



Iowa Department of Public and the University of Iowa Division of Child and
Community Health

2016 Title V Needs Assessment Report

Final Report May 2015

Table of Contents

Process	3
Goals, Framework, Methodology	3
Stakeholder Involvement.....	7
Quantitative and Qualitative Methods	9
Data Sources	14
Interface between data collection, finalization of needs, and development of Action Plan	15
Maternal and Child Health Population Findings	20
Women’s/Maternal Health	20
Perinatal/Infant Health	35
Child Health.....	42
Adolescent Health.....	52
Children and Youth with Special Health Care Needs	58
Cross-cutting Findings	73
Title V Program Capacity.....	83
Organizational Structure.....	83
Agency Capacity	85
MCH Workforce Development and Capacity.....	90
Key MCH Leadership Staff.....	91
CYSHCN Workforce Development and Capacity.....	92
Key CYSHCN Leadership Staff.....	95
Partnerships	101

List of Appendices

- A – Criteria for Prioritization of Need Statements
- B – Prioritization Survey Results
- C – IDPH Agency Protocol for Iowa’s Title V Maternal and Child Health Program
- D – IDPH Discussion Guides for Family Focus Groups Conducted by Iowa’s Title V Maternal and Child Health Program
- E – UI-DCCH Key Informant Interview Telephone Protocol for Five Year Needs Assessment for Iowa’s Title V Program for Children and Youth with Special Health Care Needs
- F – UI-DCCH Organizations Represented in Key Informant Interviews for Iowa’s Title V Program for Children and Youth with Special Health Care Needs
- G – UI-DCCH Focus Group Procedures for Iowa’s Title V Program for Children and Youth with Special Health Care Needs
- H – UI-DCCH Recruitment Script for Focus Groups with Families of Children and Youth with Special Health Care Needs
- I – Confirmation Letter for Families of Children and Youth with Special Health Care Needs Participating in Focus Groups
- J – UI-DCCH Informed Consent for Families of Children and Youth with Special Health Care Needs
- K – UI-DCCH Informed Consent for Community-based Providers of Children and Youth with Special Health Care Needs
- L – UI-DCH Discussion Guide for Focus Group with Families of Children and Youth with Special Health Care needs
- M – UI-DCH Discussion Guide for Focus Group of Community-based Providers for Children and Youth with Special Health Care needs
- N – Demographic Surveys for Focus Group of Community-based Providers of Children and Youth with Special Health Care Needs
- O – Demographic Surveys for Focus Groups with Families of Children and Youth with Special Health Care Needs
- P –Tables of Organization: IDPH Division of Health Promotion and Chronic Disease Prevention, IDPH Bureau of Family Health Organizational Chart, and UI Division of Child and Community Health
- Q – IDPH Maternal and Child Health Contracts and Memoranda of Agreement
- R – Title V Program Service Maps

Process

Goals, Framework, Methodology

Since early 2014, the Iowa Department of Public Health's Bureau of Family Health and the Oral Health Center, along with partners at the University of Iowa Division of Child and Community Health (UI-DCCH) collaborated to conduct the five-year Needs Assessment for the Title V Maternal and Child Health Block Grant. The five-year Needs Assessment (NA) is an opportunity for the State of Iowa to evaluate progress made towards performance measures, identify new and emerging issues for Iowa, examine the state's capacity to implement Maternal and Child Health (MCH) programs, and determine priorities for the next five years.

The first step in the NA process was to identify the primary persons responsible for conducting the NA (the Core Team), which included four members from the Bureau of Family Health and Oral Health Center, and three members from UI-DCCH. The Core Team was complemented by the larger Leadership Team, which included an additional 17 senior leaders from the IDPH and UI-DCCH. The Leadership Team identified subject matter experts from multiple disciplines, including oral, maternal, child and adolescent health, and children and youth with special health care needs (CYSHCN).

Members of the Core Team were not co-located and held a weekly conference call to discuss progress towards completing milestones in the NA, any challenges that were encountered along the way and determine next steps. The Leadership Team met monthly to provide direction and guide the work of the Core Team.

The first meeting of Iowa's NA team resulted in developing the conceptual framework and establishing the common questions that would guide analytic efforts. To develop the framework, the Core Team conducted a literature review of methodologies from past Title V NA reviews, reviewed Iowa's previous NA process, comments from federal reviewers on previous NAs, and reviewed Appendix D of the [DRAFT] guidance provided by the Maternal and Child Health Bureau (MCHB) at Health Resources and Services Administration (HRSA)^{1,2,3}. Based on this information, the following Conceptual Framework was developed.

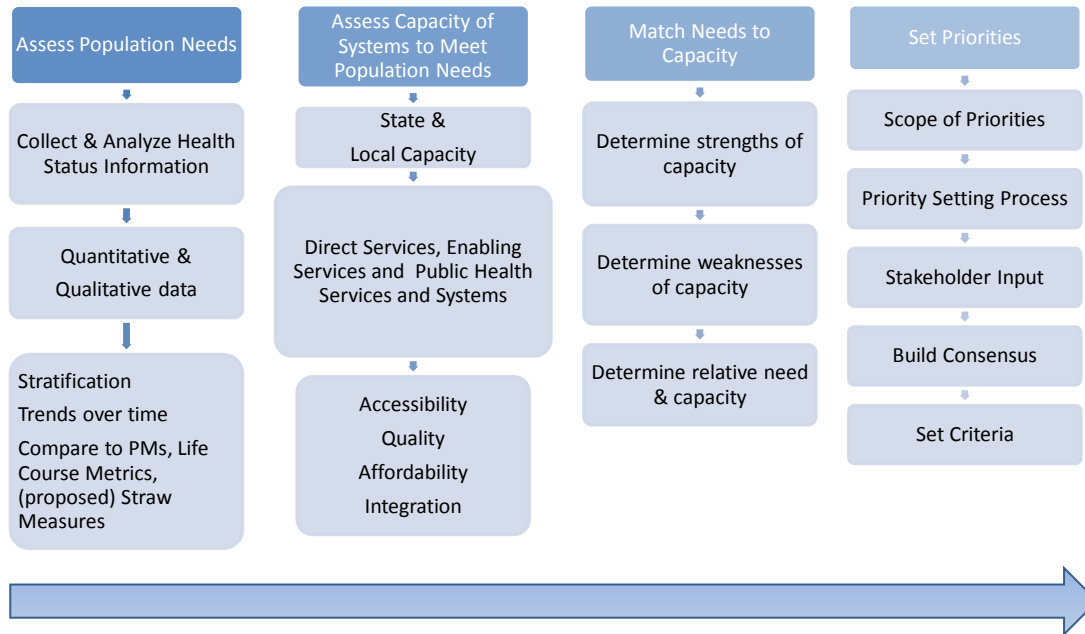
¹ Gabor, V., Noonan, G., Anthony, J., Gordon, E. (December 15, 2006) *Review of the Title V 5-Year Needs Assessment Process in the States and Jurisdictions*. (Prepared for HRSA/MCHB) Retrieved from <http://mchb.hrsa.gov/grants/tv5yearprocess12152006.pdf>.

² US Department of Health and Human Services, Health Resources and Services Administration. (December 2004) *Promising Practices in MCH Needs Assessment: A guide based on a national study*. Retrieved from <http://mchb.hrsa.gov/publications/needsassessdec2004.pdf>.

³ US Department of Health and Human Services, Health Resources and Services Administration. (October 2014) *Title V Maternal and Child Health Services Block Grant to States Programs: Guidance and forms for the Title V application/annual report*. Rockville, MD.

Conceptual Framework

2016 Title V Needs Assessment



Iowa began the NA process by assessing the MCH population, using both quantitative and qualitative methods. Disparities were considered from a variety of angles, not only differences between races and ethnicities, but also disparities according to income levels, urban and rural status, and age groups.

With the immense number of factors that potentially affect health outcomes for the MCH populations, the Leadership Team elected to use the question ‘*What defines a healthy MCH/CYSHCN population?*’ and the resource “Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs” developed by the Association of Maternal and Child Health Programs (AMCHP) and the Lucile Packard Foundation for Children’s Health as a guidepost to narrowing the analytic efforts⁴. The National Consensus Framework for Systems of Care for CYSHCN Project is a joint collaborative effort of leaders representing state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric providers, children’s hospitals, insurers, health services researchers, families/consumers, MCHB senior staff, and several others. This effort identified 10 key domains for process and structural standards necessary to advance a comprehensive system of care for CYSHCN and their families. The domains are grounded in the six core outcomes for systems of care for CYSHCN developed by the federal Maternal and Child Health Bureau, Health Resources and Services Administration and the domain of cultural competence.

⁴ AMCHP & Lucille Packard Foundation (2014). Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs. Retrieved from <http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2014/05/Developing-Structure-and-Process-Standards-Full-Report.pdf>.

From this, the Leadership Team generated a list of topic areas to explore more deeply. These topic areas were converted to the Data Detail Sheets (DDS) that were used to generate need statements. Stakeholders then prioritized those need statements. A list of the DDS topics can be found in Table 1. Full versions of the DDS can be found at www.idph.state.ia.us/titleVneedsassessment/. Each DDS contained the following sections:

- Background section;
- Health and/or Economic Impact;
- Relevant Data (trends, benchmarks, IA vs. US, geography, etc.);
- Current activities in Iowa;
- Related Performance Measures.

Table 1 Data Detail Sheet Topic List

Child Health	Maternal Health	Children with Special Health Care Needs
Health Insurance	Health Care Access	Care Coordination
Medical Home*	Oral Health Care Access	Data Sharing Across Systems for CYSHCN
Physical Activity and Obesity	Health Insurance	Family Involvement of CYSHCN
Adolescent Health	Work Environment	Integrated Systems of Care for CYSHCN
Community Level Environment	Women of Reproductive Age	Performance and Financial Incentives to Assure a High Quality, Comprehensive System of Care for CYSHCN
Home Environment	Mental Health	Transition to Adulthood for Youth with Special Health Care Needs
Developmental Screening*	Nutrition	
Oral Health Care Access	Prenatal Care	
Health Care Access	Reproductive Life Planning	
Nutrition		
Mental Health*		
Bullying Among Children and Youth*		

**denotes Child Health DDS topics that include CYSHCN-specific data*

From the data generated for the DDS, 24 need statements were developed for prioritization by stakeholders. Iowa intentionally did not try to match the need statements to MCHB's [DRAFT] National Performance Measures (NPMs). This allowed the development of need statements to be reflective of a broader range of data and to reflect input from the MCH community. The Leadership Team also felt that this allowed Iowa the opportunity to move into the selection of State Performance Measures without overburdening stakeholders by asking them to participate in multiple prioritization processes.

To prioritize the 24 needs statements, an online survey was developed for MCH stakeholders. Respondents were asked to rank each need statement based on six criteria. The criteria were selected based on Iowa's previous success with four of the criteria. Two additional criteria (in italics) were added to more fully explore the needs of CYSHCN and the opportunity to create systems change for all MCH populations. The six criteria used for the prioritization survey were:

- Number of individuals affected,
- Economic impact,
- Degree of demographic disparity,
- Severity of issue,
- *Family impact, and*
- *Systems change.*

An extensive list of MCH stakeholders was generated by the Leadership Team and stakeholders were invited to participate in the web-based prioritization survey (see *Stakeholder Involvement*).

The Leadership Team participated in an additional prioritization survey process by applying an additional four criteria to each of the 24 need statements. The additional four criteria were selected to reflect the nature of the team's knowledge on MCH issues. The four criteria were:

- Motivation to change,
- Issue can be tracked and measured,
- Effective intervention is available, and
- Organizational capacity.

Criteria are defined in Appendix A. The results were combined to create a ranked list of need statements. The Leadership Team then selected priority issues for the next five years. These priorities led to the selection of Iowa's NPMs and SPMs.

In addition to summarizing existing quantitative and administrative information in the DDS, Iowa's Title V CYSHCN program prioritized the collection of additional qualitative information obtained from key stakeholders involved in and experiencing the system of care for CYSHCN. The selection of the topics for the qualitative research was guided by the seven overall system outcomes for a comprehensive quality system of care for CYSHCN, as outlined in 2014 by the *National Consensus Framework for Systems of Care for CYSHCN Project*. Open-ended questions focused on the following System Outcomes for CYSHCN and their families:

1. Family Professional Partnerships,
2. Medical Home/Care Coordination,
3. Insurance and Financing,
4. Early and Continuous Screening and Referral,
5. Access to Easy to Use Services and Supports,
6. Transition to Adulthood,
7. Cultural Competence.

For each area, Iowa's Title V CYSHCN program sought to elicit key informant discussion and input on:

- **System strengths** in addressing the needs of CYSHCN and their families,
- **Areas for improvement** and children and families' unmet needs, and
- **Recommendations and suggestions to Iowa's Title V program for CYSHCN** to improve care, services, and outcomes for CYSHCN and their families.

During summer 2014, Iowa's CYSHCN program agreed upon the categories of key informants and optimal methods to elicit this information. Iowa's Title V CYSHCN program contracted with Vivian Gabor, an independent consultant who brought expertise in the Title V MCH Needs Assessment process, qualitative data collection and analysis skills, experience working with state CYSHCN programs and on the *National Consensus Framework for Systems of Care for CYSHCN Project*, as well as extensive experience moderating focus groups. She facilitated the development of the study plan including decisions on the core research questions, respondent recruitment and selection process, instrument development and the coding and analysis of findings.

Stakeholder Involvement

The IDPH and UI-DCCH sought the involvement of various MCH stakeholders to help inform the needs assessment process. Input from focus groups and key informant interviews guided the development of the DDS. Along with involvement from families served, UI-DCCH staff, the IDPH's external subject matter experts and the Discovery Survey, informed the prioritization survey areas and the selection of Iowa's National Performance Measures and State Priority Areas. Information from the MCH stakeholders is described in the following paragraphs.

MCH Focus Groups

Focus groups and individual interviews were held in June and July of 2014 at eight of 24 local MCH contract agencies which receive Title V funding. Agencies volunteered to participate in this project and were allowed to choose if they would like to conduct a Maternal Health or Child Health focus group, or both. A random sample of clients was pulled from the corresponding client database. The samples consisted of clients who received services from the agency in the past three months. The agency recruited 10 clients based on this list. All but one focus group was conducted in English. The non-English language focus group was conducted in Karin (spoken by Burmese refugees) due to the large number of Karin speakers in the sample. Other clients who did not speak English used the opportunity to participate in a translated individual interview. In addition, clients who were not able to attend scheduled focus groups were given the opportunity to participate in individual interviews.

CYSHCN Key Informant Interviews

UI-DCCH conducted 19 key informant interviews from stakeholders throughout Iowa's system of care for CYSHCN. These stakeholders included administrative officials in state agencies, such as Department of Human Services and Iowa Medicaid Enterprise, Iowa's children's hospitals, Iowa Primary Care Association, private insurers that cover a large number of CYSHCN, and organizations representing minority and other underserved populations.

CYSHCN Focus Groups

Thirty-one families (one parent/guardian per family) participated in four family focus groups throughout Iowa. In addition, nine community providers representing eight organizations participated in the community provider focus group that was held in North Central Iowa. An interview was also done in Spanish with the only family that attended the focus group in Northwest Iowa.

While most participants in the family focus groups were non-Hispanic White and covered by Medicaid, other races/ethnicities and insurance coverage statuses were represented. CYSHCN ranged broadly in age as well as in type and severity of special health care needs. Participant characteristics are described in the qualitative methods section.

UI-DCCH Staff Interviews

UI-DCCH's Child Health Specialty Clinics (CHSC) has 15 Regional Centers located in urban and rural communities throughout Iowa that are staffed by community child health teams. These teams are comprised of Advanced Registered Nurse Practitioners (ARNP), Registered Nurses (RN), Social Workers (SW), Family Navigators (FN), and Registered Dietitians (RD) who provided valuable qualitative data on the needs of CYSHCN in their communities.

UI-DCCH Health Care Provider Survey and Interviews

A focus group for medical providers was not successful, as none of the recruited providers attended. Instead, interviews were conducted with two primary care providers in targeted rural communities, and a web-based survey was developed and distributed to pediatricians and family practice physicians statewide.

External Subject Matter Experts

Subject matter experts external to the Bureau of Family Health, and often the IDPH entirely, were consulted in the development of the Data Detail Sheets. The external subject matter experts (ESMEs) were vital in providing context to data in areas that have not traditionally been within the BFH's domain (i.e. bullying, physical activity and occupational health risks). ESMEs were asked to review a draft version of the DDS, provide feedback on the content, suggest additional relevant data points, provide information on relevant activities in Iowa and offer a need statement based on the information collected and their knowledge of the area. The collaboration with ESMEs was essential for bringing a broader perspective to the health needs of the MCH population. Including these people early in the needs assessment increased their engagement throughout the year long process.

Discovery Survey

An additional method for engaging the MCH stakeholder group in determining Iowa's priority needs, was participation in what was called a 'Discovery Survey.' The Discovery Survey was a two question survey sent to local MCH contract agencies which receive Title V funding. The survey asked

- 1) Which MCH region do you work in? and*
- 2) What do you think are the three biggest health needs facing the families you serve?*

An email was sent requesting input from each agency's Executive Director; MCH Project Director; Maternal Health, Child Health, EPSDT, *hawk-i* Outreach, and I-Smile™ coordinators; as well as other MCH agency staff that work in the program. There were a total of 90 respondents to the Discovery Survey resulting in over 230 MCH population needs. All the responses were coded according to common themes. Access to general health providers, oral health providers and mental health providers were the most commonly stated need. This was closely followed by transportation and insurance. However, other important needs were also discovered.

Prioritization Survey

In November 2014, the IDPH and UI-DCCH released a web-based survey to obtain a rank order for the 24 need statements that had been generated based on the information gathered for the DDS. Along with an emailed invitation to the stakeholder list and families, the survey link was posted on both the IDPH and UI-DCCH websites. A press release was issued and messages were posted on the IDPH programs' Facebook pages inviting interested persons to participate in the prioritization survey. The survey was open for three weeks. Reminder emails were sent twice during that period to the stakeholder list. There were 213 completed responses to the survey from over 44 different organizations, and an additional ten families or clients completed the survey. Relevant DDS were linked to each need statement in order for respondents to have easy access to the relevant data.

Quantitative and Qualitative Methods

Quantitative Methods

The IDPH recruited two interns through the National MCH Workforce Development Paired Practicum program during the summer of 2014. The interns assisted in data collection efforts for the DDS and conducting and coding the MCH Focus Groups. Core Team members supervised the interns' work.

Initial exploration of the data began with cross-walking Iowa's current national and state performance measures with the draft national performance measures issued by MCHB in July 2014, along with a comparison to the Life Course metrics developed by the AMCHP. Iowa's Title V MCH program has a strong interest in measuring its progress according to the Life Course metrics and felt it was important to include them in the initial exploration of MCH-related data. This initial crosswalk helped to orient the Needs Assessment Core and Leadership Teams by comparing how Iowa's Title V program had been operating and how it could be impacted by the MCH Transformation. This was particularly important given the change in how performance measures would be selected for the next five-year cycle.

Data Detail Sheets

To ensure a broad range of information was included in the DDS, a list of potential indicators was developed for each topic. Staff then pulled data from a variety of sources (list of examples is provided in *Data Sources*), including national surveys, such as the National Survey of Children's Health, the National Survey of CSHCN, and state-level data including the 2010 Iowa Household Health Survey and 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 data systems for child and maternal health agency programs.

Data was examined to determine if disparities were present in terms of geography, race/ethnicity, income levels, etc. Disparities are highlighted in the '*Current Status*' section of each DDS. Also, included were comparisons between Iowa's status versus national averages and comparisons to national and state benchmarks. Highlighted in the DDS are those indicators that demonstrate Iowa's successes and areas for opportunity and targeted interventions.

Prioritization Survey Results Analyses

Survey results were grouped into eight categories to compare responses between different stakeholder groups. Respondents were asked to answer four to six demographic questions to assist with comparison among organizations and roles in organizations. Initial ranking of the need statements was by the combined score on the six criteria. Rankings were then grouped as follows:

- Combined IDPH and UI-DCCH staff
- IDPH/UI-DCCH staff, plus staff from Title V funded agencies
- Families/Clients
- Interested stakeholders
- Bureau of Family Health staff
- Oral Health Center staff
- UI-DCCH staff
- Executive Directors

These groupings allowed the Leadership Team to examine how different groups viewed and ranked the need statements. The Team was also able to visualize common priorities and those which were more significant to a specific stakeholder group. Need statements were color coded to show those need statements that ranked 1 through 5 and those that ranked 6 through 13. The full results can be found in Appendix B.

The results of the prioritization survey were examined based on the six criteria. The Leadership Team examined the strengths and weaknesses of each of the need statements by the criteria. This was particularly insightful for the Leadership Team criteria. For the majority of the need statements, general stakeholder respondents ranked them similarly for all six criteria, but there was more variation within the Leadership Team criteria for individual need statements. For example, the results showed that members of the Leadership Team perceived themselves to be highly 'motivated to change' for the need statement *Access to Specialists* (4.0), but as having less 'organizational capacity' (2.0) to improve in this area. However, this same need statement received scores of 3.9 to 4.2 for the general stakeholder criteria. The results of the general and leadership criteria were averaged to examine how the application of the leadership criteria affected the final ranking of the 24 need statements.

Qualitative Methods

The IDPH and UI-DCCH gathered qualitative data using methods specific to their target population. The IDPH conducted focus groups with clients of local child health and maternal health agencies. Additionally, the IDPH gathered qualitative input through conversations with ESMEs who informed the DDS and need statements. UI-DCCH also conducted focus groups, focusing on families of CYSHCN and

community providers in rural and small urban communities across the state. UI-DCCH also conducted interviews with key informants from a variety of organizations that serve CYSHCN, as well as staff at regional centers to gather information on needs specific to CYSHCN in each community. UI-DCCH also developed a web-based survey for health care providers.

Focus Groups with MCH Clients of Title V agencies: The IDPH staff facilitated the child health and maternal health client focus groups with no local agency staff present. Participants were informed that the focus groups were voluntary and confidential, and no client names were attached to the data. Focus groups were held in a community space, and child care was provided. A small incentive was provided to all participants for their participation. Notes were taken, and two recordings were made at each focus group from which the dialogue was then transcribed. Data were coded using a consistent comparison method, and project team group consensus was used to determine analytical codes.

