lifelong health benefits to her child. Overall, women in Iowa have increased rates of ever having breastfed their infant. There have been some fluctuations, from 2011 (82.1%) to 2015 (81.5%) with a high in 2012 of (83.4%). The rates of women who breastfeed exclusively for the first 6 months of their child's life has increased greatly from 2011 (20.1%) to 2015 (29.5%). Unfortunately, women who receive Medicaid benefits report breastfeeding in the hospital at lower rates (72.6%), than women with private insurance (88%). Additionally, a racial disparity in breastfeeding rates is also present. Women who identify as Non-Hispanic Black breastfed in the

hospital at a rate of 66.8% while women who identify as Non-Hispanic White, Hispanic and Non-Hispanic other breastfeed at rates of 82.8% to 83.1%.

Safe sleep environments have continued to have impacts on the rates of infant mortality and infant health. The now long standing recommendations to have infants sleep on their back, on a safe sleep surface have decreased infant mortality over the past 3 decades. Unfortunately, in 2016, 43 infant deaths were related to an unsafe sleep environment. Racial disparities exist among how infants are placed to sleep. Infants who are Non-Hispanic Black are placed to sleep on their backs at a rate of 69.8% while Non-Hispanic White infants are put to sleep on their backs at a rate of 89.3%, with Hispanic infants being placed to sleep on their backs at a rate of 83%.

The ability for very low birth weight infants to deliver in facilities with a Neonatal Intensive Care Unit has a high impact on infant and perinatal health. Infants born at less than 1,500 grams have a very high death rate and can be prevented if an infant is born in a facility with a NICU. Iowa has established a perinatal regionalized system of care that could have influenced the now increased rate of VLBW infants (2017, 85.3%) delivering in the most supportive settings.

Two performance measures were selected for the Infant/Perinatal population domain:

- National Performance Measure 4:
  - a. Percent of infants who are ever breastfed
  - b. Percent of infants breastfed exclusively through 6 months
- National Performance Measure 5:
  - a. Percent of infants placed to sleep on their backs
  - b. Percent of infants placed to sleep on a separate approved sleep surface
  - c. Percent of infants placed to sleep without soft objects or loose bedding

These performance measures were selected by IDPH MCAH program staff and incorporated quantitative and qualitative data as well as an assessment of state and local capacity to impact each measure.

NPM 4 was selected in response to the slight decrease in breastfeeding initiation from 2014 to 2015, and low rates of exclusive breastfeeding for six months (29.5%). Local Title V MH agencies are well-positioned to address both breastfeeding initiation and duration through individualized health education and infrastructure building activities such as educating local employers on breastfeeding laws and the benefits of supporting breastfeeding mothers who return to work. MH agencies have strong relationships with local WIC programs, birthing hospitals, and lactation consultants in their communities.

Promoting a safe sleep environment was one of the highest ranked topics in the stakeholder survey in terms of priority (90%) and importance (93%). Given the number of infant deaths reported in 2016 that were due to unsafe sleep situations and the statewide and local capacity to address these issues, NPM 5 A, B, and C were selected.

#### **Programmatic Approaches**

## Efforts to be Continued

Local efforts to support and educate women on the benefits of breastfeeding and developing referral processes with local lactation consultants. Local MH agencies will continue to have the opportunity to provide lactation classes for clients as well. IDPH staff will continue participation in the lowa Breastfeeding Coalition and maintain a strong relationship with the IDPH WIC program by promoting the

recently developed infographic about breastfeeding in the workplace and identifying opportunities for collaboration.

State-level efforts to promote safe sleep environments will include continuing the contract with the lowa SIDS Foundation for SIDS prevention and support for families who have experienced SIDS and participation in the child death review team. Local MH agencies currently provide education on safe sleep to clients. MH agencies who provide postpartum home visits have the opportunity to view the infant's sleep environment and provide individualized and culturally competent feedback to the client.

### Areas of Opportunity for New Activities

The IDPH maternal health team recognizes the barriers and educational needs to continue to help improve the health of Iowa's youngest citizens. IDPH will work with Title V agencies across the state to implement educational efforts and create community connections to support the health of everyone.

New efforts to increase the percentage of infants exclusively breastfed through 6 months include stronger requirements for local MH agencies to work with hospital lactation consultants, local breastfeeding coalitions and local workplaces to create educated, supportive communities for breastfeeding moms, increased expectations for MH agencies to work with local WIC peer counselors and lactation consults, if available, to provide as much breastfeeding support as possible to mothers they work with. MH agencies will provide a list of local breastfeeding support resources to any new or expecting mothers in addition to breastfeeding educational materials and WIC breast pump policies.

Efforts to increase the percentage of infants placed to sleep on their backs, on a separate approved sleep surface and without soft objects or loose bedding will include state-level work to implement safe sleep audits in birthing hospitals throughout the state. MH agencies will provide a minimum of one community-based education opportunity for a business or organization that serves pregnant women and connect families with local resources for cribs. Clients who obtain direct services will receive individualized safe sleep education.