A total of 39 clients were included in the data collection. Three focus groups were conducted with clients of child health agencies. There were 15 participants, primarily mothers, although three fathers also attended. In addition, there was one individual phone interview with a mother who was unable to attend the focus group. Four focus groups were conducted with women who were either recent or current maternal health clients. Four individual interviews were also conducted for women who were unable to attend a focus group but wanted to participate or for those who required the presence of an interpreter. A total of 24 maternal health clients participated in the focus groups and interviews. One of the participating maternal health agencies serves many Burmese clients. Therefore, one of the maternal health focus groups was conducted in Karin (a Burmese language) with five maternal health clients. One individual interview was conducted in Karin when other participants were all English-speaking, and one interview was conducted in Spanish.

Using the coded data, the BFH developed a summary of the frequency of various topics. From this document, representative quotes were selected to be included in the DDS. The focus groups generated representative quotes for most of the DDS. Additionally, a final report on the focus group process and results was written and distributed to stakeholders. The final report was posted on the IDPH website as a resource for the prioritization survey (www.idph.state.ia.us/titleVneedsassessment/). Appendices C and D contain the agency protocol guide and the moderator guide, respectively.

Additional qualitative input was generated during the conversations with ESMEs as to what information should be included in the DDS and in the submission of need statements.

Key Informant Interviews for CYSCHN: Iowa's CYSHCN program needs assessment team determined that one-on-one telephone interviews lasting no longer than one hour would be the optimal method to reach and obtain input from key informants. These interview protocols were developed in summer 2014 and conducted in September 2014. At the same time, the program determined that focus group discussions would allow the full and open discussions needed to establish group rapport and elicit input from families and, separately, from health care and community-based providers. These focus groups were conducted in five locations around the state (as described below) in October and early November 2014.

Key informants for the telephone interviews were selected to represent a diversity of organizations and perspectives and to include expertise in each of the seven key system outcome areas. Nineteen individuals were selected by the staff of Iowa's Title V CYSHCN program, recruited with an email from the UI-DCCH Director and a follow-up telephone call from the independent consultant, with 100% of those recruited participating in a telephone interview.

Focus Groups with Families of CYSHCN: UI-DCCH initially intended to conduct seven focus groups throughout Iowa, including three with families of CYSHCN 0-21 years, one in Spanish with families of CYSHCN ages 0-21 years, and one with families of youth ages 12-21 years. This total also included separate focus groups of community providers and health care providers in North Central Iowa. Although most of these focus groups had high participation rates, the Spanish language focus group for families and the focus group for health care providers were not well attended.

The seven planned focus groups were stratified according to geographic location (with a focus on small urban and rural communities where families were anticipated to face greater challenges accessing services for their CYSHCN than families in larger urban areas where specialty services for CYSHCN are concentrated). There was also a purposeful design to include one group of families of youth ages 12-21 years to enable a focused discussion regarding transition to adulthood, one group focused on non-English speaking Hispanic/Latino families with CYSHCN, one group of medical providers, and one group of non-medical community-based providers. UI-DCCH submitted a Research Determination form to the University of Iowa Institutional Review Board (IRB). The MCH Title V Needs Assessment was determined to be quality improvement and did not require IRB oversight.

The recruitment process to engage families and community providers through focus groups took place over a one month period. UI-DCCH created patient lists of CYSHCN that had received services in the past 12 months. Screening questionnaires were developed by the needs assessment team and recruitment calls were done by center staff. A first call was placed two weeks before the focus group occurred, and staff called every fifth family to randomize the selections, continuing through the list until reaching ten families that agreed to participate. Staff sent a confirmation letter and list of Frequently Asked Questions to the family's home address. Staff called to remind families of the focus group five days and one day before the focus group.

To recruit community providers, UI-DCCH contacted the Regional Center in that community to ask for suggestions on providers to invite from their community. UI-DCCH staff then contacted the providers and invited them to participate and asked for other recommendations for providers. These providers included professionals in special education, behavioral health, social work, respite, childcare, targeted case management, and psychiatric medical institution for children services. To recruit health care providers, UI-DCCH staff contacted the office managers at all pediatric and family practice offices in the area of North Central Iowa.

The original study plan included one focus group to be conducted in Northwest Iowa in Spanish with non-English speaking Hispanic/Latino families to gain a better understanding of the unique barriers

these families face in accessing care, as well as perspectives regarding the cultural and linguistic competency of their providers. A Spanish screening tool and focus group discussion guide were developed for this group, and a bilingual Title V CYSHCN program staff member conducted the recruitment of Spanish-speaking families by telephone. An expert bilingual moderator was hired to conduct this group, an attempt to oversample was made, and focus group location and hours were adjusted to accommodate participants' work hours. Despite these efforts, the patient list included only a small number of Latino families and many of the telephone numbers were no longer valid at the time of recruitment. Four non-English speaking families of Hispanic/Latino CYSHCN were successfully recruited, of which only one attended the focus group.

UI-DCCH intended to conduct a focus group for health care providers in North Central Iowa, but was unable to recruit providers to attend. UI-DCCH then attempted to schedule interviews with two pediatricians or family practice physicians in two rural communities. The interviews were conducted with two providers (one pediatrician and one family practice provider) and a web-based survey was developed for distribution to family practice and pediatricians statewide. The Iowa Primary Care Association sent the survey to their members, and the Iowa Chapter of the American Academy of Pediatrics distributed the survey via social media. The office managers at ten large practices throughout Iowa emailed it to their staff as well. Ten pediatricians and family medicine physicians participated in the web-based survey during December 2014.

Family focus group participants from 31 families were predominantly female and the primary caretaker of their child. All families in the focus groups were non-Hispanic White, except one mother who was African American. In all the groups, 26 families had Medicaid coverage for their CYSHCN, of which four had both Medicaid and private insurance, one child had only *hawk-i* insurance (Iowa's SCHIP program), and four were solely covered by private insurance.

CYSHCN represented ranged from age 11 months to 18 years old, with the older children's families concentrated in the Northeast Iowa group that recruited only parents of youth ages 12-21 years. All of the CYSHCN represented in the groups experienced ongoing physical, behavioral, emotional, or developmental conditions. These included primary diagnoses of Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Attention Deficit Disorder, intellectual disabilities, bipolar disorder, conditions secondary to child neglect or neonatal abstinence, cerebral palsy, Partial Trisomy 13, and dwarfism. Many of the CYSHCN with physical conditions used medical equipment or devices such as wheelchairs, feeding tubes, or monitors and most reported their children have had multiple operations or procedures, had been seen by multiple specialists, and for those with behavioral conditions had been on one or more prescription medications.

Facilitation and Data Collection Materials: The UI-DCCH independent consultant conducted each of the telephone interviews and moderated all of the focus group discussions. The lead staff member of the Iowa Title V CYSHCN needs assessment team served as note-taker for the focus groups. All focus group discussions were taped on a digital recorder and later transcribed for the coding and content analysis of those detailed discussions. The following documents are included as appendices: key informant telephone interview protocol, recruitment instructions and script, family and provider focus group

discussion guides, parent/caregiver recruitment screening tool, focus group participant confirmation letters, the consent form, brief demographic surveys completed by focus group participants (one for families and one for providers) and the list of key informants.

UI-DCCH Staff Interviews: Iowa's CYSHCN program needs assessment team also collected information on the needs of CYSHCN in various communities through group interviews with UI-DCCH Child Health Specialty Clinics (CHSC) staff at each of 14 Regional Centers. Members of the needs assessment team scheduled GoToMeeting video conferences with staff from each regional center and conducted conversational interviews the first two weeks of December 2014. Each interview lasted roughly half an hour. Interviewees included ARNPs, FNs, RNs, SWs, Registered Dietitians and secretaries. A five question survey asking about barriers for families, delivery of care, and community collaboration served as a loose interview guide. The needs assessment team analyzed the interview transcripts to identify themes and recommendations.

Data Sources

Below is a list of references, materials, etc. used to complete this needs assessment. This is by no means an all-inclusive list.

Table 2 A Partial List of Data Sources used in the 2016 Title V Needs Assessment

National Sources		State Level Sources	
Data Sets	Articles/Reports	Data Sets	Articles/Reports
Kids Count Data Center	Business Case for Breastfeeding	Iowa Youth Survey	Iowa Plan for Suicide Prevention: 2011 to 2014
CDC – Water Fluoridation Reporting System	CDC – Injury Prevention & Control: Adverse Childhood Experiences (ACE) Study: Major Findings	2012 Vital Statistics of Iowa	Youth Health Forums Report. (2013) Des Moines, Iowa: Community Youth Concepts
CDC – Reportable STDs in Young People 15-24 Years of Age, by State	HealthyPeople.gov. (2014). Access to Health Services: Overview	2010 Iowa Child and Family Household Health Survey	Healthy Iowans: Iowa's Health Improvement Plan 2012-2016
<i>CDC - 1991-2013 High School Youth Risk Behavior Survey Data</i>	National Trends in Health Insurance Coverage of Pregnant and Reproductive-Age Women, 2000-2009	<i>hawk-i:</i> Healthy and Well Kids in Iowa	Work-Related Exposures to Pesticides in Iowa, 2008-2012
2011-2012 National Survey of Children's Health	Recommendations to Improve Preconception Health and Health Care	Iowa Barriers to Prenatal Care Survey	Iowa Healthcare Collaborative. Early Elective Delivery
2009-2010 National Survey of Children with Special Health Care Needs	CDC – Oral Health Resources Synopses by State Iowa 2009	Behavioral Risk Factor Surveillance System	Extent of Food Insecurity Among Iowa WIC Participants 2011

National Sources		State Level Sources	
Data Sets	Articles/Reports	Data Sets	Articles/Reports
Child Health USA 2013	CDC – 2013 Breastfeeding Report Card		Perinatal Depression: A systematic review of prevalence and incidence
HRSA Data Warehouse – State Summary of Designated Medically Underserved Areas/Populations	The Health and Well-Being of Children: A Portrait of States and the Nation, 2011-2012. State Indicators: Iowa		Family Planning Service Grant CFDA 93.217: Needs Assessment Narrative
	AMCHP & Lucille Packard Foundation (2014). Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs		Iowa's FFY2014 Maternal and Child Health Bureau Title V Block Grant Executive Summary
	Berwick, Nolan & Wittington (2008). The triple aim: care, health, and cost.		Iowa Department of Education (2013). Autism Spectrum Disorders in Iowa: Needs Assessment.
			Iowa Department of Human Services (2014). System of care planning grant community survey results.
			Iowa Department of Human Services (2014). State Innovation Models
			Iowa Department of Human Services (2013). State Health Improvement Plan.

Interface between data collection, finalization of needs, and development of Action Plan

The Leadership Team met in December 2014 to review the results of the prioritization survey and the information compiled in the DDS. At this day-long meeting, the Leadership Team selected eight of the 15 MCHB national performance measures (NPMs). The Leadership Team also established five State Priority Areas for which State Performance Measures will be developed over the next year.

National Performance Measures

Given that the need statements were developed based on the data compiled for the DDS, feedback from stakeholders and the Discovery Survey, only a few of the need statements were directly aligned with the MCHB NPMs. Prior to the Leadership meeting, the Core Team examined the results of the prioritization survey and compared them to the NPMs and the national health outcomes. This allowed the Core Team

to match need statements to NPMs and list the matched need statements/NPMs as likely candidates for inclusion in the eight selected from the list of 15 NPMs. Using this method the Leadership Team selected NPMs for the Women/Maternal, Perinatal/Infant, Child, Adolescent, CYSHCN and Cross-Cutting population domains.

The final selected national performance measures are those shaded in green. The remaining NPMs were not selected for Iowa for the next five-year cycle.

Table 3 Iowa's selected National Performance Measures

NPM #	Performance Measure	MCH Population Domain
PM 1	Percent of women with a past year preventive visit	Women/Maternal
PM 2	Percent of cesarean deliveries among low-risk first births	Women/Maternal
PM 3	Percent of very low birth weight infants born in a hospital with a Level III+ Neonatal Intensive Care Unit	Perinatal/Infant
PM 4	A) Percent of infants ever breastfed B) Percent of infants breastfed exclusively through 6 months	Perinatal/Infant
PM 5	Percent of infants placed to sleep on their backs	Perinatal/Infant
PM 6	Percent of children, ages 9-71 months, receiving a developmental screening using a parent-completed screening tool	Child Health
PM 7	Rate of injury-related hospital admissions per population ages 0-19 years	Child Health and/or Adolescent Health
PM 8	Percent of children ages 6-11 years and adolescents ages 12-17 years who are physically active at least 60 minutes per day	Child Health and/or Adolescent Health
PM 9	Percent of adolescents, ages 12-17 years, who are bullied	Adolescent Health
PM 10	Percent of adolescents with a preventive services visit in the last year	Adolescent Health
PM 11	Percent of children with and without special health care needs having a medical home	CSHCN
PM 12	Percent of children with and without special health care needs who received the services necessary to make transitions to adult health care	CSHCN
PM 13	A) Percent of women who had a dental visit during pregnancy and B) Percent of infants and children, ages 1-17 years, who had a preventive dental visit in the last year	Cross-cutting
PM 14	A) Percent of women who smoke during pregnancy and B) Percent of children who live in households where someone smokes	Cross-cutting
PM 15	Percent of children 0 through age 17 years who are adequately insured	Cross-cutting

State Priority Areas

The following were selected as State Priority Areas. Workgroup members will develop State Performance Measures for these areas within the next year.

1) Pursue the Triple Aim for the CYSHCN population.

Reason for Selection: According to the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) only 15-20% of CYSHCN were served by a system of care that met all age-relevant core outcomes and only 47% of CYSHCN receive integrated care through a family-centered medical/health home approach. Although many successful projects and extensive efforts are occurring throughout Iowa at both the community and state level to address these issues, these efforts are disjointed. Coordination and systems integration are essential to sustainable improvement. A new approach that mobilizes high-level decision makers through a revised and unified state plan addressing the Triple Aim will be implemented. A value based approach that results in meaningful outcomes for stakeholders at all levels of the system will facilitate the necessary systems change. From the perspective of CYSHCN and their families, an integrated system will address their needs, provide holistic care, and incorporate family “voice and choice.” Pursuing the Triple Aim for the CYSHCN population may also improve the system of care for all Iowa children.

2) Access to care for the MCH population

Reason for Selection: Access to care is a multi-faceted issue. In Iowa, the issue of access centers around both an individual’s ability to physically get to a provider and the availability of specialty providers. Lack of transportation resources was the second highest ranking need statement on the prioritization survey and the Discovery Survey conducted with local MCH agency staff. Specialty providers tend to be located in Iowa’s four metropolitan areas and can have long waiting lists or may not accept low-income clients. Focusing on the concept of access from two standpoints allows Iowa a greater opportunity to address the root causes of reduced ability to access needed care.

3) Insurance coverage for MCH populations

Reason for Selection: The national performance measure on insurance is for children only. However, with changes from the Affordable Care Act, there is an increased need to improve people’s literacy regarding their insurance coverage. Because Iowa’s low-income pregnant women are eligible for Medicaid coverage for 60 days postpartum, the vast majority of women receive appropriate prenatal care. However, once their enrollment in Medicaid has expired, they do not know how to enroll in appropriate coverage. This leads to lack of continued care for chronic conditions that may have been treated during pregnancy and issues with postpartum contraception uptake. Approximately 3% of Iowa’s children are not enrolled in a medical insurance program. However, this 3% is disproportionately minority children and dental coverage is not well-utilized by either women or children. In addition, enrollment on dental plans is not as high as medical plan enrollment. Dental coverage is optional on Iowa’s marketplace and is an additional cost for consumers.

4) Access to quality child care

Reason for Selection: The need statement regarding access to quality child care was in the top 13 statements during the prioritization process. Improving the quality of child care allows Iowa to address cross-cutting MCH needs such as nutrition and physical activity, breastfeeding support, developmental screenings, and safe sleep environments. Families of CYSHCN also reported difficulties finding childcare providers that are qualified and comfortable caring for their children. Iowa has a history in working with registered day care providers, both centers and in-home, through the Healthy Child Care Iowa program. The role of child care nurse consultants (CCNCs) is based on the *Blueprint for Action* from the Healthy Child Care America campaign⁵. The CCNC program has the ability to reach a wide range of settings and provide support to day care providers in establishing practices that are medically sound and meet the objectives of Title V programs.

5) Physical activity for MCH populations

Reason for Selection: The implications for engaging in physical activity cut across the lifespan for all MCH populations. Iowa's women of reproductive age suffer from a range of chronic conditions, including obesity. Additionally, minority women are less likely to engage in the recommended amount of physical activity than non-Hispanic white women. Increasing physical activity would help to address issues of obesity and other chronic conditions that can lead to more complications during pregnancy. Additionally, CYSHCN may not perform the recommended amount of physical activity per day^{6,7}. CYSHCN often experience unique barriers to physical activity, such as functional limitations, medication side effects that cause weight gain and make physical activity difficult, the high cost of specialized programs and equipment, and a lack of nearby facilities or programs^{8,9,10,11}. When CYSHCN exercise safely and regularly, socialization increases, weight status and overall health are improved, and the progression of chronic disease and functional decline decreases¹².

⁵ US Department of Health and Human Services, Child Care Bureau and Maternal and Child Health Bureau, 1996. Revised 6/2001. <http://www.healthychildcare.org/pdf/BlueprintII.pdf>

⁶ Ghandour R, Grason H, Schempf A, Strickland B, Kogan M, Jones J, Nichols D. Healthy people 2010 leading health indicators: how children with special health care needs fared. *Am J Public Health* 2013; 103:e99–e106.

⁷ Bandini L, Curtin C, Hamad C, Tybor D, Must A. Prevalence of Overweight in Children with Developmental Disorders in the Continuous National Health and Nutrition Examination Survey (NHANES) 1999–2002. *Journal Of Pediatrics*. 2005; 146: 738–743.

⁸ Vanina Y, Podolskaya A, Sedky K, Shahab H, Siddiqui A, Munshi F, Lippmann S. Body Weight Changes Associated with Psychopharmacology. *Psychiatric Services*. 2002; 53:842–847.

⁹ Shields N, Synnot A, Barr M. Perceived barriers and facilitators to physical activity for children with disability: a systematic review. *British Journal of Sports Medicine*. 2012; 46:989–997.

¹⁰ National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 3/24/2015 from www.childhealthdata.org.

¹¹ National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 3/24/2015 from www.childhealthdata.org.

¹² The Office of Disease Prevention and Health Promotion Chapter 2: Physical Activity Has Many Health Benefits. Retrieved 3/24/2015 from <http://www.health.gov/paguidelines/guidelines/chapter2.aspx>

State Action Plan

Iowa is utilizing the results of the needs assessment and developing a state action plan that will address the priorities selected for the FFY16 Title V funding cycle. Work groups have been identified to examine current evidence-based and evidence-informed strategies to address the state selected priorities. These work groups will also be working to develop State Performance Measures for the State Priority Areas identified in the needs assessment.

Maternal and Child Health Population Findings

The following sections describe the six population domains identified by MCHB to be addressed through the Title V program. Each section includes 1) a brief overview describing the health of the population domain and provides a snapshot of the findings described in the *subsequent* sections, 2) a summary of the strengths and needs of the population, 3) a detailed description of the findings from the needs assessment (including data sources), and 4) a list of the current activities that address the needs of the population and areas for opportunity for new activities. The overview and summary sections are meant to give the reader an introduction to the population domain while the detailed description provides an in-depth account of the results of the needs assessment for each population domain. The activities section provides a review of past activities that should be continued to address each population needs as identified by the needs assessment and areas that warrant new undertakings throughout the upcoming Title V funding cycle.

Women's/Maternal Health

Overview of Health Status for Women's/Maternal Health

While many Iowa women report receiving routine medical and dental care, disparities continue to exist. Women who are in households earning more than \$75,000 are far more likely to have had a dental visit and a routine medical visit in the previous year. Minority women are more likely to be obese, and the percentage of women reporting having had Type II diabetes decreases as household income increases. Substance use (alcohol and tobacco) is higher in non-Hispanic White women than for minority women.

Fortunately, Iowa women (92.9%) have health insurance at rates higher than the national average (86.7%). Additionally, Iowa is the most inclusive state in the US in terms of Medicaid income eligibility for pregnant women and infants. However, undocumented women rely on Emergency Medicaid for Non-Qualified Immigrants for delivery when their presumptive eligibility expires.

Despite high rates of health insurance coverage, access to care (medical, dental and mental health) is a challenge to the overall health of Iowa women. Based on the IDPH's strong working relationship with Medicaid and the Title V funded maternal health agencies, lack of specialty providers and low reimbursement rates from public insurance are often cited as primary drivers of lack of access. Transportation issues are routinely cited by families and service providers as a barrier to accessing medical and dental care.

Summary of the Strengths and Needs of Women's/Maternal Health

Strengths

Iowa continues to value the care of pregnant women. Presumptive eligibility provides a critical service for pregnant women in Iowa. Iowa is the most inclusive state in the US in terms of Medicaid income eligibility for pregnant women – women living in households with incomes up to 375% of the federal poverty limit (FPL) are eligible for Medicaid assistance while pregnant and for 60 days postpartum, and their infants are eligible for one year. The majority of Iowa's pregnant women are accessing prenatal

care in the first trimester. Early entry into prenatal care has increased over the past several years to 86%, which surpasses the Healthy People 2020 goal of 77.9%.

Iowa's regionalized perinatal system of care effectively addresses maternal health across the state. The *Statewide Perinatal Care Program* provides professional training and develops standards/guidelines of care for all of Iowa's birthing hospitals. The program provides consultation to regional and primary providers and evaluation of the quality of care delivered in order to reduce the mortality and morbidity of mothers and infants. The program supports Iowa's regionalized system of perinatal care to increase the number of very low birth weight infants that are delivered at Level II regional neonatal centers or higher.

Availability of family planning services is also a positive contribution to the health of Iowa women. The Medicaid Family Planning Waiver extends the provision of family planning services to low income women who would otherwise not be eligible for coverage. Services are offered for 1-year postpartum to women who delivered a baby within the Medicaid program. Over 65,000 women accessed the waiver from 2006 to 2013. Numerous efforts are underway to increase the use of and access to long-acting reversible contraceptives, as one method to decrease the number of unintended pregnancies in Iowa.

Needs

Iowa women are a diverse population with specific needs. However, access to care is a common challenge across populations. Iowa has the fifth lowest ratio of OB/GYN providers per women of reproductive age in the US, and OB/GYN providers are often located in urban areas. Transportation is one of the most commonly cited challenges to accessing care. Women with limited financial resources are less likely to have routine medical and dental visits than women in higher earning households.

Accessing mental health services is still a tremendous challenge in Iowa. Up to 20% of childbearing women experience depression during pregnancy and up to 30% may have depressive symptoms that interfere with functioning. However, under half of women meeting criteria for clinical depression are receiving treatment. In 2012, Iowa ranked 46th in the US for psychiatrists per individuals in the state. It is predicted that mental health providers will be at the greatest risk for shortage in the next several years.

Substance use (tobacco and alcohol) is higher in non-Hispanic White women than minority women in Iowa. While the number of women ages 15-44 who are currently smoking has declined, it is still about 20%. Meanwhile, almost a quarter of women of reproductive age report binge drinking in the previous month. This, coupled with one-third of pregnancies being unintended is worrisome both for the health of women and their infants.

Detailed Description of Women/Maternal Health

Access to Health Care

In the 2010-2011 Community Health Needs Assessment, 92 of Iowa's 99 counties listed Access to Health Care as a priority need. The most commonly cited challenges were lack of transportation, lack of insurance/underinsurance, economic barriers, and lack of dental providers. Iowa has the fifth lowest number of OB/GYNs per woman of reproductive age in the US (4.18 per 10,000 in Iowa, versus the national average of 5.39). There are 79 hospitals in Iowa offering maternity care; however, only 33 of these are located in rural counties and all Level II and III hospitals are in metropolitan counties. Most Iowa women ages 18-64 report having a personal care provider (88.3%); however, 32% of minority women do not, which is higher than the national average of 25%.

Related National Performance Measures:

None

State Priority Areas:

Access to care for women of reproductive age

Related National Outcome Measure:

*Receipt of prenatal care
Severe maternal morbidity
Low, very, and moderately low birth weight deliveries
Early and late preterm births
Early term births
Non-medically indicated early elective deliveries
Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Fetal alcohol exposure
Neonatal abstinence syndrome*

Title V funded agencies were able to provide maternal health services to over 9,000 clients in fiscal year 2013. Approximately 20% of these clients identified as Hispanic and 10% as African American. Transportation and interpretation services were utilized by 10% and 6%, respectively, of the maternal health clients.

Prenatal care offers a special perspective on access to health care for women and is instrumental in early detection of risk factors and related treatment. Since 2008, the percent of women who received prenatal care in their first trimester has increased almost 10% and surpassed the Healthy People 2020 goal. In 2012, 84% of women entered prenatal care during the first trimester, an increase from 76% in 2008. Further, the percent of women receiving adequate prenatal care based on the Kotelchuck index of prenatal care adequacy has increased since 2008 and was 86.3% in 2012. Title V maternal health agencies are able to provide services which facilitates early entry into prenatal care in all 99 Iowa counties. The services include presumptive Medicaid eligibility determinations, care coordination, linking families to a medical home, transportation, interpretation, and health education on importance of prenatal care. The IDPH monitors each local Title V maternal health agency's performance on medical home rate and early entry into prenatal care.

See Cross-cutting section for information regarding access to Oral Health care access for women in Iowa.

Mental Health

In 2013, 24% of women of reproductive age reported ever having been diagnosed with depression (BRFSS). Depression was more common among White, non-Hispanic women (24.8%) than Non-White and/or Hispanic women (18.8%). The percentage of women who reported two or more stressors (e.g. a separation or divorce, homelessness, loss of a job, death of a family member or close friend, etc.) during pregnancy was 24% in 2011, 23% in 2012, and 22% in 2013.

Mental health problems are often undiagnosed during pregnancy or postpartum because many symptoms, such as fatigue and poor sleep are also associated with motherhood and pregnancy. While depression screening is an easy and inexpensive way to identify women at risk, this does not always translate to entry into treatment. Up to 20% of childbearing women experience depression during pregnancy and up to 30% may have depressive symptoms that interfere with functioning¹³. However, under half of women meeting criteria for clinical depression are receiving treatment^{14,15}.

Numerous barriers such as fear, stigma, lack of understanding of the significance of depression, lack of providers, language barriers, financial barriers or logistical barriers prevent women with depressive symptoms from

Related National Performance Measures:

None

State Priority Areas:

Adequacy of insurance coverage for women of reproductive age

Access to care for women of reproductive age

Related National Outcome Measure:

Receipt of prenatal care

Severe maternal morbidity

Maternal mortality rate

Low, very, and moderately low birth weight deliveries

Early and late preterm births

Early term births

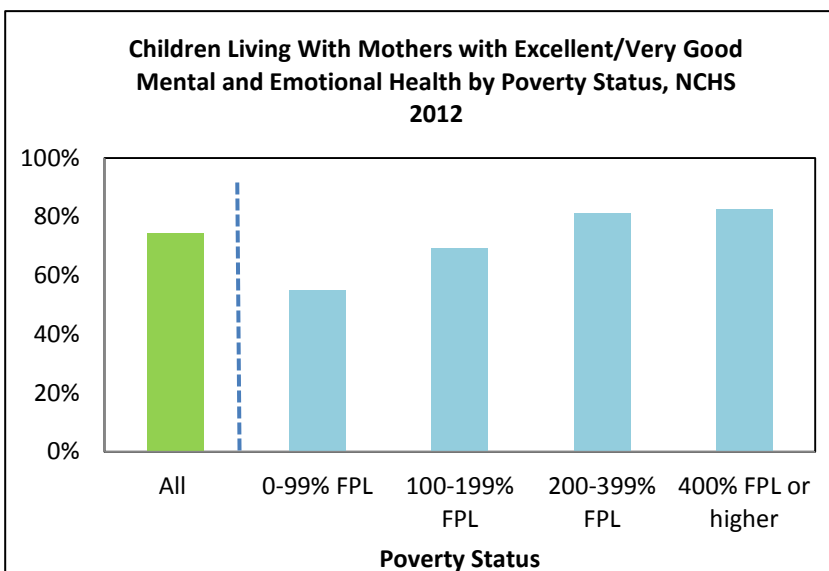
Non-medically indicated early elective deliveries

Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates

Sleep-related SUID rate

Fetal alcohol exposure

Neonatal abstinence syndrome



¹³ Kopelman, R. (Director) (2013, May 15). Screening for Depression in Caregivers. *Lunch & Learn: Clinical Resources for Caregiver Depression*. Lecture conducted from Project Launch, Des Moines, IA.

¹⁴ Segre, L., O'hara, M., Brock, R., & Taylor, D. (2012). Depression Screening of Perinatal Women by the Des Moines Healthy Start Project: Program Description and Evaluation. *Psychiatric Services*, 63(3), 250-255.

¹⁵ Ko, J., Farr, S., Dietz, P., & Robbins, C. (2012). Depression and Treatment Among U.S. Pregnant and Nonpregnant Women of Reproductive Age, 2005–2009. *Journal Of Women's Health*, 8, 830-836.

obtaining treatment.

Accessing mental health services continues to be a problem in Iowa, with 70% of counties containing at least one mental health provider shortage area. According to 2012 data from the American Medical Association, Iowa is 46th in psychiatrists per capita for the US.

A 2005 study conducted by the Center for Health Workforce Planning examined the ages of providers in 24 health occupations. Mental health providers were found to be at greatest risk of shortage by 2015 with the following occupations having greater than 20% of workers age 55 or older: psychologists (47%), marital/family counselors (38%), psychiatrists (35%), mental health counselors (34%), and social workers (28%).

Eighty-three percent of maternal health clients at Title V funded agencies received postnatal depression screenings. Iowa is exploring the use of Listening Visits (LVs) to help alleviate the shortage of mental health providers in Iowa. LVs are an evidence-based depression intervention with protocols developed for health care providers with little or no prior mental health training. The intervention focuses on exploration of a client's problems through reflective listening and addressing those problems through collaborative problem solving. As of June 2014, four maternal health agencies in Iowa had implemented LVs, and 11 more have completed training and developed protocols, but had not yet had a LV client.

Pregnancy Intention

Since 2008, the number of *intended* pregnancies in Iowa has been increasing. The percent of women reporting an *intended* pregnancy is above the Healthy People 2020 target of 56%. In the 2013 Barriers to Prenatal Care Survey, over two-thirds of women not desiring pregnancy reported that they were not using birth control at the time of conception; this number has decreased slightly from 67% in 2007 and 2008 to 66% in 2013.

Multivitamin Use: WIC reports on multivitamin consumption both

pre-pregnancy and during pregnancy through the Pregnancy Nutrition Surveillance system. In 2011, 16.3% of Iowa women were taking a multivitamin, compared to 19.2% nationwide. During pregnancy, 95% of Iowa WIC participants took a multivitamin, compared to 85% nationwide. There was little variability between races during pregnancy. However, young women and African American women had a lower consumption of multivitamins before pregnancy.

Related National Performance Measures:

*Well-woman visit
Cesarean deliveries among low-risk first births
Very low birth weight born at Level III+ facility
Infants breastfed/ exclusively breastfed to 6 months
Infants placed on back to sleep*

Related National Outcome Measure:

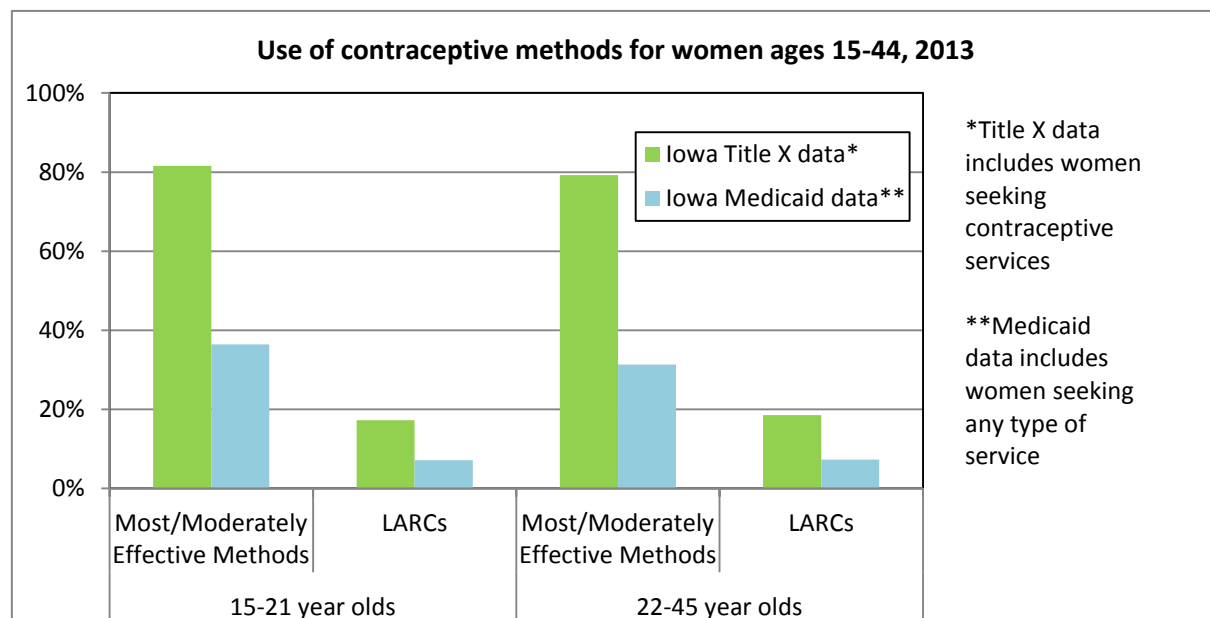
*Receipt of prenatal care
Severe maternal morbidity
Maternal mortality rate
Low, very, and moderately low birth weight deliveries
Early and late preterm births
Early term births
Non-medically indicated early elective deliveries
Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Sleep-related SUID rate
Fetal alcohol exposure
Neonatal abstinence syndrome*

Interpregnancy Intervals: In 2013, one-third of births had an inter-pregnancy interval of less than 18 months. Looking specifically at Medicaid reimbursed births, 67% had an interpregnancy interval of 19 months or more and 9.5% were less than 6 months. Women under 24 years had shorter interpregnancy intervals, as did African American women.

Inter-pregnancy contraception use: In an effort to increase inter-pregnancy contraceptive use among women at risk for close interval pregnancies, Medicaid created a billing code for hospital use to obtain reimbursement for immediate post-partum long-acting reversible contraception (LARC). Previously, providers were unlikely to provide immediate post-partum LARCs because the device costs and payment for insertion were absorbed in the global fee for delivery (personal communication with Iowa Medicaid Enterprise and Informational letter¹⁶).

Use of most or moderately effective contraception: Based on 2013 Title X family planning data, of 10,879 unduplicated visits for women seeking a contraceptive service, 80% of women received a most or moderately effective method. Eighteen percent of these women obtained a LARC. By age group, 17.2% of women ages 15 to 21 obtained a LARC and 18.5% of women ages 22 to 45 obtained a LARC.

Using Medicaid claims data, 20.8% (n=34,624) of all Medicaid women, ages 15 to 44, regardless of the visit purpose, received a most or moderately effective method of contraception; of these, 5.6% (n=9373) received a LARC (6.5% ages 15-21 and 5.3% ages 22-45). Medicaid has initiated a new billing code that will allow providers to bill for immediate post-partum insertion of a LARC. This cost was previously rolled into the global fee for delivery. The IDPH maternal health staff are working with Medicaid and providers to create policies and promote practices that support immediate post-partum LARC insertion. The number of women who receive a 6-week post-partum visit is currently unknown. Immediate post-



¹⁶ Iowa Department of Human Services, Iowa Medicaid Enterprise. Informational Letter 1349 *Long Acting Reversible Contraception* (February 3, 2014).

partum LARC insertion would be an opportunity for women to receive contraceptive services even if they do not attend their post-partum visit.

Chronic Disease Prevention

Well-visits: According to the 2013 BRFSS data, 70% of women age 18-44 reported seeing a doctor in the past 12 months for a routine check-up. Non-White or Hispanic women were more likely than non-Hispanic White women to have had a routine visit (73.4% vs. 69.7%). Women with a higher household income were more likely to have had a routine visit. In 2012, 78% of women reported having their last Pap smear within the last three years.

Reproductive Life Planning (RLP): In 2012, 71% of clients seen at an IDPH-supported family planning clinic were counselled on developing a reproductive life plan. The high percentage of clients receiving RLP counselling is encouraging, especially given that the number of clients has increased by 30% between 2010 and 2012.

Related National Performance Measures:

*Well-woman visit
Cesarean deliveries among low-risk first births
Infants breastfed/ exclusively breastfed to 6 months
Smoking during pregnancy
Children in households where someone smokes*

State Priority Areas:

Physical activity among women of reproductive age

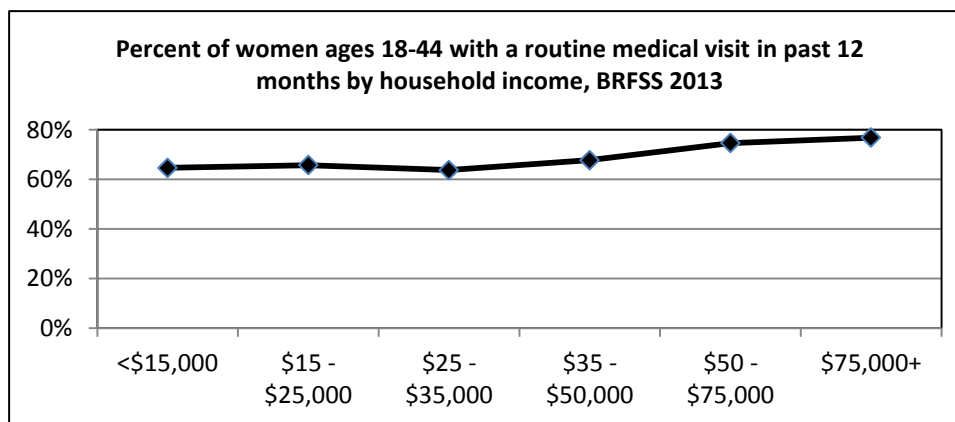
Related National Outcome Measures:

*Receipt of prenatal care
Severe maternal morbidity
Maternal mortality rate
Low, very, and moderately low birth weight deliveries
Early and late preterm births
Early term births
Non-medically indicated early elective deliveries
Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Sleep-related SUID rate
Fetal alcohol exposure
Neonatal abstinence syndrome*

Seven local MH agencies have action plans related to RLP to address and lengthen inter-pregnancy intervals and decrease the number of pregnancies that are unintended.

Activities include

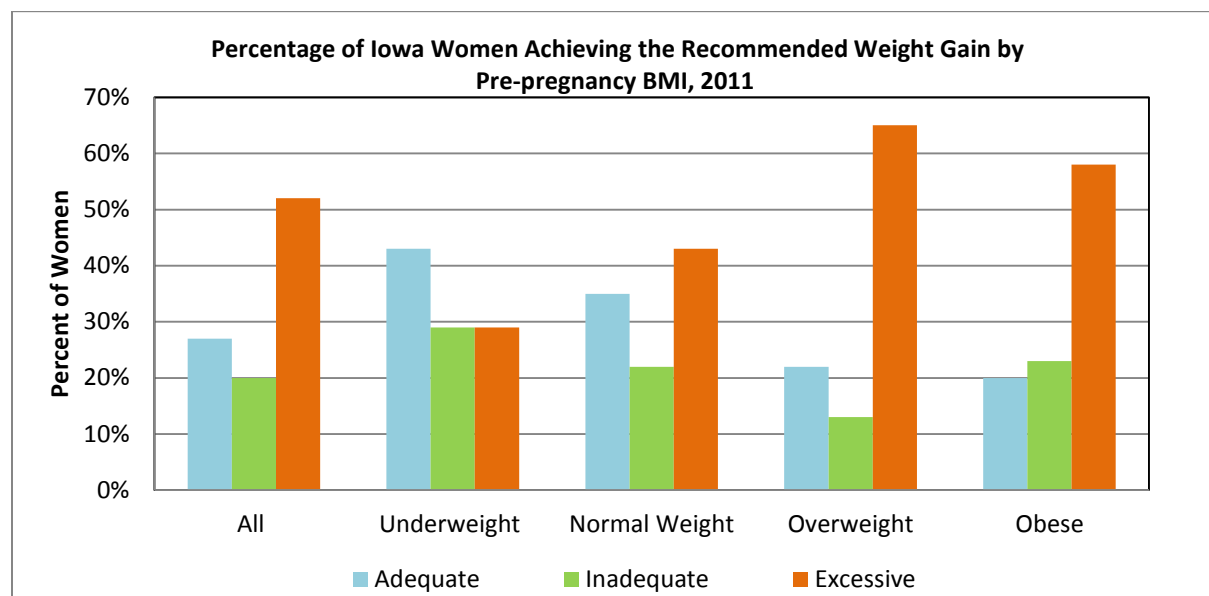
providing care coordination and referrals to women in need of further family planning education and/or counselling; providing education at third trimester and post-partum visits, including education about birth control methods; having birth control kits available at MH clinics, WIC clinics and local public health agencies, and at outreach/education classes; and training bi-lingual interpreters on RLP protocol to avoid potential language barriers due to different terminologies across cultures.



Immunizations: In the 2013 BRFSS of women of reproductive age, less than half (44%) reported receiving a flu vaccine in the last 12 months. However, in the 2013 Barriers to Prenatal Care survey distributed in hospitals to women who just delivered a new baby, 60% reported receiving a flu vaccine.

Nutrition and Healthy Weight Management: In 2013, 84.3% of women of reproductive age reported eating **less** than the recommended five servings of fruits and vegetables per day. Only 16% of Iowa women enrolled in WIC consumed a daily multivitamin before becoming pregnant. White women were more likely than African American and Hispanic women to take a daily multivitamin (18%, 9.5% and 13%, respectively). In 2013, nearly 58% of Iowa women age 18-44 years met the recommended levels of physical activity for either strength or aerobic exercise. White women were more likely to reach recommended levels, as were women with increasing household incomes.

Postpartum weight retention can lead to maternal obesity and complications during subsequent pregnancies. Women who retain one BMI unit (approximately 7 lbs.) over their pre-pregnancy BMI are at 20-40% higher risk of developing gestational diabetes, hypertension and having a large for gestational age baby during their next pregnancy¹⁷. This is worrisome given that 52% of all women in Iowa experience excessive gestational weight gain. Excessive weight gain is more common among overweight and obese women.



Diabetes and Hypertension: In 2013, 2.6% of women of reproductive age reported ever having been diagnosed with diabetes, with little difference by race/ethnicity. However, Type II diabetes diagnosis decreases with increasing income. Six percent of women in households earning less than \$15,000 reported having been diagnosed with diabetes, compared to less than 1% of women in households earning more than \$75,000. In 2013, 9.2% of women of reproductive age reported ever having been diagnosed with high blood pressure.

¹⁷ Villamor, E., & Cnattingius, S. (2006). Interpregnancy weight change and risk of adverse pregnancy outcomes: a population-based study. *The Lancet*, 368(9542), 1164-1170.

Sexually Transmitted Infections: In 2013 there were 7,812 reported cases of Chlamydia among women aged 15-44 years in Iowa. In addition, there were 783 cases of Gonorrhea in this population. Untreated sexually transmitted infections (STIs) can lead to serious long-term health consequences, especially for adolescent girls and young women, including: pelvic inflammatory disease, ectopic pregnancy, chronic pelvic pain, and infertility. Based on CDC estimates undiagnosed and untreated STIs cause at least 24,000 women in the United States each year to become infertile.

Substance Use

See Cross-cutting section for information regarding tobacco use among Iowa women.