## Child Health (CH)

Overall, Iowa children are in good health. The vast majority of children (96%) are medically insured; although 72% of parents report they are adequately insured. Non-Hispanic White children were more likely to be adequately insured (72%) than Hispanic children (62%). The percent of children who received a preventive dental visit was 84.7%. In 2016, third graders on Medicaid and Hawki were more likely to have untreated decay than those with private dental insurance. The number of dentists that will treat children on public insurance options continues to decline in Iowa. In general, Iowa does a good job in ensuring that children are tested for lead in their blood at least one time; however the percent of children being tested for lead decreases as children get older. In 2017, 88% of one year olds were tested, compared to 43% of two year olds and 14% of three year olds. Only about one-third of Iowa's children ages 6-11 years were physically active for at least 60 minutes per day.

Three performance measures were selected for the Child Health population domain:

- National Performance Measure 6: Percent of children, ages 9 through 35 months, who received a
  developmental screening using a parent-completed screening tool in the past year
- State Performance Measure 2: Percent of children ages 1 and 2, with a blood lead test in the past year

- State Performance Measure 3: Percent of early care and education programs that receive child care nurse consultant services
- State Performance Measure 5: Percent of children 0-35 Months who have had fluoride varnish during a well visit with physician/health care provider

These performance measures were selected using quantitative and qualitative data as well as an assessment of state and local capacity to impact each measure.

NPM 6, developmental screening was prioritized by survey respondents as the top National Performance measure for Title V in Iowa. In the capacity assessment, Title V contractors were found to have a high degree of capacity to address this at the local level. In 2016-2017, 28.4% of Iowa children ages 9 to 35 months received a parent-completed developmental screen, falling behind the U.S. level (31.1%).

SPM 2, 72% of survey respondents ranked Blood Lead Testing as Very or Extremely Important. The capacity assessment found Title V contractors capable of addressing this measure with 65% of current contractors already providing testing. The significant difference between children age one being tested (78%) and the children age two being tested (40%) greatly affected the selection of this measure. Work started by Title V involvement in the Maternal and Early Childhood Environmental Health Collaboration, Innovation and Improvement Network over the past 3 years strengthened the foundation for continued joint work and uncovered data and strategies to improve the testing rates of young children.

SPM 3, in 2019, 75% of working families with children under the age of 6 utilize child care. Iowa has over 4200 regulated child care providers (centers, preschools and homes) with 169,945 available child care slots. Currently there are not enough child care spaces to meet the needs of working families and almost one-fourth of Iowans live in areas that have an undersupply of regulated child care options. That number is even higher when looking for infant and toddler child care. Nationwide there has been an increase in childhood chronic health conditions and allergies. Child Care Nurse Consultants provide best practice guidance, assessment visits, medication administration training and care planning for children with special health needs to improve child care quality. In 2019, 37% of child care programs participated with child care nurse consultant services including 4322 on-site child care visits completed, 6227 technical assistance provided, 217 group trainings, and 698 children with special health needs identified, 92% with a care plan in place at the child care program.

SPM 5, children are recommended to see a dentist before their first birthday. However, many dentists are not comfortable seeing children this young. Tooth decay is the most common chronic disease in children, five times more common than asthma. Left untreated, children with active tooth decay may experience mouth pain, difficulty learning and concentrating, impaired eating leading to growth delays, and delayed speech development. Children see a physician up to 11 times by their third birthday, yet in 2018 only one in five children saw a dentist before turning 3. Recognizing the need to prevent dental disease, lowa's Medicaid program adopted a policy several years ago to reimburse physicians for application of topical fluoride varnish during well-child visits for children up to 36 months of age. And although I-Smile™ Coordinators have provided trainings for medical offices for many years on how to apply the fluoride, very few offices have incorporated the service as part of routine care. Cavity Free lowa is an initiative focused on increasing the number of children who receive preventive fluoride varnish at well-child medical appointments and dental referral. In 2019, 61% more Medicaid-enrolled children ages 0-3 years received a fluoride varnish application from a medical provider than in 2018. As more medical offices participate around the state, the number of children receiving fluoride varnish is

expected to increase over the next 5 years and the National Outcome Measure (decay experience) to decline.

## **Programmatic Approaches**

#### Efforts to be Continued

Gap filling developmental testing by contractors and partnership with lowa's 1st Five program to encourage providers to include developmental screening as part of the well visit. Provide gap filling blood lead testing by contractors. Sustain and enhance partnership between the Childhood Lead Poisoning Prevention Program and Title V at the state level. Nursing visits, technical assistance, quality improvement tools, trainings and special needs child care planning with child care providers in lowa will also continue. Oral health care is integrated into Title V program activities throughout the state. Iowa's Title V funded agencies are able to provide oral health services to clients, including establishing a dental home for women and children. Oral health activities are a required component of services. I-Smile to ontinues to promote access to preventive oral healthcare for children, in addition to building referral networks with dentists. The UI College of Dentistry operates a dental clinic where dental students gain first-hand experience in working with CYSHCN, utilizing a multi-disciplinary care team approach.

### Areas of Opportunity for new activities

New activities include contractors meeting criteria being required to test one and two year olds, environmental scans to determine blood lead testing and developmental screening practices of providers. Title V contractors and Childhood Blood Lead Poisoning Prevention contractors are being required to partner together via both program's contracts.

I-Smile<sup>™</sup> Coordinators are required to visit all pediatric medical offices to promote the age one dental visit; offer training on oral screenings and fluoride varnish applications; and provide oral health educational and promotional materials. (Coordinators will make visits to all family practice medical offices in counties with no pediatrician.) I-Smile<sup>™</sup> Coordinators will provide onsite training (developed by OHDS staff) for offices interested in becoming a "Cavity Free Iowa" participant and assist with referrals to local dentists for care. OHDS staff is researching options to offer continuing education credits for medical staff who participate in the fluoride varnish training.

## Adolescent Health (AH)

lowa adolescents receive well visits at a high rate relative to the national average, with 81.1% of all lowa adolescents reporting having a preventive medical visit in the last year. However, lowa still needs to improve the quality of the well visits and address disparities among youth covered by Medicaid. Iowa adolescents have critical mental health needs that are not always addressed, and access to mental health professionals is difficult throughout Iowa. 94% of adolescents ages 12 - 17 received a preventive dental visit in 2016-2017. About 9% of children (ages 0 - 17) in Iowa were reported to have ongoing emotional, developmental, or behavioral conditions that require treatment or counseling. This is true for about 17% of adolescents ages 12-17. Vaping continues to increase in teens in Iowa. When asked if they had done "any vaping" in the last 12 months, 37.3% of 12th graders reported that they had, compared to only 27.8% in 2017.

Two performance measures were selected for the Adolescent population domain:

• National Performance Measure 10: Percent of adolescents ages 12 through 17 with a preventive medical visit in the past year

• State Performance Measure 4: Percent of adolescents who report that during the past 12 months they have felt so sad or hopeless almost every day for 2 weeks or more in a row that they stopped doing some usual activities

These performance measures were selected based on quantitative and qualitative data and an assessment of state and local capacity to impact each measure.

NPM 10 was selected in response to the CAH program's overall vision is to promote healthy outcomes for lowa's children and adolescents. Adolescents are much less likely to receive a well visit than the 0-5 years population. According to the CMS 416 report in 2018 51% of 10-14 year olds and 45% of 15-17 year olds received a well visit. Adolescence like early childhood is a time of dramatic physical, psychological and social growth and development.

SPM 4 was selected in response to ongoing concerns for the mental health of youth in our state. When surveyed, lowa students in 6th, 8th, and 11th grade responded "yes" to the SPM at a rate of 16% in 2012 growing to a rate of 25% in 2018. Mental health conditions such as anxiety, depression, eating disorders and drug and alcohol abuse impact the mental health of the adolescent population. According to the CDC, one in five adolescents 13 - 18 years old has or will have a serious mental illness. Fifty (50) percent of lifetime mental illnesses start by age 14, and 70% of youth in local and state juvenile systems have a mental illness. The CDC Morbidity and Mortality Weekly Report, reports that emergency department visits for suicidal ideation, self-harm, or both increased by 33.7% among girls ages 10 - 19, and by 62.3% among boys 10 - 19 between 2016 and 2018. Adolescence is also a crucial period for developing and maintaining social and emotional habits important for mental well-being.

### **Programmatic Approaches**

#### Efforts to be Continued

Efforts to be continued include: maintaining partnerships with organizations that support adolescents in receiving an annual full well visit as well as supporting LGBTQI youth and collaborate in the development of evidence based strategies improving the mental health of adolescents.

#### Areas of Opportunity for new activities

IDPH recognizes the barriers and increasing health disparities reported in both the data and the needs assessment surveys and interviews and strives to work with Title V agencies across the state to meet the needs of Iowa's Children and Adolescents.

Explore standardized psychosocial assessments for Adolescents in primary care settings and billing options for local Title V agencies to provide gap filling services; providing adolescent mental health training to Title V agencies; collaborate with the Iowa Department of Education and local school districts in assessing gaps or barriers to adolescent mental health services in local communities; and assist in the advancement of the efforts ordered by the Governor of Iowa in the establishment and implementation of Iowa's Children's Behavioral Health System State Board (Children's Board) and promote state and local Title V agency level participation.

Addressing the adolescent well visit as well as adolescent mental health will involve conducting environmental scans to identify which providers are conducting these services, and at what ages they are routinely offered and sharing this with providers and community stakeholders. Partnerships will be formed with other adolescent serving organizations including the Children Mental Health Systems by

region. In addition, agencies will work with adolescents or organizations serving adolescents to increase health literacy, promote healthy behaviors and promote well visits. The aim is to also provide culturally and linguistically appropriate resources for adolescents.