Alcohol Use: According to the 2011 Iowa Barriers to Prenatal Care survey, approximately 50% of women consumed at least one drink per week in the 3 months prior to becoming pregnant. One drink was defined as 12 oz. of beer, 4 oz. of wine or 1.5 oz. of liquor. Binge drinking has become more of an issue in recent years. In 2013, BRFSS reported that 23.8% of women age 18-44 years reported binge drinking in the past month. This is considerably higher than the US average of 17.6% overall. Non-White and/or Hispanic women reported heavy drinking at 3.5%, compared to 6.5% of non-Hispanic White women. Drinking can increase risk for alcohol-related effects in the fetus and newborn.

Illicit Drug Use: According to the National Survey on Drug Use and Health, 7.4% of men and women in Iowa ages 12 and older reported using illicit drugs in the past month, compared to 8.9% overall in the US during 2011-2012. Iowa's rate of illicit drug use has increased from 4.1% in 2007-2008.

In 2014, 9,067 women, ages 15-44, were screened for substance use by a licensed substance abuse treatment program in the state, and 6,120

Related National Performance Measures:

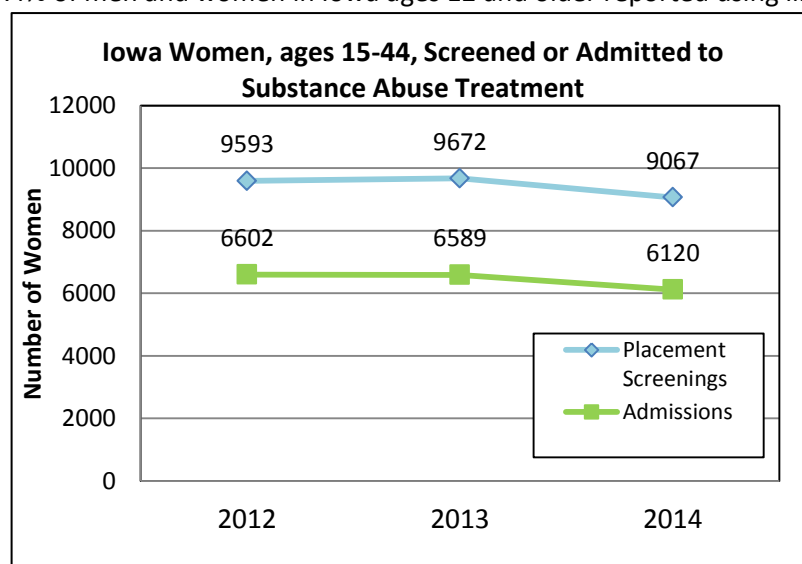
*Well-woman visit
Cesarean deliveries among low-risk first births
Infants breastfed/ exclusively breastfed to 6 months
Smoking during pregnancy
Children in households where someone smokes*

State Priority Areas:

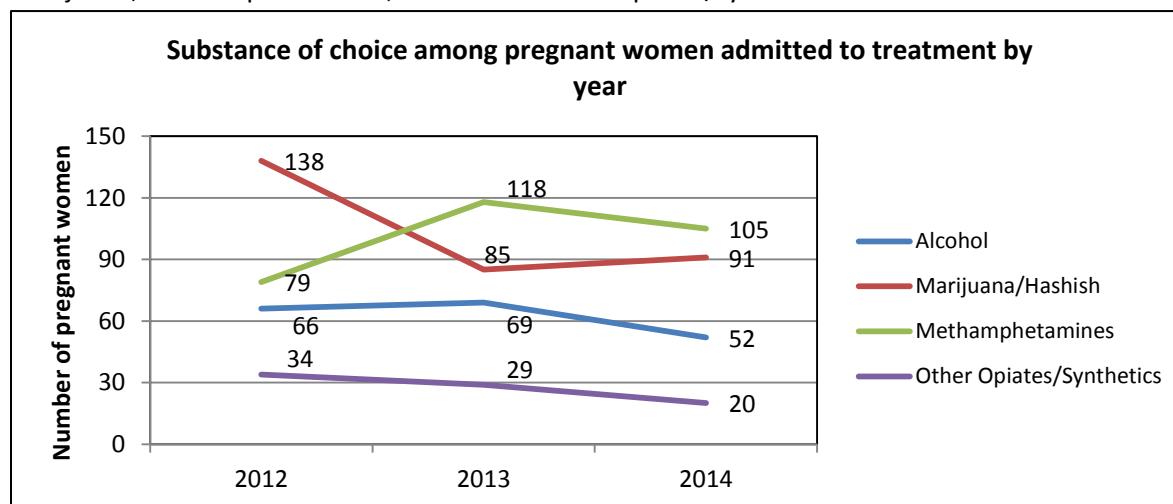
Physical activity among women of reproductive age

Related National Outcome Measures:

*Receipt of prenatal care
Severe maternal morbidity
Maternal mortality rate
Low, very, and moderately low birth weight deliveries
Early and late preterm births
Early term births
Non-medically indicated early elective deliveries
Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Sleep-related SUID rate
Fetal alcohol exposure
Neonatal abstinence syndrome*



were admitted for treatment. Similarly, 294 pregnant women were admitted for treatment, a decrease from 320 in 2013 and 345 in 2012. However, there are an unknown number of women who have not encountered the substance use treatment system in the state and are therefore, not included in these statistics. The numbers available only reflect those who have an encounter with a substance screening and were current substance users. The substances most frequently used by pregnant women include marijuana, methamphetamines, alcohol and other opiates/synthetics.



The Appendices to the *Guidelines for Perinatal Services 8th Edition*, 2008 were updated in 2013. Included in the updated version is *Appendix 19: Perinatal Illicit Substance Exposure in Infants and Pregnant Women*, which details voluntary recommendations for consent for testing, testing procedures and treatment referrals for mothers who test positive for illicit substances. Copies of the new appendices were distributed to all Iowa birthing hospital; however, an inventory of birthing hospitals implementing the recommendations has not been conducted.

Social Determinants of Health

Iowa's Title V program examined a variety of social determinants of health, particularly those that are included in the AMCHP Life Course Metrics. Below is a brief description of factors related most specifically to maternal health which were considered in the course of the Title V Needs Assessment.

Educational Attainment: Over 92% of women in Iowa age 25 and over had at least a high school education in 2013, and slightly more than 27% had a bachelor's degree or higher. However, African American and Hispanic women over age 25 were more likely to have less than a high school education than non-Hispanic White women (18% vs. 39% vs. 7%, respectively). There were over 84,000 women in Iowa with advanced degrees in 2012, and women made up almost 60% of the enrollment in Iowa's private and public universities and colleges in 2013.

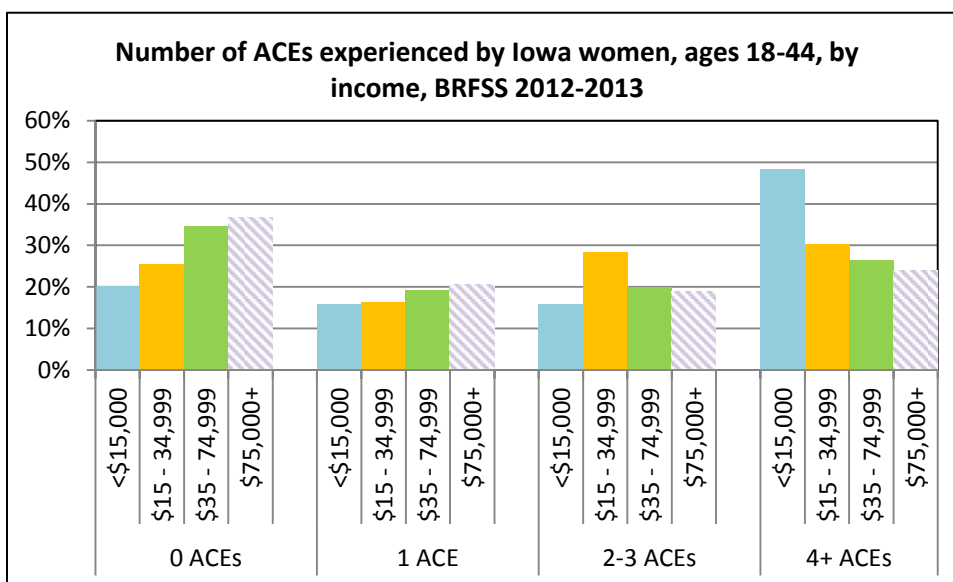
Single-parenthood: In 2012, 21.4% of children under 18 were living in single-parent households with their mother, compared to 7.7% living with their father. This compares to 70% of children living with both parents. In 2012, 39.4% of households headed by women with children under 18 years old were

below 100% of the FPL. The corresponding rate for married-couple families with children under 18 years was 5.4%. Additionally, within Iowa households headed by a woman, African American and Hispanic households were more likely to live below 100% of the FPL (62% and 51%, respectively,) compared to non-Hispanic White female headed households (37%) in 2013.

Women in poverty: Just over 14% of women in Iowa ages 18 to 64 years were considered to be living in poverty (100% of the FPL) in 2013 according to the American Communities Survey. African American women had a poverty rate of nearly 38%, which is higher than the national average (27%), and higher than non-Hispanic White women (12.5%) and Hispanic women (24.4%). In 2012, women who worked full-time in the previous 12 months earned a median income of \$35,947, compared to men who earned \$46,411. For recently pregnant women, almost 50% of African American mothers reported an income of less than \$10,000 on the 2012 Barriers to Prenatal Care Survey.

Women experiencing Adverse Childhood Experiences (ACEs): ACEs are incidents that may harm social, cognitive and emotional functioning and can upset the safe, nurturing environments children need to thrive. Studies have shown that ACEs experienced in childhood may have consequences in the health and wellbeing of a person throughout their lifetime. Iowa included ACE questions on the Behavioral Risk Factor Surveillance System (BRFSS) in 2012 and 2013, which asked adults to report on their childhood experiences. Women in households earning \$75,000 or more were less likely to have 4 or more ACEs compared to

women in households earning less than \$15,000 (24% vs. 48%). Men in this age group had a similar distribution of ACEs according to their income, however, the differences were not as stark for those with 4 or more ACEs (14% vs. 31%).



Incarcerated women: Of all women incarcerated in Iowa in 2014 (approximately 650 women), 87% are between the ages of 18 and 50 years, 79% are white and 18% are African American. Most of these women are serving sentences of 5 to 20 years. Of all incarcerated women, 320 reported having at least one dependent, with the majority of the dependents being minor children (dependent status was unknown for 100 women). Many of the women incarcerated in Iowa have a mental health diagnosis. The most commonly reported diagnoses were substance use disorders, depression and major depressive

disorders, anxiety, and posttraumatic stress disorder. Over 280 women were reported to have a substance abuse disorder.

Domestic Violence: In 2010, the National Intimate Partner and Sexual Violence Survey (NISVS), conducted by the Centers for Disease Control & Prevention estimated that 31.3% of Iowa women have experienced rape or physical violence and/or stalking by an intimate partner in their lifetime. Based on a module included in the 2005 Iowa BRFSS survey, 18.5% of Iowa adult women reported they had ever been physically hurt by an intimate partner. In the next few years, Iowa expects to obtain more specific information about lifetime and annual prevalence of domestic violence through the NISVS survey, and will begin to use that data to monitor trends in this area. Additionally, one maternal death in 2010 and one in 2012 were attributed to intimate partner violence.

In an effort to increase access to domestic violence services, Title V maternal health agencies perform domestic violence screenings and assist with referrals. Psychosocial services are offered to clients by maternal health program providers. Additionally, Title V *child* health agencies began domestic violence screenings of adult care givers in 2014 as part of services offered to families.

Medicaid Reimbursed Births: Based on the Iowa Medicaid Birth Certificate Match Reports, in 2013, Medicaid reimbursed almost 40% of births to Iowa women. The majority of births to American Indian, African American and Native Hawaiian women and those who reported they were of more than one race were reimbursed by Medicaid (80%, 75%, 72%, 72%, and 64%, respectively). In contrast, Medicaid reimbursed 36% of births to Asian women and 35% of births to White women.

The percent of Medicaid-reimbursed births among African American women decreased significantly, from 81.3 percent in 2012 to 74.8% in 2013. However, the percent of Medicaid-reimbursed births among White women increased significantly from 33.5% in 2012 to 34.8% in 2013. In 2013, 70% (n=2,221) of births to all Hispanic women in Iowa were reimbursed by Medicaid. Thirty percent (30.0%; n=952) of births to Hispanic women were not reimbursed by Medicaid, compared to 36% (36.2%; n=12,990) of births to non-Hispanic women were reimbursed by Medicaid. Sixty-three percent (63.8%; n=22,845) of births to non-Hispanic women were not reimbursed by Medicaid.

Medicaid reimbursement for births is inversely related to the mother's age. For example, in 2013, 77% of births to girls ages 17 and younger (76.6%; n=454) were reimbursed by Medicaid. However, just 24% (23.9%; n= 3,508) of births to women ages 30 and older were reimbursed by Medicaid.

Food Security: In 2012, 12.7% of all people in Iowa were food insecure. Of these, 40% were living above the 185% of the FPL threshold for all nutrition supplementation programs. Participants in the 2014 Title V Focus Groups reported despite accessing WIC and SNAP, that it was still difficult to eat healthily.

"Even if you get WIC and Food Stamps, it's hard 'cause you have to eat healthy, but a hamburger costs less than a salad."

- Title V Maternal Health Client

Women/Maternal Health Programmatic Approaches

Efforts and Activities to be Continued

- Iowa's Title V **Maternal Health Program** is a public-private partnership serving over 9,000 women annually. Services are provided by 21 community-based maternal health agencies covering all of Iowa's 99 counties. Agencies are able to:
 - provide services to improve birth outcomes and maternal and infant health, with a particular focus on reducing health disparities and ensuring racial equity;
 - help pregnant women establish medical and dental homes for their pregnancy
 - improve health care by linking women to community-based, culturally appropriate services, and supporting their ability to get the services they need; and
 - recognize the values of psychosocial support in promoting healthy pregnancy.
- As with the Child Health program, the existing **IDPH-Medicaid working relationship** should be continued and monitored for new and expanded opportunities to promote client access to care. This supports the federal mandate for collaboration between Title V and Title XIX. The current quarterly meeting of the Medicaid Maternal Health Task Force provides an excellent opportunity to address emerging issues and implement quality improvement practice and policy change. Monthly meetings are also held with representatives from the IDPH maternal health staff and Medicaid.
- **Epidemiological support** to ensure evidenced-based programming and policies is provided through Iowa's MCH CDC Assignee, who has been with the IDPH since 2004, the addition of the PRAMS grant in 2011 and a Council of State and Territorial Epidemiologist (CSTE) Fellow starting in 2014. Currently, a report that links Vital Records data from birth certificate to Medicaid claims data is done on an annual basis with analysis of the data being completed by the MCH Epidemiology staff. MCH Epidemiology staff provide support in tracking progress towards national, state and Healthy People 2020 performance measures, as well as assisting with annual report to the Iowa Legislature on the Obstetrical workforce in the state. Epidemiology staff is also providing Statewide Perinatal Care Program with hospital-specific data for use in site visits.
- Top initiatives for the **OB Statewide Task Force** include:
 - reducing preterm births by reducing early elective deliveries (<39 weeks) and increased use of 17P
 - screening for critical congenital heart disease
 - reducing maternal adverse events through a focus on safe and consistent use of Pitocin, improved management of hypertension/eclampsia, and improved management of postpartum hemorrhage
 - improving access and communication

All of these are ongoing efforts that show a need to be continued.

- The **Regionalized System of Perinatal Care** is one of Iowa's strengths in addressing maternal health in Iowa. The Regionalized system is defined in Iowa Code, identifying the functional capacity and staff capabilities of Iowa birthing hospitals to provide care to at risk pregnant women and infants. The *Statewide Perinatal Care Program* is a team of healthcare professionals, which includes a neonatologist, a maternal/fetal specialist, a neonatal nurse and an obstetrical nurse. This team is committed to provider education and quality improvement to healthcare professionals at all of

Iowa's birthing hospitals. *Perinatal Guidelines Advisory Committee* serves as an advisory group to the Statewide Perinatal Care Program and updates Iowa's Guidelines for Perinatal Care Services, a resource for Iowa's birthing hospitals.

- **Iowa Family Planning Network** (Medicaid 1115 waiver) helps to reduce unintended pregnancies by allowing improved access to family planning services and birth control methods. Title V maternal health agencies include education on IFPN to all clients. This effort is congruent with other efforts to improve postpartum care and interpregnancy contraception use; as such the IDPH will continue to provide outreach and education on the IFPN waiver program.
- The IDPH is an outreach partner and the State of Iowa is the lead in **text4baby**, the first mobile information service designed to promote maternal and child health through text messaging. Title V maternal and child health agencies have been invited to become outreach partners and include the web enrollment button on their web page. Iowa is currently ranked 46 of 50 states in participation, so outreach efforts need to continue.

Areas of Opportunity for New Activities

- Expansion of **Listening Visits** as an intervention for postpartum depression is an opportunity to alleviate the difficulty Iowa women experience in accessing mental health services.
- **New screening programs** are being developed by Title V funded agencies, including STI screenings, more screening options for alcohol and substance abuse, as well as improving the number of agencies screening for domestic violence is needed, these are all areas for quality improvement and expansion.
- **Outreach efforts to vulnerable populations**, in particular undocumented women as they are more likely to lack prenatal care and utilize the Emergency Medicaid for non-Qualified Immigrants when delivering in Iowa hospitals, need to be improved.
- **Postpartum care** uptake and content for Iowa women is an area for improvement. Items to be addressed include improved visit rates, use of LARCs, and better data surveillance of number of Medicaid women who receive a postpartum visit. Iowa has started to address this area through efforts to promote use of LARCs. In 2014, Medicaid provided a billing mechanism for providers and hospitals to be reimbursed for LARC insertion performed immediately postpartum at a birthing hospital. Education efforts to improve implementation are ongoing.
- In 2015, **provider training** including use of simulation and team work will be held on management of hypertension, eclampsia and hemorrhage and maternal early warning signs in six regional areas across Iowa.
- The **OB statewide task force work plan** will be implemented as planned.
- An amendment to the Iowa Administrative Rules language on the regionalized system of perinatal care to restructure the level of care definitions to align with American Academy of Pediatrics 2012 article "**Levels of Neonatal Care**" is being drafted and will be put forward for the next legislative meeting.
- There are numerous opportunities for more in-depth **surveillance of maternal health issues**. For example, as the Title V program in Iowa embraces the Life Course theory as a basis for providing services, more information is needed about maternal morbidity in Iowa. The Perinatal Periods of

Risk is a new undertaking in Iowa as an evaluation of Iowa's plan for immediate postpartum LARC insertion.

Perinatal/Infant Health

Overview of Health Status for Infants

Iowa's successes in maternal health have led to healthy infants. Iowa has a low infant mortality, with 4.2 deaths per 1,000 live births. Iowa's babies also generally have a healthy weight at birth and only 11.1% are born preterm. Racial disparities do exist across all of these outcomes, as Iowa's African American infant mortality rate (11.7 per 1,000 live births) is three times higher than it is for non-Hispanic White infants (3.7).

Iowa's infants generally start their life healthy. Iowa is successful in providing early screenings for babies, with tests for 51 conditions, including metabolic screenings, hearing screenings and critical congenital cardiac defect screenings. Later in the first year of life, 32.1% of Iowa infants are breastfed at 1 year, more than the national average of 27%, though Iowa is still below the Healthy People 2020 objective. Iowa also has developed programs to address Shaken Baby Syndrome and is increasing efforts to increase the number of infants who are put to sleep in a safe sleep environment.

Summary of the Strengths and Needs of Perinatal/Infant Health

Strengths

Iowa's strengths in Perinatal/Infant health are based on the success of earlier programs. Iowa's infant mortality rate is relatively low, below the national average. The strongest contributor to infant mortality nationwide is preterm birth¹⁸. The percentage of Iowa's infants born prematurely has been on the decline since 2006. Iowa has also had tremendous success recently in reducing the number of early elective deliveries.

Iowa's Regionalized System of Perinatal Care is the department's program for stratification of care in an increasing order of intensity and complexity for both maternal and neonatal care. Iowa has been utilizing a perinatal regionalization system since the 1970s, and the state has begun a modernization effort to meet the new American Academy of Pediatrics (AAP) Levels of Neonatal Care and American Congress of Obstetricians and Gynecologists (ACOG) consensus statement. For 2012, 82% of very low birth weight (VLBW) infants were delivered in a Level III hospital.

Iowa's *Statewide Perinatal Health Care Program* consists of a team of health care professionals contracted by the IDPH to support the regionalized system of perinatal care and provide services to decrease perinatal morbidity and mortality. The team provides education for Iowa health care professionals to promote evidence-based and evidence-informed care of pregnant women and newborns. The Perinatal Program provides consultation to regional and primary providers of perinatal care and promotes practice changes when needed through sharing best practice ideas, policies, and procedures. The Program promotes maternal-fetal transfer if the delivery of an at-risk infant is anticipated and a higher level of care is expected.

¹⁸ Callaghan, W., MacDorman, M., Rasmussen, S., Qin, C., & Lackritz, E. (2006). The Contribution Of Preterm Birth To Infant Mortality Rates In The United States. *Pediatrics*, 118(4), 1566-1573.

Iowa has successfully implemented an evidence-based curriculum, *The Period of PURPLE Crying*, statewide. The program aims to reduce the number of babies who have shaken baby syndrome and abusive head trauma. Currently 87% of births occur in hospitals teaching *The Period of PURPLE Crying* to all new birth parents.

The early screening programs are also an area of strength for Iowa. Iowa has strong programs for both Early Hearing Detection and Intervention (EHDI) and Iowa Newborn Screening Program. All of the recommended conditions on the Universal Screening Panel are included in Iowa's newborn screening panel. Results show that of those needing treatment for positive screening results, 100% are receiving follow-up and treatment.