## **Children and Youth with Special Health Care Needs (CYSHCN)**

Approximately 18.8% of Iowa's 732,000 children have special health care needs, including a range of diagnoses, conditions, and levels of severity. Chronic conditions such as asthma and diabetes, developmental or behavioral disorders like autism or attention deficit hyperactivity disorder, and more complex medical issues like spina bifida or cerebral palsy are all considered special health care needs. In Iowa and the US, older children are more likely to have a special health care need than younger children. Iowa's adolescent population has a higher proportion with special health care needs than nationwide.

In lowa, approximately 9% of children have an ongoing emotional, developmental, or behavioral condition that requires treatment or counselling. Iowa has a higher proportion of adolescents with behavioral and emotional health needs than those nationwide. Behavioral and emotional health is receiving increased attention in Iowa due to statewide efforts culminating in the creation of a new comprehensive Children's Mental Health System, codified in May of 2019.

Complex health needs can have lasting impacts on children, families, and the health care system. There are various ways to define the concept of "complex health needs." The National Survey of Children's Health (NSCH) through the Data Resource Center for Child and Adolescent Health Initiative defines complex health needs as those whose special health care needs include more special services than just the need for prescription medications. By this definition, 13.2% of lowa's children have complex health needs, which is comparable to the US as a whole.

Children and Youth with Special Health Care Needs (CYSHCN) in Iowa were less likely to be reported as having a medical home than those without special health care needs (51.9% vs 57.4%). For children with more complex health needs, 43.9% were reported to have a medical home. Most children in Iowa have a primary care provider, often a family practitioner. The Standards for Systems of Care for CYSHCN list "pediatric specialty care integrated with the medical home and community-based services" as a core component. Pediatric specialty providers are primarily located in central and east central Iowa. Families often travel long distances for visits, and those who do not have reliable transportation often face obstacles to attending their appointments. Telehealth is becoming more readily available and is increasingly seen as an alternative to travel for psychiatric visits, as well as for follow-up appointments with other pediatric specialty providers.

In lowa, 23.1% of CYSHCN received services necessary to transition to adult health care. When looking specifically at children with more complex health needs, it was 15.1%. Among focus group participants, many stated that they are not prepared to help their child navigate this transition. Many families interviewed stated that they predict that preparing for their child's transition to adult health care will be challenging.

lowa NSCH data show that 16% of CYSHCN live in a household with parenting stress, compared with 2% of those without special healthcare needs. For children with complex health needs, the percent is even higher (20% often feel aggravated). The discrepancy is so stark that DCCH worked with a Quantitative Methods student from the University of Iowa College of Public Health to conduct a more thorough analysis. Using a definition of Complex Health Needs where respondents needed to answer affirmatively to 3 or more screener questions, we found that children with complex health needs had 11.5 times the risk of experiencing parenting stress.

Most quantitative data for the above profiles of CYSHCN in Iowa came from the population-based National Survey for Children's Health. The sampling strategy allows for estimating various state level factors. In Iowa, the data collected for this survey generally does not allow for reporting by race or ethnicity due to small sample size. Although there were attempts to address this through qualitative methods, this is an area that needs more in-depth study to truly determine needs.

Three performance measures were selected for the CYSHCN population domain:

- National Performance Measure 11: Percent of children with and without special health care needs who have a <u>medical home</u>
- National Performance Measure 12: Percent of adolescents with and without special health care needs who received services necessary to make <u>transitions to adult health care</u>
- State Performance Measure 7: <u>Family support</u>: Percent of caregivers of CYSHCN who report overall satisfaction with support services received through Title V

These performance measures were selected based on needs identified through quantitative and qualitative data analyses and input from DCCH staff.

NPM 11 was selected because findings revealed that access to health care remains a major concern for families of CYSHCN, especially access to pediatric specialty providers. Having a medical home can help provide support for families who need to access care for their child.

NPM 12 was selected because the percent of youth with families reporting that they received services associated with transition to adulthood for their child was low. Families reported that they were anticipating challenges associated with this transition.

SPM 7 was selected because data shows us that having a source of support can help mitigate some of the stress associated with parenting CYSHCN. Significant stress associated with raising CYSHCN was well documented in all aspects of the needs assessment data collection.

#### **Programmatic Approaches**

## Efforts to be Continued

Iowa Title V CYSHCN efforts will continue to build on the existing Family Navigator Network to provide family-to-family support and systems navigation for parents. Workforce development for family leadership and primary care providers will continue. Additionally, gap-filling services and supports

including care coordination, will be provided through 13 Child Health Specialty Clinic Regional Centers located throughout the state.

#### Areas of Opportunity for new activities

The focus of activities for the lowa Title V CYSHCN program will be on building infrastructure and providing services and supports primarily focused on children with chronic and complex health needs, developmental and intellectual disability, and children with mental health service needs. The approaches will focus on workforce development, family partnerships, and direct and enabling services. The CYSHCN program will seek new ways to increase opportunities to partner with families of CYSHCN from traditionally underserved backgrounds.

# **Identifying Priority Needs and Linking to Performance Measures**

The 5-year needs assessment cycle guides the development of activities, monitoring, and evaluation. These needs are listed below with descriptions of the NPMs and SPMs that were selected to address them.

#### Infusing Health Equity within the Title V System

SPM 6: Percent of Title V contractors with a plan to identify and address health equity in the populations they serve

Ensure that all Title V NPMs and SPMs work towards addressing health inequities and disparities within the state and local system. Develop and implement a data analysis plan to assess distribution of Title V resources and services through a health equity lens. Develop partnerships with organizations, agencies or programs and/or those specifically designed to serve priority populations, including communities of color.

### Access to care for the MCH population

NPM 4: A) Percent of infants who are ever breastfed B) Percent of infants breastfed exclusively through 6 months

Provide education to maternal health clients on the benefits and methods of breastfeeding. Ensure maternal health nursing staff have the education and ability to provide breastfeeding education to clients. Establish links among birthing hospitals and community breastfeeding support networks. Develop partnerships and training opportunities for businesses on the topic of breastfeeding policies and best practices.

NPM 6: Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year

Promote parent and caregiver awareness of developmental screening. Continue to work with provider champions in associations of health professionals to promote developmental screenings within clinical settings. Facilitate collaboration between Title V, early care and education settings, and home visiting providers on the provision of developmental screenings.

NPM 10: Percent of adolescents, ages 12 through 17, with a preventive medical visit in the past year

Work with local primary care practitioners and other providers serving adolescents to increase the numbers served and enhance the quality of adolescent well visits. Collaborate and share resources with school nurses and adolescent serving organizations across the state to promote adolescent well visits.

#### **MCAH Systems Coordination**

NPM 14: A) Percent of women who smoke during pregnancy B) Percent of children, ages 0 through 17, who live in households where someone smokes

MH staff will collaborate with staff from the Division of Tobacco Use and Prevention (DTUP). Title V will support staff in the DTUP in implementing an incentive program for pregnant women who smoke to participate in the Quitline maternal tobacco use program. All local MH agencies providing direct services to pregnant women in Iowa will provide individualized health education, in a culturally and linguistically appropriate manner, on the importance of tobacco use cessation and refer interested clients to the Quitline.

SPM 1: Number of pregnancy-related deaths for every 100,000 live births

Title V staff will provide local agencies training and communication related to the most recent Maternal Mortality Review Committee (MMRC) findings and recommendations. Local Title V MH agencies provide screenings and education on topics specific to preventing maternal mortality. MH agencies are required to conduct screenings for depression, substance abuse, domestic violence, and tobacco all MH clients receiving direct services. Clients also receive health education which includes specific topics related to recommendations from the MMRC recommendations such as the importance of chronic disease management, nutrition, and physical activity.

SPM 4: Percent of adolescents who report that during the past 12 months they have felt so sad or hopeless almost every day for 2 weeks or more in a row that they stopped doing some usual activities

Explore and research the use of psychosocial assessments provided to adolescents in primary care settings across the state. If gaps in services are identified, lowa will partner with the Iowa Medicaid Enterprise (IME) to identify billing codes that local Title V agencies can pursue under their purview of their child screening center designation. Title V staff will continue to be involved in the development and implementation of the newly codified Iowa's Children's Behavioral Health System State Board.

### Dental Delivery Structure of the MCAH Population

NPM 13.1: Percent of women who had a preventive dental visit during pregnancy

NPM 13.2: Percent of children, ages 1 through 17, who had a preventive dental visit in the past year

SPM 5: Percent of children 0-35 Months who have had fluoride varnish during a well visit with Physician/health care provider

Outreach with medical and dental providers to educate on the need for integration. Inform, educate and disseminate scientific evidence on the importance of prenatal dental screening and treatment. Continue to advocate for dental providers to increase the acceptance of new Medicaid covered patients. Assure statewide care coordination network that includes dental home referral, tracking, and follow-up for children. Continue to expand preventive school-based sealant programs such as I-Smile@School.

#### Safe and Healthy Environments

NPM 5: A) Percent of infants placed to sleep on their backs B) Percent of infants placed to sleep on a separate approved sleep surface C) Percent of infants placed to sleep without soft objects or loose bedding

Women who are receiving Title V direct care services will receive safe sleep education based on the mother's needs, taking into account any personal or cultural beliefs the mom or family express, on the following topics: back to sleep, safe sleep environment (crib), no co-sleeping, no extra items in the crib and other recommendations from the AAP and the report from the Child Death review team.

SPM 2: Percent of children ages 1 and 2, with a blood lead test in the past year

Local Title V agencies will coordinate blood lead screening with primary care providers, local public health agencies, local Childhood Lead Poisoning Prevention Programs (CLPPPs) and others providing blood lead testing in the community. Educate parents on the importance of blood lead testing at appropriate intervals. Contractors are encouraged to partner with an agency or group serving one of the priority populations to promote blood lead testing in more culturally targeted ways.