Needs

Iowa would benefit from stronger programs in Perinatal/Infant health. Iowa is participating in the MCHB Collaborative Innovation and Improvement Network (ColIN) to Reduce Infant Mortality. This is a multiyear, national movement engaging federal, state and local leaders, public and private agencies, professionals and communities to employ quality improvement, innovation and collaborative learning to reduce infant mortality and improve birth outcomes. The Iowa ColIN focuses on the following three strategy areas: 1) SIDS/SUID/safe sleep, 2) preconception/inter-conception health, and 3) prevention of preterm and early term births. Again, while Iowa has a relatively low infant mortality rate of 4.2, the rate for non-Hispanic African Americans is 11.7, more than three times the rate of 3.7 for White infants.

Sleep related mortality is a significant cause of death for Iowa's infants. Sleep related deaths reported by Iowa's Child Death review team include those involving unsafe sleep position, conditions or environments, and cases of sudden unexplained infant death (SUID or SIDS), and any undetermined/unknown cause of death. The incidence of these deaths has not changed over the last five years. Many of these deaths are preventable. In 42% of the deaths, an infant was sleeping with a blanket, 23% in the presence of a pillow, and in 29% there was co-sleeping with an adult. This is an opportunity for prevention.

Breastfeeding is associated with decreased risk for infant morbidity and mortality, as well as maternal morbidity, and provides optimal infant nutrition. The Healthy People 2020 Goals establishes breastfeeding initiation, continuation, and exclusivity as national priorities.

The Maternity Practices in Infant Nutrition and Care (mPINC) Survey is a national survey from the CDC that assesses infant feeding care processes, policies, and staffing expectations in maternity care settings. Of the 79 eligible facilities in Iowa, 94% participated in the CDC's 2013 mPINC Survey. Iowa's state mPINC score was 69 (out of 100), ranking Iowa 45th out of 53 participating states and territories. There are many opportunities to protect, promote, and support breastfeeding in Iowa. Opportunities including initial skin to skin contact with infant, initiating breastfeeding within the first hour of life, not separating mother and infant during hospital stay, improving staff training on breastfeeding education and breastfeeding policies that includes all ten Baby Friendly Hospital model policy elements.

Immunization reporting is not mandated by state law in Iowa. The IDPH's immunization database, Immunization Registry Information System (IRIS), contains only records for children whose providers choose to submit data. This makes it difficult to quickly make an assessment of an infant/child's immunization status as many private health care providers do not document in IRIS.

Anecdotally, Neonatal Abstinence Syndrome seems to be an emerging issue in Iowa. The IDPH has initiated a more in-depth look at this issue starting with Medicaid as an initial data source. Eventually, IDPH would like to look at women participating in private insurance programs as well.

There are threats to a regionalized system of care. This primarily relates to reimbursement rates based on the hospitals assigned level of care and the growth of hospital systems which encourage the transfer of patients within a hospital network rather than geographically structured systems. Evidence suggests that survival and outcomes of low birth weight infants are better if the infant is born at a Level III center.

Detailed Description of Perinatal/Infant Health

Delivery Outcomes: Infant Mortality Rate, Low Birth Weight and Preterm Births

Iowa's infant mortality rate was 4.2 per 1,000 live births in 2013, lower than the US average of 6 per 1,000. The 2013 numbers continue a downward trend over the last 5 years. There are significant racial disparities in the infant mortality rate, with the African American rate (11.7 per 1,000 live births) three times as high as the non-Hispanic White rate (3.7) in 2013.

Iowa also does better than the national average on the percent of births that are low birth weight, with 6.6% of births in Iowa vs the national average of 8.0%. African American women are more likely to give birth to low birth weight babies than other races (10.9%).

Related National Performance Measures:

Very low birth weight born at Level III+ facility

State Priority Area:

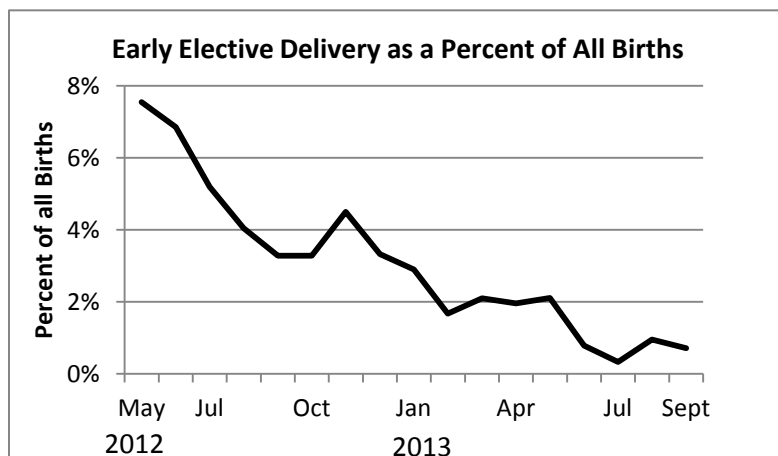
None

Related National Outcome Measure:

Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates

Non-medically indicated early elective deliveries

Children in excellent or very good health



Through a partnership with the Iowa Healthcare Collaborative, a provider led nonprofit, Medicaid and the IDPH, Iowa has had tremendous success reducing the number of early elective deliveries, reducing the rate by 90.6% between May of 2012 and September of 2013 from 7.6% of all live births to 0.7%. 11.1% of births were preterm in 2013, below the national average of 11.4%. This partnership has provided educational materials to physicians

and helped them develop new policies and performance plans to reduce the number of early elective deliveries.

Iowa is working to improve the percent of births born in the appropriate perinatal regional hospital, as the majority of maternal mortality and poor outcomes for the infant occur in lower level hospitals¹⁹.

Iowa has had a regionalized system of care for many years, but is updating the definitions to align better with 2015 ACOG and Society for Maternal-Fetal Medicine's 2015 Obstetrical Care consensus document²⁰ and the 2012 AAP article on levels of neonatal care²¹.

Breastfeeding

In 2013, Iowa women initiated breastfeeding at the same rate as the national average, 76.5%. Iowa women are more likely to continue breastfeeding for longer and breastfeed exclusively. However, on all measures relating to breastfeeding, Iowa still fails to meet the Healthy People 2020 objectives. On the Barriers to Prenatal Care Survey, 78% of women reported that they had discussed breastfeeding techniques with a healthcare professional and 83% of women reported that they were encouraged to breastfeed in the first 24 hours. The survey also shows that a higher percentage of White and Hispanic mothers are receiving support from healthcare professionals for breastfeeding than African American women.

Related National Performance Measures:

Infants breastfed/ exclusively breastfed to 6 months

State Priority Area:

None

Related National Outcome Measure:

Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates

Sleep-related SUID mortality

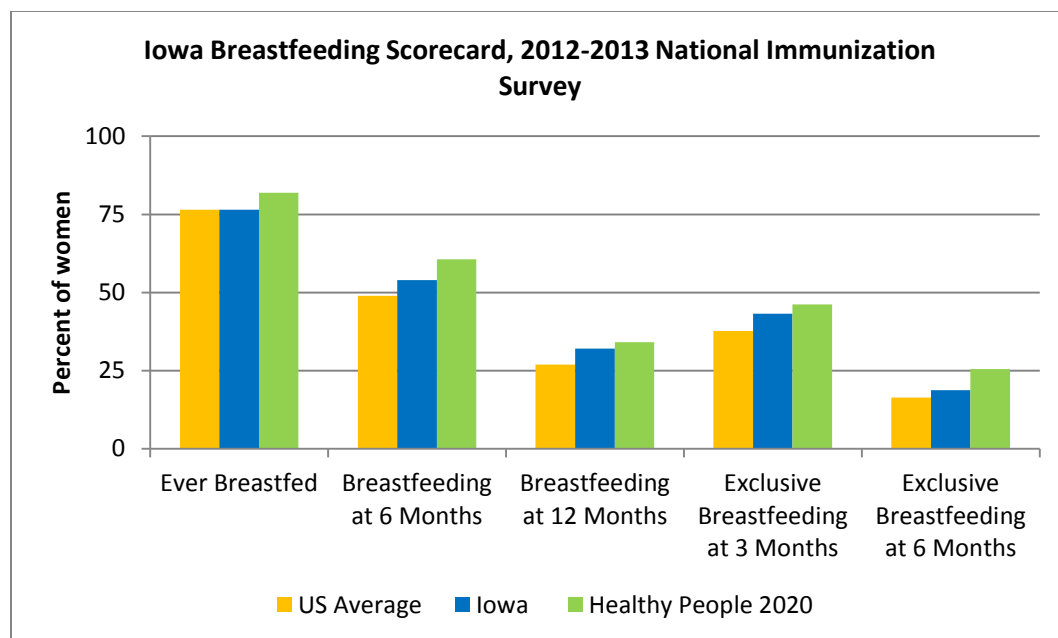
Low birth weight and preterm birth rate

Children in excellent or very good health

¹⁹ Hein, H. (2004). Regionalized perinatal care in North America. *Seminars in Neonatology*, 111-116.

²⁰ Levels of maternal care. Menard, M. Kathryn et al. American Journal of Obstetrics & Gynecology , Volume 212 , Issue 3 , 259 – 271. Retrieved from www.acog.org/-/media/Obstetric-Care-Consensus-Series/oc002.pdf?dmc=1&ts=20150331T1336118116.

²¹ Levels of Neonatal Care. Committee on Fetus and Newborn. Pediatrics. Vol. 130 No. 3 September 1, 2012 pp. 587 -597 (doi: 10.1542/peds.2012-1999). Retrieved from <http://www.pediatrics.org/cgi/doi/10.1542/peds.2012-1999>.



Iowa's hospital system is not as supportive of breastfeeding as the rest of the nation. The 2011 Maternity Practices in Infant Nutrition and Care Survey found that only 10.1% of the hospitals had more than 90% of infants who are rooming-in, compared to the national average of 37.0%. Furthermore, 47.9% of Iowa's hospitals have 90% of babies who are skin-to-skin, as opposed to the national average of 54.4%. However, several Iowa hospitals are working towards Baby Friendly Certification, and one has already received it. Baby-Friendly Certification is an accreditation program that shows that hospitals are using best practices, especially related to breastfeeding initiation. Iowa was one of only ten states with no hospitals certified in 2013.

Safe Sleep and Shaken Baby Syndrome

Between 2009 and 2013, Iowa reported only five diagnosed cases of Shaken Baby Syndrome. However, there were 651 children younger than 1 year old who were discharged from the hospital with a diagnosis of Abusive Head Trauma (AHT) in the same time period. Iowa used the narrow definition of AHT in determining these numbers²². There were 158 deaths due to SIDS from 2006 to 2011.

In the 2013 Barriers to Prenatal Care Survey, 53% of

Related National Performance Measures:

Infants placed on back to sleep

State Priority Area:

Access to quality child care

Related National Outcome Measure:

*Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Sleep-related SUID mortality
Low birth weight and preterm birth rate
Children in excellent or very good health*

²² Parks SE, Annest JL, Hill HA, Karch DL. *Pediatric Abusive Head Trauma: Recommended Definitions for Public Health Surveillance and Research*. Atlanta, GA: Centers for Disease Control and Prevention; 2012.
<http://www.cdc.gov/violenceprevention/pdf/pedheadtrauma-a.pdf>

women reported that they had discussed sleep positions with a healthcare professional, and 45% reported that they had discussed the dangers of shaking an infant.

Iowa is already taking steps to reduce the number of deaths due to SIDS and Shaken Baby Syndrome. Over 87% of births occur in hospitals that are participating in the shaken baby prevention. Iowa is also piloting a program to provide free cribs to any family who wants one in four of the highest risk counties for SIDS deaths.

Early Screenings

Iowa has strong infrastructure for performing early screenings on its infants. Iowa has recently expanded the types of screens that newborns receive. As of October of 2013, all birthing hospitals report universal screenings of newborns. Examples include screens for Phenylketonuria, Congenital Hypothyroidism, Galactosemia, Sickle Cell Disease, Biotinidase Deficiency, Cystic Fibrosis, and Congenital Adrenal Hyperplasia. Iowa's system also follows up all positive screenings for confirmation, and all infants that required treatment received it. Iowa law requires newborn hearing screenings for all infants. The state provides funds to the EHDI program to pay for hearing aids for uninsured children. In 2013, 23 children under the age of 2 years received assistance from EHDI.

Related National Performance Measures:

None

State Priority Area:

None

Related National Outcome Measure:

Percent of newborns screened and followed up with for heritable diseases

Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates

Children in excellent or very good health

Perinatal/Infant Health Programmatic Approaches

Efforts and Activities to be Continued

- Iowa hospitals have begun a **Shaken Baby Syndrome Prevention** program meant to educate new parents about healthy methods to help a crying infant. Of the 78 birthing hospitals, 63 are providing *The Period of PURPLE Crying* curriculum, including a DVD, to birth families.
- **The Early Hearing Detection and Intervention System (EHDI)** works to ensure that all newborns and toddlers with hearing loss are identified as soon as possible and provided with timely and appropriate audiological, educational, medical intervention and family support.
- In January 2015, Iowa Administrative Code 641 IAC 4 was amended to address statewide **newborn screenings** for Critical Congenital Heart Disease. All providers are required to screen all newborns for CCHD. The screening methodology uses pulse oximetry. They are required to use guidelines published by the American Academy of Pediatrics, the American Heart Association, and the American College of Cardiology Foundation.
- Iowa has four hospitals working towards **Baby Friendly Hospital Certification** and one that has already been certified.
- On January 3, 2013, **Iowa Medicaid expanded the availability of 17P** to more women to encourage its use and avoid preterm births in high risk pregnancies.
- Iowa's hospitals have been regionalized for several decades, and the program is working to **update the perinatal regionalization** definitions to match recent guidance from ACOG and Society for Maternal-Fetal Medicine.

- Iowa is participating in a **COIIN to reduce infant mortality**, focusing on 3 areas: 1) SIDS/SUID/safe sleep, 2) preconception/inter-conception health, and 3) prevention of preterm and early term births.
- **The Child Death Review team** reviews each child death to help find patterns in risk factors for childhood deaths in Iowa and to provide prevention education.

Areas of Opportunity for New Activities

- Iowa still has not met the Healthy People 2020 objective for **breastfeeding initiation and continuation**. Though many women plan to continue breastfeeding their baby, they lack the support needed to do so.
- Iowa has started a **safe sleep pilot** to increase the number of infants with a safe sleep environment. The IDPH and Meridian Health Plan are partnering with the National Cribs for Kids program. The program's goal is to reduce SIDS deaths by providing a free portable crib (i.e. a pack-n-play) to any family who does not have a crib at the time their baby is born. The pilot program has begun in four of the Iowa counties with the highest SIDS death rates.

Child Health

Overview of Health Status for Children

Overall, Iowa children are in good health. The 2011-2012 National Survey of Children's Health shows that only 2.6% of Iowa parents believe their child to be in fair to poor health. The vast majority of children (97%) are medically insured. Dental coverage for children has increased since 2005, and more young children are engaged in physical activity on a daily basis.

However, disparities continue to persist for children of low-income and minority families. This is particularly worrisome in terms of developmental delays, where almost 13% of African American children have a developmental delay compared to 3% of non-Hispanic White children. Lower-income children are more likely to be overweight or obese than higher income children. Likewise, more low-income children live in a household where one or both parents smoke.

Despite the majority of Iowa children receiving both a routine medical and dental visit, access to care (medical, dental and mental health) is of concern. Lack of specialty providers and low reimbursement rates from public insurance are primary drivers of lack of access. Transportation issues are routinely cited by families as a barrier to accessing medical and dental care.

Summary of Strengths and Needs of Children's Health

Strengths

Iowa's strengths lie in its systems and programs designed to address the ongoing health needs of Iowa's children. In Iowa, the Medicaid benefits for children in the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program uses guidance provided by *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, Third Edition, as developed by the American Academy of Pediatrics Recommendations for Preventative Pediatric Health Care.

Further, enrollment into Medicaid allows for coverage of infants ages birth to one year up to 375% of the federal poverty level (FPL), and children and teens ages 1 to 18 years up to 167% of the FPL. Nineteen and 20 year olds are covered up to 133% of the FPL through the Iowa Health and Wellness Plan or the Marketplace Choice Plan and receive full EPSDT benefits. **hawk-i**, Iowa's State Children's Health Insurance Program (CHIP), and **hawk-i** Dental Only cover children and teens ages 1 to 19 years from 167% to 302% of the FPL. Iowa has the most generous income requirements for infant enrollment in Medicaid compared to other states in the nation. For **hawk-i**, Iowa's 2014 eligibility requirements were more generous than 32 other states at 302% of the FPL.

There is a recently strengthened effort to address the assessment and interventions for developmental needs for Iowa children. The 1st Five Healthy Mental Development Initiative is a public-private partnership bridging primary care and public health services in Iowa. The 1st Five model supports health providers in the earlier detection of social-emotional and developmental delays and family risk-related

factors in children birth to 5 years and coordinates referrals, interventions and follow-up. Pending further expansion of the model, only 49 of Iowa's 99 counties are actively participating in 1st Five.

Currently, local Child Health agencies funded by Title V also utilize developmental screening tools and refer based upon need. For the 0 to 3 year population, agencies refer to Early ACCESS (Iowa's IDEA Part C interagency system for early intervention services) for infants and toddlers with a 25% delay or a condition that puts the child at risk for a delay. For those children who may not qualify for Early ACCESS, the Title V child health agency provides services through developmental monitoring and support.

Since its inception in 2005, I-Smile™ has had a significant impact on the number of low-income children receiving dental care. Compared to 2005, there was a 61% increase in children birth to 12 years receiving at least one dental visit in 2013.

Needs

Iowa continues to face issues related to accessing health services. Many of these issues are related to Iowa being a rural state, although 65% of Iowa's population 19 years old and younger lives in urban areas. There are only nine metropolitan areas throughout the state. Out of Iowa's 99 counties, 79 counties have a designated health professional shortage area (HPSA) for primary medical care, 74 counties have a designated dental HPSA, and 95 counties have a HPSA for mental health care. This illustrates the severe lack of health providers throughout the state. Clients of Title V funded agencies report transportation as one of the biggest barriers to accessing care. Additionally, while 80% of Iowa children without special health care needs are reported to have a medical home, only 68% of all children 0-19 years living below 133% of the FPL report a medical home, leading to less preventive care and more unmet needs.

Other issues that impact the health of Iowa children include dental care, healthy weight/nutrition and physical activity, unintentional injuries and developmental delays. Almost 14% of Iowa children ages 10 to 17 years are obese, while another 15% are overweight. Older children are not participating in the recommended amount of physical activity, with only 22% of 12 to 17 year olds participating in 20 minutes of exercise on a daily basis. Fruit and vegetable consumption is also low for 12 to 17 year olds, with 61% meeting the recommendation for fruits and only 19% for vegetables.

Despite decreases in recent years, unintentional injuries continue to occur in Iowa's youth. Over 9,000 injuries resulted in a visit to an Iowa hospital for in-patient or out-patient treatment. Motor vehicle accident deaths disproportionately affect male children after the age of one year. Between 2006 and 2011 there were 144 deaths of males (ages 6-17) due to motor vehicle accidents, compared to 118 deaths of females in the same age group.

According to the 2012 NSCH, minority children are disproportionately reported to be at moderate to high risk for developmental, behavioral, or social delays. Based on parent report in the 2012 NSCH, almost 50% of African American and 63% of Hispanic children are at moderate to high risk, compared to 19% of non-Hispanic White children.

Detailed Description of Children's Health

Access to Health Care

Access to health and dental care is a multifaceted issue for Iowa's families. In the 2014 Title V focus groups, parents reported lack of transportation, finding a provider, and ability to schedule visits as their primary barriers to receiving health care for their children. According to the 2013 Iowa Health Fact Book, Iowa has 8 general practice pediatricians per 100,000 people, located primarily in 30 of Iowa's 99 counties. Despite the low number of children's pediatricians and pediatric dentists, 71% of Iowa children ages 1 to 17 years received both routine medical and dental care visits in the year prior according to the 2012 National Survey of Children's Health (NSCH). According to the same survey,

Hispanic children and children in low-income families were less likely to have received both preventive medical and dental visits.

Related National Performance Measures:

None

State Priority Area:

Access to care for children, including specialty care

Related National Outcome Measure:

Child and adolescent mortality

Adolescent suicide

Autism spectrum disorder diagnosis

ADD/ADHD diagnosis

Children treated/counseled for a mental/behavioral condition

Children in excellent/very good health

Children and adolescents overweight/obese

Received routine vaccines

Received influenza, HPV, Tdap and meningococcal conjugate vaccines

The availability of transportation and interpreter services are barriers for health care access. Transportation was repeatedly identified as a barrier to accessing health and dental care in the 2014 Title V focus group discussions. To address these barriers to care, Iowa's Title V agencies offer transportation and interpreter services to their clients. From 2008 to 2013, over 11,000 transportation services and over 1,800 interpretation services were provided to Title V clients without special health care needs.

Based upon data from the 2010 Iowa Household Health Survey (IHHS), 80% of Iowa children had a medical home. This did not differ statistically by age. However, children in lower income groups were less likely to meet the definition of having a medical home; 68% of children living below 133% of the FPL had a medical home, along with 75% of those between 134% and 199% of the FPL, and 84% of those over 200% of the FPL. CYSHCN were less likely to have a medical home than children without special health care needs.

In the 2010 IHHS, of all children, 29% needed a referral to see other doctors or receive other services. Of those who needed referrals, 86% were able to receive them without a problem. In the lower income group, 46% of children needed a referral, compared with 29% of those between 134% and 199% of the FPL group. Families between the 100% and 133% of the FPL had the most trouble receiving a referral, with 26% reporting having a problem receiving needed referrals.

Social and Emotional Health

According to the 2012 NSCH, Iowa's minority children are at a higher risk for developmental delays than white, Non-Hispanic children, as are those children in households with annual incomes of less than \$20,000. Additionally, compared to the US, Iowa's minority parents have more concerns regarding their children's physical, behavioral, or social development. For example, 83% of African-American parents in Iowa had concerns, versus 45% of African-American parents nationwide. The same was true for Iowa parents in lower-income brackets who were also more concerned about their children's development compared to parents nationwide. Iowa's Title V agencies provide a safety net for the 2% of children younger than age three years referred to Early ACCESS who are not found eligible.