SPM 3: Percent of early care and education programs that receive Child Care Nurse Consultant services

Outreach to local early care and education programs regarding the participation in CCNC services. Promote the utilization of CCNCs to provide Health and Safety pre-service/orientation training for child care providers to meet the requirement within the Child Care Development Block Grant.

Access to services, pediatric specialty providers, and care coordination

NPM 11: Percent of children with and without special health care needs, ages 0 through 17, who have a medical home

To address barriers to access to care for CYSHCN, DCCH will focus on: 1) Providing access to specialty care through CHSC Regional Centers; 2) Strengthening infrastructure and increasing opportunities for specialty care through telehealth; and 3) Increasing Primary Care capacity to treat children with complex and/or mental health needs, and developmental and intellectual disabilities.

#### Support for making transitions to adulthood

NPM 12: Percent of children with and without special health care needs who receive services necessary to make transitions to adult health care

DCCH plans to continue existing initiatives and implement new strategies to address needs for youth ages 12 - 21 years who are in the process of transitioning to adulthood and adult health care. A 3-pronged approach will assure that goals are met: 1) Continuing direct services to YSHCN (youth with special health care needs) and families; 2) Updating transition-to-adulthood resources for youth and families; 3) Creating and implementing transition-to-adulthood resources that directly address issues for YSHCN from underrepresented backgrounds.

#### Support for parenting CYSHCN

SPM 7: Percent of caregivers of CYSHCN who report overall satisfaction with support services received through Title V

The support for parenting CYSHCN program area focuses on three areas: 1) Providing family support services to Iowa families of CYSHCN, including recruiting and supporting ethnically diverse staff and cultural liaisons; 2) Increasing support for direct services staff statewide to build understanding about barriers to family participation in health care; 3) Assuring caregiver confidence and capacity to advocate for CYSHCN on all levels (personal/family, community, and policy), including family training to underserved/underrepresented populations.

# **Title V Program Capacity**

# **Organizational Structure**

The lowa legislature designates IDPH, a cabinet level agency, as the administrator for Title V and MCH services. The legislature also directs IDPH to contract with Child Health Specialty Clinics (CHSC) within the UI-DCCH to administer the CYSCHN program. Statutory authority identified in the Code of Iowa (Chapter 135, Iowa Administrative Code 641, Chapter 76) provides further reference for the purpose and scope of Iowa's program. Legislative authorization for state expenditure of federal funding under the federal block grant is identified through the appropriations process of the Iowa General Assembly. Contracts between IDPH and DCCH outline the responsibilities of both agencies for fulfilling the mandate for MCH services.

## **Agency Capacity**

Iowa's MCH/CYSHCN programs promote the development of systems of health care for children (with and without SHCN) ages 0-21 yrs, pregnant women, and their families. Iowa strives for services that are collaborative, comprehensive, flexible, coordinated, culturally competent, developmentally appropriate, family-centered and community- based. Iowa's Title V program serves to advance the service delivery of the core public health functions of assessment, policy development and assurance.

## MCH Workforce Development and Capacity

lowa's Title V MCH System is implemented through a community utility model and strives to improve access to care for pregnant women, children, and families. At the state level there are a total of 6.2 FTEs directly funded by Title V. Within BFH there are 39 professional staff and 4 support staff that work (directly and indirectly) on behalf of the Title V program. Iowa has 24 local MCH agencies with a combined workforce of 156.12 FTEs covering Iowa's 99 counties. Local MCH agencies are chosen through a competitive selection process every five years. Local and state MCH partners focus on fostering integration within the public health system and across organizational boundaries/sectors.

# **Key MCH Leadership Staff**

<u>Marcus Johnson-Miller</u> has served as Iowa's Title V MCH Director and Bureau Chief of the Bureau of Family Health at the Iowa Department of Public Health since September 2014, but has been involved in Title V coordination and implementation for over 18 years.

<u>Bob Russell, DDS, MPH</u> has been the Public Health Dental Director at the Iowa Department of Public Health for 15 years. Dr. Russell assures the Title V program is infusing dental practices in all aspects of the programs.

<u>Debra Kane, PhD</u>, is a MCH epidemiologist assigned to IDPH through a contractual agreement with the Centers for Disease Control and Prevention.

# **CYSHCN Workforce Development and Capacity**

DCCH administers Iowa's Title V program for CYSHCN. UI-DCCH delivers its public health, systems building, enabling and direct services through 13 community-based centers across Iowa. The total number of DCCH employees is 95, with 73.08 FTEs. MCHB Title V funds support 64employees, equating to 20.7 FTEs.

## **Key CYSHCN Leadership Staff**

<u>Thomas Scholz, MD</u> is Professor of Pediatrics in Cardiology and Child and Community Health at the UI Carver College of Medicine. He is Director of the Division of Child and Community Health and Director of Community Relations for the Department of Pediatrics. He is board certified in Pediatric Cardiology.

<u>Jessie Marks, MD</u> is Clinical Associate Professor of Pediatrics in the UI Carver College of Medicine. She is the Medical Director for the Division of Child and Community Health. Dr. Marks is board certified in General Pediatrics and Pediatric Hospital Medicine.

<u>Rachel Charlot</u> is a certified Family Peer Support Specialist and has been a Family Navigator since 2008. She has worked in Early ACCESS, lowa's Early Intervention system, has been an AMCHP family Scholar and is currently Iowa's MCH Title V Family Delegate.

<u>Jean Willard, MPH</u> manages Iowa's Title V CYSHCN Program for the Division of Child and Community Health for the University of Iowa Stead Family Department of Pediatrics.

<u>Alejandra Escoto, MPH</u> coordinates Population Health Programs for the Division of Child and Community Health for the University of Iowa Stead Family Department of Pediatrics.

## **Promoting and Providing Culturally Competent Delivery of Services**

Although Iowa is less racially diverse than some states, its diversity is increasing. Iowa's Asian and Hispanic communities are the fastest growing population groups. Key informants noted there has been an increase in immigrant and refugee populations, resulting in small groups of people from several different countries, residing within a single community.

UI-DCCH collects race/ethnicity data for CYSHCN receiving services through UI-DCCH. UI-DCCH recognizes that collection, analysis, and dissemination of data related to health disparities and greater outreach to minority and underserved populations are essential to improving Iowa's system and the availability of culturally competent care for CYSHCN.

# **Partnerships**

IDPH and UI-DCCH maintain many formal and informal partnerships benefiting Iowa families. This leveraging of resources to plan and implement MCH, including CYSHCN, programs results in a strong statewide network.

**MCHB Investments**: Iowa manages several MCHB projects, including the State System Development Initiative and Maternal, Infant, and Early Childhood Home Visiting, Early Childhood Systems of Care grants. Other projects include participation in the MCH Public Health Leadership Institute, Regional Autism Assistance Program, the National MCH Workforce Development Center, and Innovative Evidence-based Models for Improving System Services for CYSHCN.

Other Federal Investments: IDPH and UI-DCCH manage and/or work closely with other federal agency's programs that include the PREP, AEGP, Title X Family Planning, Infant and Child Death Review, the Council for State and Territorial Epidemiologists, the National Science Foundation, and Head Start. Projects through the Centers for Disease Control and Prevention include an Oral Disease Prevention grant, a MCH Epidemiologist (CDC assignee), the Pregnancy Risk Assessment Monitoring System, and Early Hearing Detection and Intervention. Strong collaborations exist with the US Department of Agriculture's Special Supplemental Nutrition program for Women, Infants, and Children and the University of Iowa eHealth Extension Network Project.

**Other HRSA Programs**: Federally Qualified Health Centers and Rural Health Clinics are important referral sources for MCH contractors for provision of medical and dental care for Medicaid-enrolled families. The MCH program also works with the Behavioral Treatment through In-Home Tele health for Young Children with Autism and the IPDH STD/HIV/AIDS program.

State and Local MCH Programs: IDPH contracts with local health departments and private, non-profit agencies to conduct MCH program activities. In addition to families, these local MCH contractors work with each county board of health within their service area, including participation in regular community health needs assessments and health planning. IDPH programs such as the 1<sup>st</sup> Five Healthy Mental Development and I-Smile ™ dental home programs are administered through CH contractors. Both projects rely on local program-specific coordinators to facilitate partnerships and referrals with medical and dental offices and community organizations. Other state and local partnerships include programs addressing adolescent health, bullying prevention, and the Child and Youth Psychiatric Consult Project of lowa.

Other Programs within IDPH: The MCH program, including CYSHCN, has strong linkages within IDPH Bureaus of Immunizations, Oral and Health Delivery Systems, Chronic Disease Prevention and Management, as well as Vital Records & Health Statistics, Multicultural and Minority Health, and Substance Abuse Prevention and Treatment programs. IDPH's Office of Disability, Injury & Violence Prevention supports state and local efforts to improve services for victims of domestic and sexual violence.

Other Governmental Agencies: A strong partner of the MCAH program is Iowa's DHS. A Medicaid policy specialist at DHS provides technical assistance and support to state and local MCH staff. Interagency contracts between IDPH and DHS cover quality service provision for MCH, 1<sup>st</sup> Five, and I-Smile™; Hawk-i outreach and PE; data sharing; and care coordination reimbursement. Collaborations also include the

Healthy Child Care Iowa program, work with the Autism Support Program, and training and certification for adults with serious persistent mental illness and families of children with SED. Early Childhood Iowa and the Department of Education's Early ACCESS (IDEA, Part C), Regional Autism Assistance, Head Start State Collaboration Office, and School Nurse Consultant are also partners.