According to the 2012 NSCH, 10% of children in Iowa ages 2 to 17 years currently have a diagnosis of ADD/ADHD, compared to 7.9% nationally. Eight percent of children with an ADD/ADHD diagnosis in Iowa take medication for this condition, compared to 2.5% of children nationally who have a diagnosis of ADD/ADHD. Out of all Iowa CYSHCN, 35.9% currently have ADD or ADHD. This makes ADD/ADHD the most prevalent emotional health challenge faced by youth in Iowa.

In 2013, Iowa had only 43 psychiatrists seeing children, most of whom were located in three urban centers, though many providers will not accept children under age 14 as patients. According to the American Medical Association, in 2012,

Related National Performance Measures:

Developmental screening

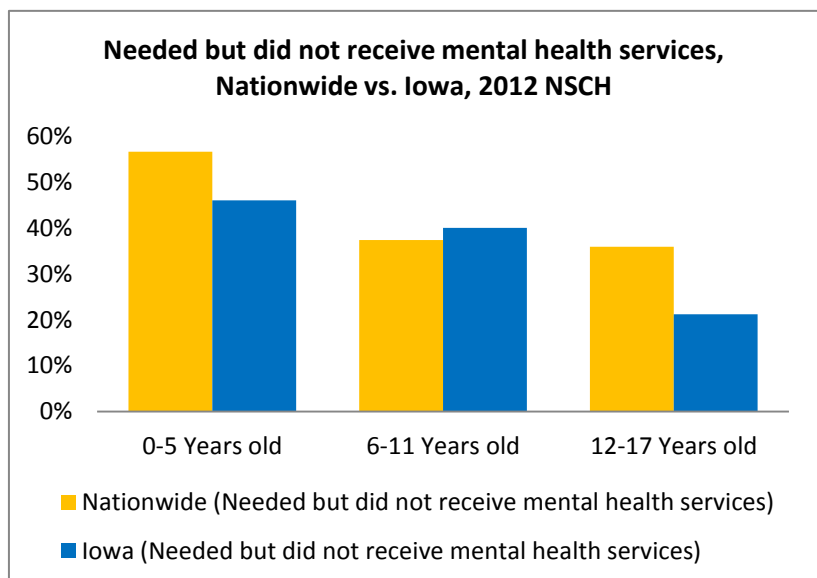
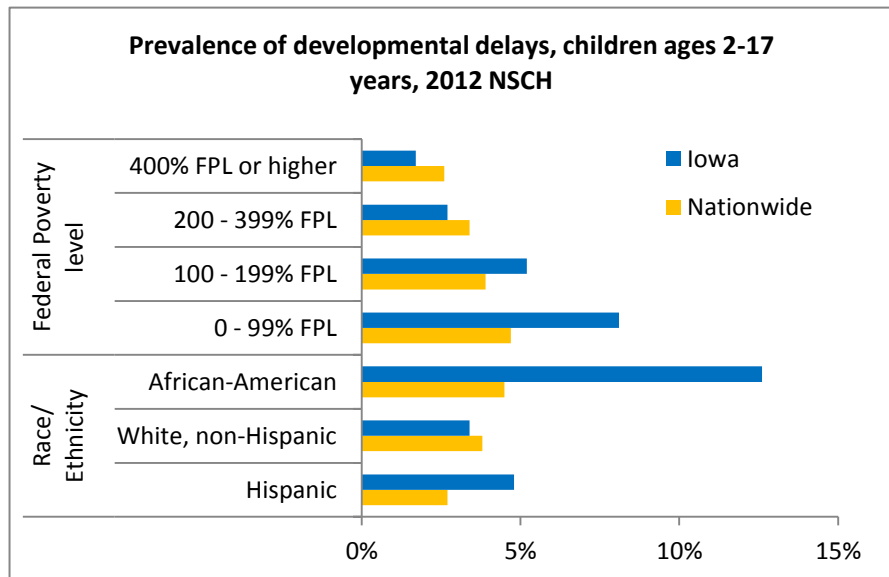
Related National Outcome Measure:

School readiness

Autism spectrum disorder diagnosis

ADD/ADHD diagnosis

Children treated/counseled for a mental/behavioral condition



Iowa ranked 42nd in the nation for child and adolescent psychiatrists. The 2010 IHHS indicated that about one in ten (9%) Iowa children and youth ages 0 to 17 years were reported to need behavioral or emotional care in the past 12 months. Among children and youth who needed behavioral or emotional care, about one in six (15%) could *not* get this care in the previous 12 months.

Environmental Health

Iowa law (Iowa Administrative Code Rule 641.67) requires children to obtain a blood test to measure lead levels prior to entering kindergarten. The IDPH recommends that children be tested regularly starting at 12 months of age, with retests appropriate to their risk level. The highest risk of child lead poisoning occurs between 1 and 4 years of age.

Related National Performance Measures:

Smoking during pregnancy
Children in households where someone smokes

Related National Outcome Measure:

School readiness
Child and adolescent mortality
Children in excellent/very good health

In 2013, 38% of children were not tested until between 3 and 6 years of age. Iowa data reveals that the state still has a significant number of children with blood lead levels higher than the Centers for Disease Control and Prevention (CDC) reference level of 5 micrograms per deciliter (µg/dL). Iowa has a disproportionate number of children with an elevated lead level that do not return for follow-up testing. In 2012, Iowa performed lead screenings on 68,673 children younger than age 6 years. There were 0.41% of children with an unconfirmed test >10 µg/dL. Twenty-four percent of the children who had a level >5 µg/dL did not receive a follow-up test within 12 weeks.

Radon has been identified as the second greatest contributor to lung cancer, following exposure to cigarette smoke or tobacco. According to the National Cancer Institutes, lung cancer can be induced by low to medium dose radon exposure in the home over time. The Iowa Radon Survey indicates that Iowa has the largest percent of homes in the United States (71.6%) that have radon levels above the EPA's action level of 4pCi/L. Iowa also has older houses, which may not have been built to properly address modern radon considerations.

Nutrition and Healthy Weight Management

According to the 2012 NSCH, almost 14% of Iowa 10 to 17 year olds were obese, with another 15% being overweight. This is lower than the national data for obese (16%) and overweight (16%) children but higher than the Healthy People 2020 goal of 9.6%. Additionally, the highest portion of children who were underweight (16%) were in the lowest income bracket. Disparities were also present by race/ethnicity. Almost 50% of Iowa Hispanic children ages 10 to 17 years were either overweight or obese compared to 25% of African American children and 26% of non-Hispanic White children.

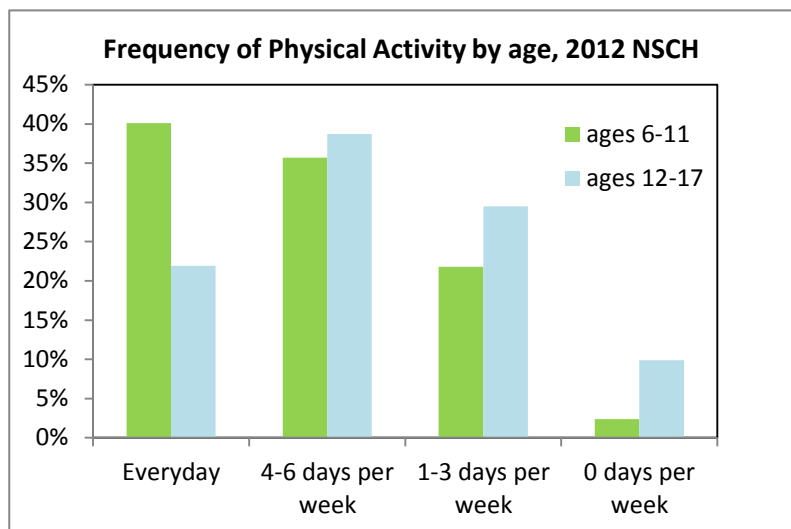
Related National Performance Measures:

Children who are physically active

Related National Outcome Measure:

Child and adolescent mortality
Children in excellent/very good health
Children and adolescents overweight/obese

According to the 2012 NSCH, children in Iowa ages 6 to 11 years were more likely to get 20 minutes of strenuous physical activity *everyday* than those aged 12 to 17. In the 2010 IHHS, approximately 80% of families reported that their neighborhoods have sidewalks or walking paths. I-Walk Schools, an Iowa walkability program administered by the IDPH and Iowa State University Extension and Outreach, and implemented by communities across Iowa, reported that an average of 19% of kids walked or biked to school during the data collection periods from 2010 to 2014.



According to the 2010 IHHS, 70% of children ate 2 or more servings of fruit per day, and 22% ate 3 or more servings of vegetables per day. Younger children were more likely to meet recommended nutrition guidelines. However, 61% of children ages 12 to 17 year olds, met recommendations for fruit consumption but only 19% met the recommendation for vegetables.

Unintentional Injury

In Iowa, although unintentional injury of children ages 0 to 14 has declined over the past few years, it is still a major issue for the state. In 2012, about 14% of children age 0 to 19 experienced an unintentional injury resulting in either in-patient or out-patient care at an Iowa hospital, down from 19% in 2010.

Related National Performance Measures:

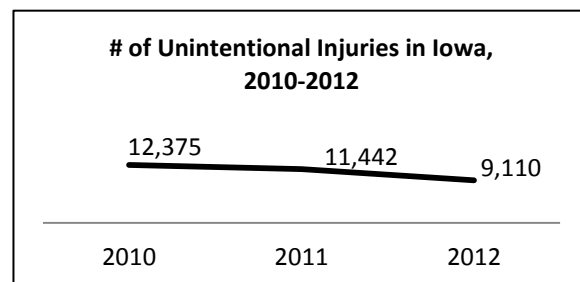
Injury-related hospital admissions

Related National Outcome Measure:

Child and adolescent mortality

Children in excellent/very good health

According to the 2011 Iowa Child Death Review Team Report, there were 342 deaths involving Iowa children ages 17 years and younger. There were 41 more deaths in 2011 compared to 2010; however, the number of deaths that occurred in 2011 is 5% lower compared to the previous five years. Of importance is the increase in deaths among children ages 6 to 12 and 13 to 17 years. From 2010 to 2011 the number of deaths among 6 to 12 year olds increased from 20 to 35 (5-year average was 30). For children 13-17, deaths increased from 68 to 78 for the same period (5-year average was 71). Deaths were due primarily to natural causes and motor vehicle accidents. In 2011 there were 18 deaths due to suicide (all in children ages 13 to 17 years old), 15 of which were in males.



The majority of deaths occurred within the Caucasian population, as expected as the majority of Iowa's population is Caucasian. However, 7% of deaths were among African American children, which is nearly twice the proportion of African American children in Iowa. A similar disparity was evident among ethnicity as Hispanics comprise only 5.5% of Iowa's population under age 18, but 9% of the children who died in 2011 were Hispanic.

The 2011 Iowa Child Death Review Team Report, further stated that after children reach the age of one year, the leading known cause of death shifts to motor vehicle accidents and continues through age 17. Motor vehicle-related deaths in children ages 6 to 17 were more often male victims than females. The deaths resulting from motor vehicle collisions can be attributed to not wearing seat belts, carelessness, and impairment. The primary types of motor vehicles involved in fatal accidents were automobiles and ATVs.

Child Care Access

There are approximately 533,000 children in Iowa under the age of 12 years, with almost half of these children between 0 and 5 years old. In 2013, almost 77% of Iowa families with children under 6 years old were households where all parents who lived in the household were active in the workforce. On the other hand, since 2008, the number of known child care slots has been decreasing.

Iowa has three basic types of child care environments:

- **Registered in-home care** – These are termed *Child Development Homes* by the Iowa Department of Human Services (DHS), include four different levels of providers, and must meet training guidelines and regulations set by DHS.
- **Licensed centers** – These include both Department of Education and DHS run centers and preschools. They must comply with requirements for personnel, staff ratios, child records, health and safety policies, activity programs, discipline policies, building standards, and food services.
- **Non-registered home care** – These providers are not monitored by DHS and are not required to meet training or regulation guidelines.

Related National Performance Measures:

None

State Priority Area:

Access to quality child care

Related National Outcome Measure:

Infant, child and adolescent mortality

Sleep-related SUID rate

School readiness

Children in excellent/very good health

Children and adolescents overweight/obese

Received routine vaccines

Received influenza, HPV, Tdap and meningococcal conjugate vaccines

According to the Iowa Department of Human Services (DHS), there are approximately 1,300 licensed centers in Iowa and over 3,500 registered in-home care providers. It is difficult to calculate an exact number of non-registered home care programs operating in the state; however, there are almost 3,000 non-registered home care providers participating in some type of DHS-sponsored program (i.e. the Child Care Food Program). One of the challenges to providing quality child care in Iowa is that the number of

providers is not stable or located where they are most needed. Also, DHS (as the regulatory agency) has historically had a difficult time in tracking the number of slots available and in what type of facility.

Iowa uses a voluntary Quality Rating System (QRS) to rate DHS Licensed Centers and Preschools, Department of Education programs, and registered in-home care (Child Development Homes). QRS was developed to raise the quality of child care in Iowa, and by extension raise the number of high-quality child care settings and educate parents about quality in child care. Of the licensed programs in Iowa, about 50% have participated in a QRS program. For registered in-home care, 14% are participating in the QRS.

According to the Iowa DHS, the number of confirmed or founded child abuse cases by a home or center-based child care provider was at 153 cases in 2009, declined in 2010 to 81 cases, and has been rising since. In 2013, the number of cases was 114. During State Fiscal Year 2014, there was one child death in a non-registered child care home, and none in a registered in-home care or licensed centers.

Social Determinants of Health

In addition to more traditional measures of children's health, Iowa's Title V program examined a variety of social determinants of health, including those that are included in the AMCHP Life Course Metrics. Below is a brief description of factors related to children's health which were considered for the Title V Needs Assessment.

In the 2010 Iowa Household Health Survey, over 10% of Iowa families reported they did not always have enough to eat, and the percentage was even higher for low income families (38%).

According to the 2012 NSCH, Iowa is ahead of the national average with over 95% of parents reporting that their neighborhood is safe. However, over 10% of families earning less than 200% of the FPL report that their neighborhood is unsafe.

Late identification of developmental delays means children may not be ready to start school. According to the Kids Count report, in 2013, minority fourth graders were less likely to be reading at the fourth grade level. Additionally, 77% of 4th graders eligible for reduced/free lunch level were not reading at their grade level, compared to 52% who were not eligible for reduced/free lunch.

Related to the home environment, according to the 2010 IHHS, 11% of Iowa children live in a household where tobacco was used, 9% with alcohol abuse, 2% with prescription or illegal drug abuse, and 2% with gambling addiction. In 2013, over 6,300 families were referred into 1st Five, 4% of those to address caregiver depression. Seven percent of all connections made were mental-health service related, including mothers, children, and other caregivers.

According to the 2011-2012 Behavioral Risk Factor Surveillance Survey, Iowa has a greater percentage of the population experiencing *no* ACEs than the general U.S. population (45% vs. 36%). More Iowans

experienced 4 or more ACEs compared to the U.S. population (14% vs. 12%). According to the 2012 NSCH, minority children and those enrolled in public insurance had a higher incidence of ACEs.

Using data provided by the Iowa Department of Human Services (DHS), Prevent Child Abuse Iowa (PCAI) analyzes issues related to child abuse and neglect. According to PCAI's annual report, in 2013, 12,276 children were abused, which is a 5% increase from the number of children abused in 2012 (11,637). Additionally, almost half of child abuse victims were under 6 years old. Almost four out of five child abuse cases in 2013 were due to denial of critical care, which indicates a parent or caretaker failed to provide adequate food, shelter, clothing, or other care necessary for a child's well-being. Additionally, each year up to 5,000 Iowa children enter foster care to address child safety or public safety. For most, foster care is a short term placement designed to allow time to address the primary reason for removal from their home and to receive the support and services necessary for children to return to their family.

Child Health Programmatic Approaches

Efforts and Activities to be Continued

- Contracts with **local MCH agencies** promote access to health care services. Providers at the community level can best meet client needs by linking to services within their local service area.
- The existing **IDPH-Medicaid working relationship** should be continued and monitored for new and expanded opportunities to promote client access to care. This supports the federal mandate for collaboration between Title V and Title XIX.
- The **Healthy Child Care Iowa** campaign works to ensure safe and healthy child care environments. This strengthens early learning and school readiness in childcare environments, where a majority of Iowa children spend a significant amount of time.
- **hawk-i** (SCHIP) outreach ensures children have access to healthcare coverage. This supports access to regular, preventive healthcare services for children as they age and grow.
- **Developmental screening** efforts, including Early ACCESS and 1st Five in local MCH agencies, provide early identification of developmental concerns and ensure appropriate referrals. Early identification supports addressing concerns at a young age to optimize growth and development.
- **Informing and care coordination** services provided through local agencies (promoting EPSDT well-visits through medical homes) help families to understand and use these benefits to promote health and prevent chronic disease.
- Continue utilization of the **Life Course metrics** as guideposts for activities designed to alleviate social determinants of health. Use of the Life Course metrics helps to ensure a broader approach to health and wellness throughout the life span. Incorporating the social determinants of health and Life Course metrics into MCH services promotes healthy Iowa families.
- Continue the expansion of 1st Five to additional counties.

Areas of Opportunity for New Activities

- **Home visiting programs** offer an opportunity for greater integration with Title V/MCH, especially as home visiting expands and patient-centered care becomes the primary model.
- **Preventing ACEs** by providing resources, services, and support for Iowa children and families is another area of opportunity and builds capacity to ensure healthy families.

- ***Lemonade for Life*** is a tool that addresses ACES for family support professionals to help build resiliency in families who have experienced adverse experiences. This strengthens the capacity of Iowa providers to serve families.
- Work with Accountable Care Organizations (ACOs) and private practice providers to cooperate on **care coordination**. This includes promoting the experience and expertise of local Title V MCH agencies on population health and care coordination services to the medical community. This allows both MCH agencies and medical providers to maximize existing resources and best serve their communities.
- Expansion of **1st Five** to statewide capacity will promote healthy mental development for all children in Iowa. Healthy mental development is crucial to ensuring school readiness and optimizing growth and development.
- Improve access to health care for Iowa families by expanding **transportation services**.
- Improve access to health care for Iowa families by expanding **interpretation services**.
- Develop partnerships to attain recommended levels of **physical activity**, which would aid in reducing the incidence of obesity and chronic disease.

See Cross-cutting section for information regarding Oral Health care access for children in Iowa.

Adolescent Health

Overview of Health Status for Adolescents

Adolescence is an important time in a person's life, as the body and brain are both in a period of rapid development. Iowa's adolescents are in mostly good health, but still have many needs that are unaddressed.

Iowa's teen pregnancy rate has declined steadily over the last 15 years. The overall teen pregnancy rate has declined by nearly 50% since its peak in 1991. This decline is seen in all racial and ethnic groups; however racial disparities still exist between young women who are non-Hispanic White and those that are African American or Hispanic.

Iowa adolescents receive well visits at a high rate relative to the national average, with 84.5% of all Iowa adolescents reporting having a preventive medical visit in the last year. However, Iowa still needs to improve the quality of the well visits and also address the disparities of the Medicaid population. Only 72% of adolescents covered by Medicaid have received a preventive medical visit in the last year, below the federal EPSDT mandate that at least 80% of children under the age of 21 receive a preventive screening.

Iowa adolescents have important mental health needs that are not always addressed. Nearly 23% of high school students reported that they had felt sad or hopeless for almost every day for two weeks. Furthermore, access to mental health professionals is difficult in many areas of Iowa.

Bullying is another important issue facing adolescents in Iowa. Surveys and focus groups have shown that the occurrence of bullying is lower in older students, and that students may be finding ways to address bullying by building stronger social connections with each other. However, too many students still report being bullied and feeling depressed. The Governor has championed an anti-bullying campaign, so Iowa is primed to address the needs of adolescents.

Summary of the Strengths and Needs of Adolescent Health

Strengths

Iowa adolescents outperform the national average across many indicators. They have lower rates of depression, and intimate partner violence is less common. Furthermore, teen pregnancy rates have shown dramatic declines, physical activity has increased between 6th and 11th graders, and substance use has declined, including an overall later introduction to illegal substances.

Needs

Teen pregnancy rates are higher in the state's minority communities than in White communities. There is lack of programming around emerging substance use such as e-cigarettes and smokeless tobacco, binge drinking and prescription drug abuse. Bullying rates are higher than the national average, and though there have been laws enacted to help reduce the amount of bullying, there is a lack of enforcement of the legislation. Another need for adolescents is for better programming awareness around intimate partner violence, such as victim assistance and reporting. Mental health access is also a

need, both receipt of counseling services and reduction of cultural barriers to accessing them sooner. Finally, there is a low rate of adolescents aged 10 to 14 who are receiving well child visits and corresponding medical care.

Detailed Description of Adolescent Health

Sexual Behaviors

In the 2011 Iowa Youth Risk Behavior Survey, 56.1% of 9th-12th graders reported that they had never had sexual intercourse, and 67.0% were not currently sexually active. The majority of respondents (95.8%) reported that their sexual debut was after the age of 13, and 93.3% of adolescents who were sexually active reported that they used at least one method to prevent pregnancy during the last time they had sexual intercourse, with 61.4% reporting that they used a condom, and 36.8% used birth control pills, IUD or implant, or a contraceptive shot, contraceptive patch or birth control ring.

Teen pregnancy is declining in Iowa, falling by 48% from its peak in 1991 to 22.1 births per 1,000 young women aged 15-19. This rate is slightly below the national average of 29.4 per 1,000 young women aged 15-19. Though the rate has fallen dramatically among all races, racial disparities still exist. The 2012 rate was 19.8 per 1,000 young women who were non-Hispanic White, while it was 51.4 for African American women and 57.9 for Hispanic women. The teen pregnancy rate is also higher in rural counties than it is in urban ones.

In 2013, there were 7,560 cases of chlamydia diagnosed among Iowans aged 15-24, making up over two thirds of all cases in Iowa. For Iowans ages 15-24, there were 808 cases of gonorrhea, which is, about 55% of all cases. Eighteen adolescents ages 15-24 were diagnosed with HIV in 2013, down from the peak of 28 in 2008.

Related National Performance Measures:

None

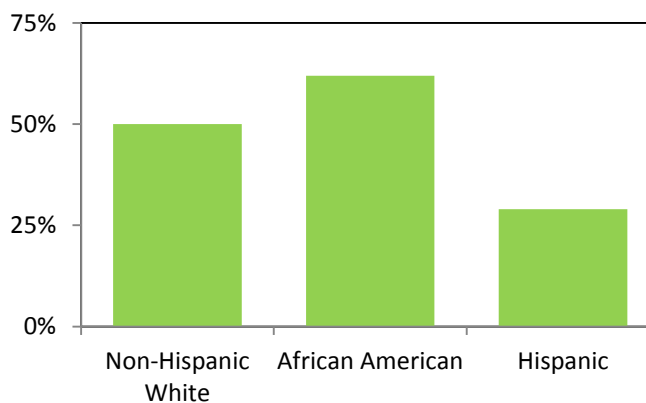
State Priority Area:

None

Related National Outcome Measure:

Maternal Mortality and Severe Morbidity
Low birth weight and early deliveries
Infant mortality rate

Percent Decline in Teen Birth Rate Between Peak (1991) and 2012



General Health and Wellbeing

In the 2011-2012 National Survey of Children's Health (NSCH), 84.5% of adolescents aged 12-17 reported that they had a preventive medical care visit in the last year, which is above the national average of 81.7%. However, Iowa is not as successful serving its Medicaid population. In FFY 2013, only 72% of Medicaid-enrolled adolescents the same age received their well-child visit, which is below the federal mandate of 80%.

Related National Performance Measures:

*Preventive visit for adolescents
Children and adolescents who are physically active
Adolescents who transition to adult health care*

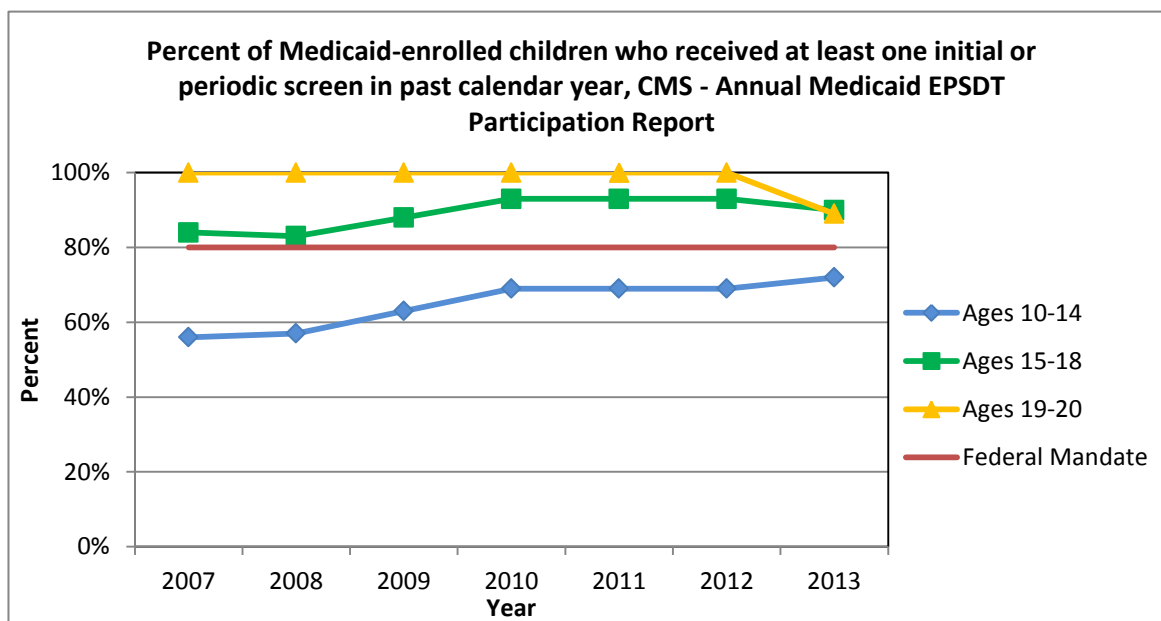
State Priority Area:

MCH population who are physically active

Related National Outcome Measure:

*Received influenza, HPV, Tdap and meningococcal conjugate vaccines
Children and adolescents overweight/obese*

In 2013, the National Immunization Survey reported that 41.9% of Iowa young women ages 13-17, and 13.7% of Iowa young men the same age have received a complete series of the HPV, approximately the same as the national average. The recommended Tdap vaccine was received by 79.6% of Iowa adolescents and 63.7% have their Meningococcal conjugate vaccine. Both rates fall below the national average. In January 2013, the IDPH Bureau of Immunization completed the administrative rules process to require a Tdap vaccine for students enrolling in 7th grade. The change requires a one-time booster dose of Tdap vaccine for applicants in grades 7 and above, if born on or after September 15, 2000, regardless of the interval since the last tetanus/diphtheria containing vaccine.



Adolescence is an important time to set many of the habits related to nutrition and physical activity. In 2011, 13.2% of high school students reported being obese and an additional 14.5% reported that they were overweight. Nearly one third of adolescents described themselves as being slightly or very overweight on the NSCH. Iowa high school students are more physically active than the national average, with 91.0% reporting being physically active for 60 minutes at least one day in the last week compared to 86.2% of the US as a whole. Though Iowa adolescents exceed the national average for

performing the minimum amount of physical activity, they are not more likely to meet the national guidelines of 60 minutes per day, according to the NSCH.

Substance use is also often initiated during adolescence. The 2012 Iowa Youth Survey shows that alcohol is the most commonly used substance among Iowa's 6th, 8th and 11th grade students with 23% of them reporting having used alcohol, and 13% reporting that they had used alcohol in the last 30 days. Of all 11th grade students, 48% reported having ever used alcohol. Tobacco use is relatively common among Iowa high school students. According to the 2011 Youth Risk Behavior Survey, 18.1% of Iowa's high school students have smoked in the last 30 days, equal to the percent of high school students in the country as a whole.

Marijuana is the next most common substance, showing a dramatic increase in use between 8th and 11th grade, with 22% of 11th graders having ever used it compared to 6% of 8th graders. Prescription drugs used differently than the doctor's direction are the next most common drug use, with 4% of all students in 6th, 8th and 11th grade reporting use in the last 30 days.

Graduation rates are another important indicator for adolescent health. Statewide, the class of 2012 had a 92% 5-year graduation rate, a slight increase over both the 2010 and 2011 numbers. African American (80% 5-year graduation rate), Hispanic (82%) and American Indian (83%) students all have lower graduation rates than their White counterparts (93%).

Mental Health and Bullying

Adolescence is an important time in mental development, and Iowa's adolescents have many mental health needs. Among Iowa's high school students, 22.8% reported that they had felt sad or hopeless for almost every day for two weeks, and 14.6% had seriously considered attempting suicide in the last year. Many do not get the help they need. Access to mental health professionals is a challenge for Iowans of all ages, including

adolescents, especially in rural areas. Between the years 2009-2013, 139 adolescents died from suicide, which is the second leading cause of death for that age group.

Bullying is increasingly recognized as a source of harm for an adolescent's mental health and wellbeing. The percent of adolescents who are bullied has remained level at nearly 57% in the 2008, 2010, and 2012 Iowa Youth Survey. The surveys also show that bullying is more prevalent in younger grades, which mirrors findings from our adolescent focus group of high school students who reported that bullying was not as much of a concern to them as it was when they were younger. The Youth Risk Behavior Survey asks students about both cyber bullying and bullying on the premises of their school, which showed that both males and females are more likely to be bullied electronically (26.4% for females and 23.5% for males), but males report higher rates of in-person bullying (18.6% vs 10.2% for females).

Related National Performance Measures:

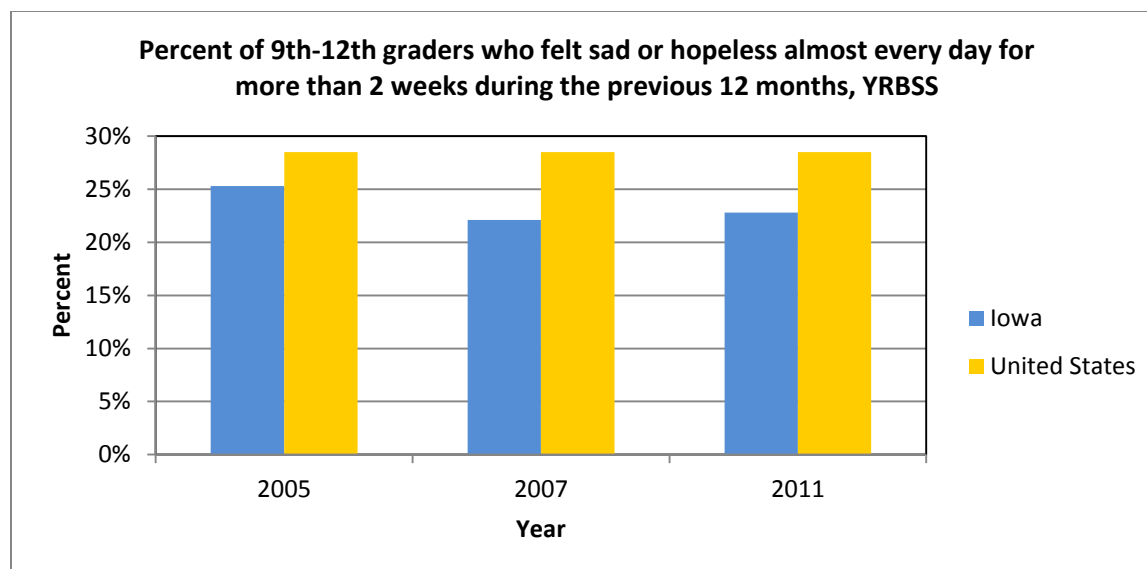
Adolescents experiencing bullying

State Priority Area:

None

Related National Outcome Measure:

Children treated/counseled for a mental/behavioral condition



Injuries and Violence

Unintentional injuries are the leading cause of death among adolescents between ages 10-24 years. Injuries from motor vehicle traffic are the most common cause of unintentional injury death, followed by falls.

Violence and sexual abuse are also challenges facing Iowa's youth. Results from the Youth Risk Behavior Surveillance System include 6.9% of teens reporting that they were physically forced to have sexual intercourse when they did not want to in 2011, 24.4% reporting that they had been in a physical fight in the last 30 days, and 6.3% had been threatened or injured with a weapon on school property in that time.

Related National Performance Measures:

Injury-related hospital admissions

State Priority Area:

None

Related National Outcome Measure:

Adolescent mortality

Adolescent suicide

Adolescent motor vehicle mortality

Adolescent Health Programmatic Approaches

Efforts and Activities to be Continued

- **The Adolescent Health Collaborative** is an intra-agency collaborative, consisting of programs and services offered to Iowa's youth. These programs include: tobacco use prevention; HIV, STI, and hepatitis prevention and awareness; substance abuse prevention and surveillance; pregnancy prevention; immunization promotion and provision; as well as programs to address adolescent health needs among minority and multicultural populations. Since the beginning of 2014, the collaborative has come together to educate one another about intra-agency adolescent health services, to reduce service duplication, and to share and leverage resources.
- **Iowa's Personal Responsibility Education Program (PREP)** is an adolescent development initiative that provides comprehensive sexuality education to assist Iowa's youth in reducing their risk of

unintended pregnancy, HIV/AIDS, and other STIs while addressing life skills to prepare youth for a successful adulthood. Since 2012, PREP has delivered evidence-based programming to more than 1,200 youth in Iowa.

- **The Abstinence Education Grant Program (AEGP)** supports decisions to abstain from sexual activity by providing abstinence education, along with mentoring, counseling and adult supervision. Since 2012, the AEGP has delivered programming to more than 560 youth in Iowa.
- **The Sexually Transmitted Disease (STD) Program** maintains a condom availability program as part of their cooperative agreement with the Centers for Disease Control and Prevention. The goals of this program include increasing condom use among sexually active individuals and subsequently reducing the incidence of STDs. There were 344,000 condoms distributed with the initial rollout to more than 70 sites in Iowa.
- **Iowa's Youth Suicide Prevention Program** includes specific steps to reduce suicides, suicidal behaviors, and suicide risk among youth and young adults aged 10-24 by implementing evidence-based screening at substance abuse treatment program, implementing an evidence-based gatekeeper training program for middle and high school educators in all middle/junior high and high schools, and reaching youth using social media. Your Life Iowa is an online resource for students, parents and educators seeking information and assistance for bullying and suicide prevention via the website, a toll free telephone hotline, and texting.
- **The Strategic Prevention Framework of Iowa** works to develop plans for prevention infrastructure and supporting selected local communities in implementing effective programs, policies and practices to reduce substance abuse and its related problems. The goals are to prevent the onset and reduce the progression of substance abuse, including childhood and underage drinking; reduce substance abuse-related problems in communities, and build prevention capacity and infrastructure at the state and community level. Prevention campaigns have included adolescent populations with Stay Classy Iowa (www.stayclassyiowa.org) and What Do You Throw Away When You Drink? (www.whatdoyouthrowaway.org)
- **Iowa Adolescents Making Choices to Control Their Future** (www.IAMincontrol.org) includes personal stories, information and resources on topics ranging from fitness and nutrition to bullying and suicide. The website, which averages 300 unique visitors monthly, includes a live chat feature and a 24/7 hotline for adolescents.
- **Iowa's Youth Development grant** provides evidence-based substance abuse prevention programming for youth that includes out-of school time activities and opportunities for character development, youth development, leadership, and community service. Funding is allocated to 8 agencies to program effective in reducing substance abuse in children and for specific out-of school youth development and service opportunities in the community.
- **Families in Focus** aims to improve treatment and recovery support services for adolescents with substance use or co-occurring substance use and mental health disorders. The goals include supporting Iowa's behavioral health providers in moving toward a more coordinated effort to service adolescents and their families, expanding and enhancing family treatment, developing Iowa's professional workforce, and process and outcome evaluation.

- **hawk-i**, Iowa's state children's health insurance program, offers two different plans, as well as a dental only plan, for children ages 1-19 needing coverage. There are currently 11,803 youth ages 13-18 enrolled in **hawk-i**.
- In recent years, the Governor's office has organized a campaign around creating a **Bully Free Iowa**, including a statewide summit and promoting legislative action to provide resources for students, parents and schools to address bullying.

Areas of Opportunity for New Activities

- **A Well-visit Promotion and Education program** which could develop and distribute new resources. The target Population for this program would be school nurses, primary care providers, parents to provide talking points for the importance of well-visits and other adolescent health issues. This would address the important gap of 80% participation for EPSDT rate, which Iowa has not yet met the goal for children ages 10-14.
- **Positive Youth Development (PYD)** engages youth within their communities, schools, organizations, peer groups and families in a manner that is productive and constructive. PYD promotes positive outcomes for young people that are important to Iowa, such as teen pregnancy risk reduction and increased graduation rates.
- **Systems building activities for the Adolescent Health Collaborative** will be focused on continued involvement and raising awareness with new partners to address adolescent health issues both at the local and state level.
- **Mental health programs targeted at adolescents** need to be developed for our MCH agencies. Identifying the needs of agencies engaging in local bullying prevention efforts and providing necessary resources. For MCH agencies, addressing bullying will be new to their scope of services. A program to create a community of practice for sharing best practices would increase the speed at which best practices are disseminated.

Children and Youth with Special Health Care Needs

Overview of Children and Youth with Special Health Care Needs

Children and Youth with Special Health Care Needs (CYSHCN) are a diverse group ranging from children with one or more chronic conditions such as asthma, diabetes, or autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children and youth with behavioral or emotional conditions. The most common conditions among Iowa CYSHCN are: Attention Deficit Hyperactivity Disorder (40%), Asthma (35%), Anxiety, (22%), Depression (19%), Behavioral or Conduct Issues (17%), Autism Spectrum Disorder (10%), Brain Injury (7%) and Intellectual Disability (6%).

CYSHCN and their families typically receive services and supports from multiple systems: health care, public health, education, mental health, juvenile justice, and social services. CYSHCN may be served by multiple providers and community-based agencies. Many CYSHCN require extra coordination between the fragmented medical and mental health care system and outside entities such as education/schools, and social service agencies. Navigating these complex and fragmented systems of care can be difficult

for families, and are exacerbated by socioeconomic factors such as cultural issues, poverty, lack of insurance, and parental education levels.

CYSHCN move through a variety of life stages and must manage several domains as they strive to lead full and meaningful lives. The Life Course perspective emphasizes that a person's experiences during childhood and other stages can affect their health over the entire lifespan. As the child ages, the family is still involved in their life, but takes on a different role. Youth and young adults start taking a larger role in making their own decisions about their lives. Iowa's Maternal and Child Health Advisory Council has identified the need to build a system of care that incorporates a life course approach. Life course perspective strategies should be oriented towards the optimal health of all children, youth, and families at every stage of development, and also must address children across a range of needs, including CYSHCN. Applying the life course perspective to the care for children with or at risk of chronic conditions can result in positive outcomes both short and long term. These outcomes include "enhanced health and wellbeing and reduced impact and severity of chronic conditions in children and in the adults they will become."²³ The University of Iowa Division of Child and Community Health (UI-DCCH) will continue to work with stakeholders to promote a life course approach throughout the system of care for CYSHCN.

Summary of Strengths and Needs of Children and Youth with Special Health Care Needs

The strengths and needs of the CYSHCN population, as well as the strengths and needs that cross all three MCH population groups, are organized by the Lucile Packard Standards' Overall System Outcomes for CYSHCN. These standards delineate characteristics of an effective system of care for CYSHCN. Strengths and needs discussed here are gathered from the MCHB Title V Data Detail Sheets, focus groups, key informant interviews, and provider and UI-DCCH staff surveys. All statistics reported below are from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN 09/10) unless otherwise noted.

Detailed Description of Children and Youth with Special Health Care Needs

Family Professional Partnerships

Strengths

During the focus groups conducted with families of CYSHCN, most families said they felt like partners in the care that their child received at the Child Health Specialty Clinics (CHSC) regional centers administered by, Iowa's Title V Program for CYSHCN. Most families also spoke highly of the approach to shared decision-making taken by CHSC staff in Early ACCESS, Iowa's Part C Early Intervention Program.

²³ Bethell, C., Newacheck, P. Fine, A., Strickland, B., Antonelli, R., Cambria, L., et al. (2014). Optimizing health and health care systems for children with special health care needs using the life course perspective. *Maternal and Child Health Journal*, 18:467-477.

Key informants from stakeholders serving CYSHCN recognize the importance of family engagement and partnerships at the program, organization, and policy levels. Many efforts are underway statewide to incorporate families in the planning, implementation, and evaluation of services for CYSHCN.

Needs

There is a need for increased focus on shared decision-making at all levels of care for CYSHCN in Iowa. Nearly 1 out of 3 of CYSHCN in Iowa do not receive family-centered care, and the families of nearly 1 out of 4 CYSHCN feel they are *not* partners in shared decision-making for their child's optimal health. Families from diverse groups, families of children or youth with emotional or behavioral issues, and families living in poverty are less likely to report that they receive family-centered care and are partners in shared decision-making.

All stakeholders surveyed would like organizations serving CYSHCN to include families not only on advisory councils, but also on internal committees and decision-making bodies. There is a need for expanded availability of trainings for new and current family support peer specialists, as well as training for parents to help them to be partners with their children's providers and advocates for their children.

Some families explained they did not feel listened to by their child's healthcare providers or educators. Iowa needs more training for medical providers and school staff on providing family-centered care.

Medical Home/Care Coordination

Strengths

Iowa's Title V program for CYSHCN provides care coordination, family to family support, and gap-filling direct clinical services for Iowa CYSHCN ages 0-21 years. In fiscal year 2014, CHSC provided direct clinical care, care coordination, or family to family support to 6,749 CYSHCN and their families.

Based on data from the 2010 Iowa Household Health Survey, 80% of Iowa children had a medical home. However, the NS-CSHCN 2009/10 shows that only 47% of Iowa's CYSHCN received all necessary components of care through a medical home.

In 2012, a State Plan Amendment allowed Iowa Medicaid Enterprise to enroll children covered by Medicaid with a diagnosed Serious Emotional Disturbance (SED) and functional impairment into health homes, known as the Pediatric Integrated Health (PIH) program. PIH staff partner with health care providers to assure "whole-person" care. PIH program services are delivered by a team of providers and community resources and include care coordination, family to family support, health and wellness education, resource direction, family wraparound services, and transitional care support. PIH sites receive coaching, training and guidance to ensure they have the expertise and skills needed to effectively deliver specialized services. Providers are trained to work with children with SED and their families and participate in practice transformation and quality improvement activities. Providers receive support to deliver a wraparound System of Care approach that addresses multiple needs, such as physical health, mental health, education, recreation, and social services.

Needs

Iowa would like to increase the percent of CYSHCN in Iowa that receive coordinated, comprehensive and family-centered care through a medical home from 47% to 100%.

Primary care providers (PCPs) and other health care staff would benefit from learning about community and other resources for CYSHCN and how to refer CYSHCN to these services. Iowa families of CYSHCN would benefit from an increased number of qualified care coordinators collaborating with primary care medical practices, specialty clinics, and other organizations serving large numbers of CYSHCN and their families.

Insurance and Financing

Strengths

Ninety-two percent of CYSHCN in Iowa had insurance for the entire past year. All of the CYSHCN whose families participated in the focus groups had health insurance. Families agreed that having insurance opened doors to needed medical and behavioral health care. Those families covered by Medicaid felt it provided comprehensive coverage for their children.

Representatives from multiple state organizations and family advocacy groups felt the Medicaid Home and Community-Based Services (HCBS) waivers and the PIH program provide comprehensive services and support services for CYSHCN and their families. The stakeholders also highlighted the importance of Iowa's *Children at Home* program, which operates in 32 of Iowa's 99 counties and funds services and equipment for *underinsured* CYSHCN.

Needs

Despite the majority of CYSHCN having insurance, over one-third of families with insurance report that the coverage does not meet their needs. In general, many reimbursement policies of health care plans can create financial disincentives for providers to deliver comprehensive, high-quality care to CYSHCN, especially for the large number of PCPs serving CYSHCN in rural and low-income areas across Iowa.

There is also a need for a simplified application process and expanded funding for Iowa's Medicaid HCBS waiver programs.