**Public Health and Health Professional Educational Programs and Universities**: Iowa's Title V program benefits from long-standing collaborations with several public health and health professional education programs, including UI Colleges of Nursing, Medicine, Public Health, and Dentistry; the University of Northern Iowa; Des Moines University; and community colleges. Activities include education and training for students within health provider training programs, training for MCH contractors about depression screening and Listening Visits, and assistance developing standards of care and evaluating quality of care to reduce mortality and morbidity of infants.

**Family/Consumer Partnership and Leadership Programs**: Some of the ways that IDPH and UI-DCCH hear family and consumer viewpoints are through focus groups, advisory councils, the Access for Special Kids Resource Center, and Family Voices.

Other State and Local Public and Private Organizations that Serve the State's MCH Population: IDPH and UI-DCCH appreciate many public-private partnerships with organizations such as Delta Dental of Iowa Foundation, the Iowa AAP, ChildServe, Blank Children's Hospital, the Iowa Primary Care Association, Magellan Behavioral Health, Meridian Health Plan of Iowa, the National Alliance on Mental Illness Iowa Chapter, and Child and Family Policy Center. Opportunities range from funding for school-based dental sealant programs, participation on health advisory councils, and evaluating program data.

#### Family/Consumer Partnerships

Nature and substance: The UI-DCCH employs 41 family members of CYSHCN as Family Navigators (FN). FN work in regional centers, contributing to Title V activities and other programs for CYSHCN and their families. A Family Advisory Council (FAC) began in 2014. IDPH maintains family partnerships through 21 MH and 22 CH contract agencies that work directly with families within their service areas, providing care coordination, referral assistance, and gap-filling preventive health services. Families are represented on the Title V MCH Advisory Council (MCHAC) and on local health coalitions and similar types of councils.

<u>Diversity of members engaged</u>: The UI-DCCH FN vary in age, urban or rural geographic location, military family status, and special health care needs of their child. Members of the FAC are diverse regarding gender, race and ethnicity, socio-economic descriptors, and age. Family diversity is woven into the fabric of the MCH program. Contractors regularly respond to the changing needs and backgrounds of families using assessments and feedback from those families and incorporating specific outreach to racial and ethnic minorities. In 2014, 34% of CH clients and nearly 20% of MH clients were of Hispanic or Latino ethnicity. Racial makeup of MCH clients included African-American, American Indian, and Asian.

Number engaged, the degree of engagement, compensation, and MCH core competencies: The UI-DCCH FN are employed full-time, permanent part-time or hourly part-time. Members of the FAC are compensated for meeting attendance and receive stipends for mileage. The FN and members of the FAC receive training on MCH core competencies. The MCHAC includes three family representatives. All members of the MCHAC are given resources for self-training in the MCH core competencies and orientation to the Title V program. Compensation is not provided for participation on MCHAC. The MCHAC assists with assessing needs, prioritizing services, establishing objectives, and encouraging public

support for MCH and family planning programs. MCH contractors engage families often and respond to families' needs based upon interactions. Client surveys help evaluate satisfaction, determine if program services meet client needs, and identify changes to improve program quality. This feedback is not typically compensated.

Evidence and range of issues being addressed: UI-DCCH uses family-to-family and peer support, to help families develop self-advocacy skills. FN promote the importance of family priorities and concerns as part of care planning and management to health care providers. UI-DCCH engages child-serving systems through support networks that benefit CYSHCN and their families and include family-driven principles when developing policies and procedures. IDPH works through local Title V MCH contractors to assure health services for families, which include helping clients become better consumers and navigators of the health care system. Contractors report that the majority of family issues they address are related to medical/dental appointments and health issues and services. Contractors also work with families to find assistance with transportation, translation, food, clothing, and housing as well as referrals to other programs such as WIC.

Impact on programs and policies: UI-DCCH values the perspectives of FN and is committed to supporting development of family leadership among employees and families of CYSHCN. FN communicate gaps and barriers to care during policy discussions, providing realistic perspectives on family life for CYSCHN. FN are represented as AMCHP Family Scholars and Delegates, and one FN is on the AMCHP Family and Youth Leadership Committee. MCH contractors seek input of families/consumers and respond through changes to programs and policies (e.g. using text messaging for care coordination, use of language lines, and transportation to mental health services).

Efforts to build and strengthen for all MCH populations: UI-DCCH has built a virtual meetings network to deliver training and support to FN. Monthly meetings build staff competencies, provide updates on issues affecting Iowa families of CYSHCN, and foster collaboration among FN. UI-DCCH disseminates best practices and also provides training opportunities that include Bridges out of Poverty, Trauma Informed Care, Behavioral Health Ethics, and Mental Health First Aid. IDPH provides oversight and consultation for MCH contractors through phone and email communication, annual site visits, quarterly regional meetings, an annual seminar, and regular program-specific meetings such as I-Smile™ trainings. Staff provides technical assistance, monitors data, discusses promising practices, and verifies contractors' progress toward performance objectives to assure family-centered approaches and overall program quality.