Early and Continuous Screening and Referral

Strengths

Iowa's 1st Five Healthy Mental Development program supports the use of developmental surveillance and screening tools in primary care practices, as well as connects families of children ages 0-5 years to needed community resources upon referral from their PCP. 1st Five currently reaches providers and families in 49 of Iowa's 99 counties. This program helps to identify children who have or are at risk for developing a special health care need and connects them with early intervention services.

Early ACCESS (IDEA Part C) is Iowa's early intervention system for families of children, birth to three years old, who have developmental delays or conditions known to impact development. In fiscal year 2013, Early ACCESS served 5,931 children. Each child has all areas of their development evaluated and assessed, including nutrition and health.

CHSC regional centers universally administer developmental screens for all pediatric patients. CHSC regional centers also use standardized screening tools to screen for autism and mental health concerns.

Needs

There is a need for language in health plan contracts inclusive of Medicaid to assure early identification of CYSHCN, provision of specialized care coordination for identified CYSHCN and their families, and sharing of information across organizations and providers.

There is a lack of developmental specialists in Iowa who are able to administer a comprehensive evaluation upon a positive screen. There is a need for increased workforce development, as well as development of a process to increase access to these providers.

1st Five has been successful in identifying children with or at risk for developing a special health care need, but there is a need to expand 1st Five to all 99 counties.

Easy to Use Services and Supports

Strengths

Through pilot projects with the University of Iowa Children's Hospital, UI-DCCH delivers pediatric specialist services to CYSHCN through the Regional Centers. Nutrition, neurology, genetics, and psychiatry services are delivered via telehealth. UI-DCCH also has a number of initiatives to coordinate and integrate services for CYSHCN.

Needs

Entry points into mental health services and other specialty care need to be defined for families and implemented in an easy-to-use way, such as a publicly accessible (web-based) clearinghouse of information on available services for CYSHCN.

Expansion of telehealth services would help increase access to care and address geographic disparities for CYSHCN and their families. Although telehealth may increase access to providers, Iowa will still have a shortage of some health care professionals (child psychiatrists, providers of Applied Behavioral Analysis services, pediatricians).

Transition to Adulthood

Strengths

UI-DCCH and Iowa's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program partner to coordinate the efforts across the state related to transition, in order to assure youth with special health care needs (YSHCN) have access to comprehensive transition planning by age 14 years.

Needs

Only 45% of Iowa YSHCN received needed transition services as specified by the NS-CSHCN. The rates are even lower for racial or ethnic minority groups and for YSHCN who are uninsured, do not have a medical home, or youth with specific diagnoses.

There is a need for reimbursement policies that compensate providers for delivering care coordination and transition planning services.

Community providers noted that young adults with special health care needs would benefit from a range of supportive housing options and vocational resources, especially in rural areas. Specialized support groups and other resources would help YSHCN and their families acquire skills needed for independent living. Youth in foster care also need additional placements and support services as they become young adults.

Cultural Competence

Strengths

Overall, families of CYSHCN who participated in the focus groups said health care providers treat them with respect and are warm and accepting. Families felt that health care providers are also good at using appropriate language and explaining terms and procedures.

Needs

There is a need for efforts to increase community awareness about disabilities and the unique needs of CYSHCN, especially in rural Iowa communities. There is a need for training on how child care and other community-based organizations can partner with CYSHCN and their families. Iowa's Title V program needs to explore creative ways for engaging minority populations to better identify needs.

Iowa's Title V program needs to engage leaders within immigrant and underserved communities to discuss the most effective ways to partner.

National Performance Measures and Iowa's Progress

Medical Home

Successes

Iowa's Pediatric Integrated Health (PIH) program uses a System of Care approach, allowing CYSHCN under 19 years of age with a serious emotional disturbance (SED) and functional impairment who are eligible for Medicaid to receive coordinated, whole-person care in their communities. Wraparound funding pays for services that prevent entry into more intensive services, such as in-home skill building.

Recently expanded to all 99 counties in Iowa, the PIH program is anticipated to serve approximately 15,000 children annually.

UI-DCCH provides care coordination with medical homes through its teams of ARNPs, RNs, FNs, registered dietitians, and social workers at 15 CHSC regional centers across Iowa. ARNPs provide clinical care and coordination with subspecialists, RNs provide patient education and care coordination with medical homes, FNs provide family to family support, and Social Workers (SWs) provide coordination with social service agencies. To provide additional support to PCPs, the Division is vetting an enhanced care coordination algorithm to guide MCH Child Health Agencies in determining when a CHSC care coordinator could provide enhanced services to CYSHCN.

UI-DCCH's Regional Autism Assistance Program (RAP) has teams in 15 sites to provide care coordination with the medical home and other providers, family to family support, mid-level screenings for Autism Spectrum Disorder (ASD), and connections to Applied Behavioral Analysis (ABA) therapy.

Challenges

Although most Iowa children have a medical home, CYSHCN are less likely to have a medical home. Only 47% of CYSHCN in Iowa receive all necessary components of comprehensive, coordinated, and family-centered care through a medical home. Moreover, the majority of families of young children in the focus groups conducted in October 2014 did not feel at the center of the system, and they experienced additional stress because they did not have anyone helping them coordinate care. Parents of older CYSHCN were more likely to feel that they were closer to experiencing a coordinated and family-centered model of care, but emphasized that it had taken many years and struggles to reach this level.

Families and key informants reported that some health care providers may lack knowledge about special health care needs and knowledge of the resources available for the child and/or family. Some families, especially of children yet to receive a full diagnosis, felt that some health care providers lacked the skills necessary to develop a partnership with the child and family. Some families did not feel included when developing the treatment plan and felt it may have taken longer for their child to be diagnosed because their family's perspective was not considered.

Although the medical home model may be working in some large primary care and pediatric subspecialty practices in urban areas, some key informants noted that smaller practices and those in rural areas may struggle to deliver a medical home model with limited resources.

Variable financial reimbursement for providing comprehensive, high-quality care under the current insurance system is another challenge, particularly for PCPs serving CYSHCN. Many of the PCPs serving CYSHCN report large caseloads in rural and low-income areas of the state. Iowa's Medicaid reimbursement rates may create a barrier and challenge for PCPs to perform comprehensive screening and care coordination. Furthermore, providers working with families of CYSHCN often do not communicate with one another in a systematic way. They often lack information about existing care coordination resources in their area and face fiscal challenges to provide coordinated care. Additionally,

some providers are reluctant to screen children if resources are not available in the community for children who are identified.

Transition to Adulthood

Successes

UI-DCCH developed and piloted tools to facilitate transition planning among youth, families, and health care providers. The Center for Disabilities and Development and Psychiatry Departments at the University of Iowa Hospitals and Clinics (UIHC) recently began transition clinics for youth over age 12 with disabilities. The Division is researching opportunities to coordinate efforts with UIHC, Department of Education and other organizations serving people with disabilities to provide CYSHCN with access to transition options.

All students enrolled in public schools, including those with special health care needs, use the web-based *I Have a Plan Iowa* tool developed by the Iowa College Student Aid Commission to explore options for a career and post-secondary education. Some of Iowa's Area Education Agencies offer transition workshops and tools for YSHCN and their families on topics relevant to education and life skills. Realizing Educational and Career Hopes (REACH) is a two-year certificate program through the University of Iowa that allows students with intellectual disabilities to learn transition skills and provide a college experience.

Before Iowa created the Iowa Health and Wellness Plan in 2013 to provide comprehensive health care coverage to low income adults, lack of health insurance contributed to the health concerns of young adults. The plan offers coverage to adults age 19-64 with an income up to 133% of the Federal Poverty Level (FPL).

Challenges

Iowa's system faces several challenges in preparing YSHCN and their families for transition to adulthood. The current adult model of care is problem-focused and expects patients to self-advocate. In addition, some adult health care providers may not be equipped to serve young adults with special health care needs.

Health care providers serving adults may benefit from training to assist them in partnering and serving young adults, such as shared decision-making, addressing the developmental stages of youth and young adults, and involving legal guardians in the plan of care.

Although family focus group participants were supportive of the need for them to be engaged in transition planning for their child, many felt too overwhelmed with managing their adolescent's condition to engage in long-term planning. Families of CYSHCN with SED in the focus groups reported difficulty in obtaining an Individualized Education Plan (IEP) through their school district, despite already having a diagnosis and recommendation from the health care provider. Beginning at age 14 years, an IEP identifies the services and supports that will allow youth to live, learn, and work in the community. The

difficulty in obtaining an IEP implies that families are getting little assistance from their school district in planning for transition to adulthood or finding resources tailored for a youth or young adult with a special health care need.

Emerging State Priority Areas

Pursue the Triple Aim for the CYSHCN population.

Successes

Iowa's Health Resources and Services Administration (HRSA) funded Systems Integration Grant (SIG) uses the Triple Aim as its guide to develop a systematic approach to synergize the many activities of multiple partners, facilitate cross-system collaboration, and reduce "silos." The outcomes of the SIG will improve coordination among programs in the medical, education, and social service systems. At the family level, providers will be able to easily communicate with the family and community-based organizations, which will help ease the burden on families and reduce gaps in service and duplication of services. Family voice will be integrated into every level of the SIG to assure the needs of Iowa's families and CYSHCN are met.

UI-DCCH is exploring a value based payment methodology that supports integration across systems and would address health care costs through reimbursements for improved quality and care coordination. Iowa is exploring coordination of data systems at the community and state levels of care through health information technology and accompanying policies needed for uniform data collection policies. CYSHCN would benefit from enhanced services that are coordinated across all systems.

UI-DCCH's Family Navigator Network consists of 41 Family Navigators (FNs) employed at Regional Centers across the state. All are parents or primary caregivers of CYSHCN; the FNs provide family to family support and care coordination services in a variety of state and federally funded programs. FNs complete a 40-hour core competency training and receive ongoing peer mentoring and continuing education.

Challenges

According to the Iowa Department of Human Services as of March 2015, there are 3,929 CYSHCN ages 0-21 years on the waiting list for HCBS waivers (Health and Disability, Intellectual Disability, Brain Injury, and Children's Mental Health). Long waiting lists are due to a multitude of challenges, including a detailed application process, enrollment caps, and transportation barriers to evaluation. Families typically wait two years or longer to get insured through the HCBS waiver program.

Iowa faces major gaps and disparities in the systems serving different populations. For example, it is often difficult to coordinate mental health and behavioral health care for children in the foster care or judicial systems. First, there are multiple funding streams that provide the services needed, but they often do not allow crossover to meet the needs of CYSHCN. Second, it is difficult for community providers in one sector to obtain information on the services a child receives from another sector due to

privacy laws. Third, it is often difficult to coordinate care and maintain a consistent treatment plan if children move frequently and transition to independent living.

Although Iowa is less racially diverse than some states, its diversity is increasing rapidly. There has been an increase in new populations, resulting in small groups of people from several different countries residing within a single community. Families often lack transportation and have multiple jobs that may not allow the time off for medical appointments. Individuals may have diverse beliefs about the causes of special health care needs. This may influence the desire to seek assistance and the type of care requested. Providers in Iowa may find it challenging to tailor programs to meet the needs of small numbers of diverse populations.

Racial disparities are evident in the prevalence of CYSHCN. Twenty-one percent of African American and 20.8% of children from other groups are identified as having a special health care need (SHCN), while only 14.7% of non-Hispanic white children and 10.2% of Hispanic children have a SHCN. According to one key informant, Iowa health care providers are predominantly White, speak English as a primary language, and are not bilingual. Focus group participants felt there is a lack of understanding and awareness of disabilities among some members of the public. Addressing this need may create a more inclusive and supportive environment for CYSHCN and their families.

The prevalence of CYSHCN in Iowa increases as children age. Of Iowa's total child population, 8.5% of young children 0-5 years have a SHCN, compared to 17.2% for those 6-11 years, and 19.0% of those 12-17 years. Although Iowa has many programs to support healthy development of young children, this support drops off as children enter middle childhood and adolescence. This gap in the system is critical and has the potential to reverse the positive effects of support received earlier in life.

Poverty is a significant concern. Twenty-one percent of CYSHCN in Iowa and their families live below 100% of the FPL, and 16.2% of families live between 100% and 200% of the FPL. Poverty is associated with poorer health outcomes. Many CYSHCN with chronic conditions require ongoing provider visits and this compounds the financial problems families face. There are also income disparities based on geographic locations; among CYSHCN living below 200% of the FPL, 41% of those living in rural areas are in poverty, compared to 36% of those living in urban areas being in poverty.

Easing the burden on families is a key element of improving the patient experience. Some focus group participants noted that they currently don't have access to respite care, and many families that received respite services experienced significant delays in applying for the waiver and overcoming the challenge of finding qualified providers that were available.

While the agencies and professionals serving CYSHCN attempt to involve families on the policy and program levels, not all families experience this partnership as a part of their child's care. Families, providers, educators and other program staff may benefit from training in the provision of family-centered principles. Expanding access to both formal and informal family to family support would allow families to select the type and level of support they need.

Access to Care (Transportation and Specialty Care)

Successes

Iowa's PIH program uses a System of Care approach and serves children with SED in all 99 counties. Early results show positive effects on health outcomes for children with SED, such as a decrease in self-harm reports, emergency room visits, and school absences. Through the Child and Youth Consultation Service of Iowa (CYC-I), CHSC targets PCPs caring for children and youth 0-21 years with mild or moderate behavioral health needs. Services include psychiatric consult with a University of Iowa child psychiatrist to a PCP by phone, mental and behavioral health focused training for the PCP, web-based resources for the PCP and families, and care coordination.

UI-DCCH's RAP program provides care coordination and family to family support for children with ASD and connects their families to medical, education, and community resources. The program has community-based sites in 15 locations across Iowa. UI-DCCH's ARNPs are trained to screen children for ASD using the Screening Tool for Autism in Toddlers - MD. Children are connected to providers of evidence-based ABA services either in person or through telehealth, although there are shortages of ABA service providers.

CHSC ARNPs and RNs also provide nutrition and health assessments for young children in their communities, which are shared with the children's medical homes.

Challenges

Iowa is a rural state and resources are not evenly distributed. CYSHCN living in rural areas may experience less access to services. Of Iowa's 99 counties, 79 are designated rural. Iowa has 9 communities of approximately 20,000 residents each and three small urban areas, which leads to a shortage and unequal distribution of both primary care and specialty providers.

There are very few pediatricians and fewer pediatric subspecialists working in rural areas of the state, where one-third of Iowa's population resides. Furthermore, 80% of psychiatrists are concentrated in the state's three most populated cities. Many families lack financial resources, or do not have the ability to take time off from work to travel to urban areas for appointments. As a result, rural families depend on local PCPs who may lack training in diagnosing and treating CYSHCN. Most rural PCPs do not have access to locally-based pediatric specialists. Families who travel to tertiary centers may face access and fiscal challenges. Reforming payment to cover telehealth and training providers could alleviate some problems with accessing specialists.

There is a lack of access to services for school-age children with SED. There has been attention on screening and early intervention during the first few years of life, but there is a growing unmet need for behavioral health services for school-age children, particularly for those with mild or moderate conditions. Many of Iowa's health care providers and educators also need training on the impact of trauma and in utilizing a trauma informed approach to care delivery.

Although the PIH program has shown positive child and family outcomes, the population served is limited by payer, condition, age and it currently excludes many CYSHCN who could benefit from the PIH care delivery model. Similarly, 1st Five has been beneficial to participating children and their families, but there is a continued need for families of all CYSHCN regardless of age or geographic location to share in decision-making with their PCP and access resources after a screening indicates the need for follow-up.

Access to Child Care

Successes

Iowa now provides financial incentives for child care providers who serve CYSHCN, and a few providers in urban areas are receiving these incentives.

Challenges

Child care facilities serving CYSHCN often have waitlists of at least one year, and few are located in rural areas. Families of CYSHCN often need to stop or reduce working hours to care for their child. Key informants noted that some child care providers also lack training on the unique needs of CYSHCN.

Physical Activity

Successes

CHSC clinicians are trained in motivational interviewing and regularly discuss physical activity needs of CYSHCN and their families. FNs help families overcome barriers and advocate for their child's inclusion in recreational programs. CHSC also educates other providers on the unique needs of CYSHCN relating to physical activity and resources available to them.

Challenges

Several studies have shown that people with disabilities are more likely to be sedentary²⁴. CYSHCN often experience unique barriers to physical activity, including the child's own functional limitations, the high cost of specialized programs and equipment, and a lack of nearby facilities or programs.

Bullying

Successes

UI-DCCH conducts various initiatives to reduce bullying, including training CHSC regional center staff to discuss and address bullying with CYSHCN and their families. CHSC added questions regarding bullying to intake forms and developed lists of community resources for families of CYSHCN who experience bullying.

²⁴ Rimmer, James K., PhD, Jennifer L. Rowland, Ph D, PT, MPH, and Kiyoshi Yamaki, PhD. "Obesity and Secondary Conditions in Adolescents with Disabilities: Addressing the Needs of an Underserved Population." *Journal of Adolescent Health* 41 (2007): 224-29.

Challenges

Children and youth with disabilities are two to three times more likely to be victims of bullying than their non-disabled peers, and current data shows no decline in bullying. More initiatives centered on CYSHCN and bullying are needed.

CYSHCN Programmatic Approaches

Efforts and Activities to be Continued

- Provide care coordination and family to family support through Community Child Health Teams (CCHTs) in 15 CHSC Regional Centers throughout Iowa. FNs, RNs, SWs and ARNPs will continue to comprise the CCHTs.
- Partner with the Health and Disease Management program, also administered by UI-DCCH, to inform policy and provide care coordination for CYSHCN in the Health and Disability HCBS waiver program.
- Utilize care coordination standards UI-DCCH created in accordance with the Standards for Systems of Care Serving CYSHCN developed by the Association of Maternal and Child Health Programs (AMCHP) and the Lucile Packard Foundation. Integrate the Care Coordination Standards into practices of other entities in Iowa.
- Spread the use of transition tools UI-DCCH developed and pilot tested, to assist youth, families, care coordinators, and PCPs in planning for the transition to adulthood. Continue to examine policy barriers and best practice strategies relating to transition to adulthood.
- Assure families are involved at all levels of decision making by including family members on advisory committees and MCH Title V Block Grant review teams. Continue the Family Advisory Council CHSC created in 2014, comprised of 14 family representatives and two youth members. Train and mentor participants on peer to peer support and advocacy. Continue to partner with Family to Family Iowa, an advisory group to Iowa's Family to Family Health Information Center to enhance networking among UI-DCCH family resources and other Iowa family advocacy groups.
- Utilize telehealth to improve access to families living in underserved areas of the state and continue partnerships with the Center for Child Health Improvement and Innovation (CCHII) to increase telehealth availability.
- Participate as LEND faculty to inform pre-service interdisciplinary professionals of CYSHCN needs and Title V system of care principles.

Areas of Opportunity for New Activities

- Maximize opportunities to work with contracted Medicaid Managed Care Organizations to enhance their program of services for CYSHCN, as Iowa enters into an expanded managed care environment within proposed state-level initiatives through the Iowa Medicaid program. New managed care initiatives will include children who are covered by Medicaid as well as **hawk-i** (Iowa's SCHIP program) and children whose coverage is provided through all of Iowa's HCBS waiver programs.

- Partner with HRSA Systems Integration Grant (SIG) and Regional Autism Assistance Program (RAP) to post tools and training on SIG web portal for families, including shared decision making tools to enhance family-provider interaction, self-advocacy resources, and other information needed by families and providers of CYSHCN.
- Identify “things to look for when choosing health insurance” that are common to the needs of many young adults with special health care needs. Educate health insurance navigators and families about these needs and the principles for their delivery.
- Collaborate with the RAP Advisory Committee to expand the payer network for Applied Behavior Analysis (ABA) therapy in Iowa to include more private insurers and reduce other barriers to ABA availability in rural areas.
- Coordinate transition systems building efforts with other youth-serving systems such as the Iowa Department of Education, Vocational Rehabilitation, and the Parent Training Information Center.
- Investigate value-based payment methodology as part of Iowa’s new CYSHCN state performance, to achieve the Triple Aim for the CYSHCN population: 1) Lower costs; 2) Improved patient experiences; 3) Better patient outcomes.
- Explore new methodologies to disseminate materials to families and providers, including use of social media and web portal accessibility.
- Provide information and educate PCPs, pediatric specialists, community providers, and health plans on community resources for referral upon assessment.
- Collaborate with the IDPH grantees, 1st Five providers, and other health care delivery systems to assure children with complex needs receive care coordination from CCHTs with expertise in serving CYSHCNs.
- Develop new and innovative partnerships with faith-based and community-based programs to reach additional underserved and minority populations. Adapt approaches based on the health beliefs and concerns among members of diverse populations.
- Work collaboratively with the existing HRSA funded project that supports systems integration, the AMCHP learning collaborative, and other projects led by community and state partners. UI-DCCH’s collaborations, commitment to family involvement at all levels, and continued outreach to underserved populations will allow Iowa to move the needle in achieving the Triple Aim for Iowa CYSHCN and their families.
- Improve the capacity of the University of Iowa’s (UI) electronic medical record (EPIC) to assure entry of transition information for YSHCN served by UI transition programs, with metrics and a transition registry. Also improve EPIC capacity to capture care coordination data that can be readily accessed.
- Develop a universal plan of care template that can be used by multiple systems. Provide training for families and providers on the universal plan of care.
- Develop and execute data sharing agreements to reduce barriers between HIPAA, FERPA, and social services data sources, which will improve families’ abilities to use a universal plan of care and reduce their need to repeat their stories multiple times. Participate in statewide initiatives to improve patient data collection and sharing (e.g. Iowa Health Information Network (IHIN)).
- Participate in Medicaid Modernization policy development to include standards for health plans related to follow-up to the child’s medical home and other members of the child’s care team after the referral is made.

- Collaborate with family organizations and other community partners to develop, promote, and provide training for families of CYSHCN in areas such as: utilizing the medical home, cultural competence, shared-decision making, care coordination, and advocacy.
- Collaborate with public and private health insurance plans to incentivize delivery of Bright Futures services. Collaborate with UI-DCCH CCHII to enhance the skills of pediatric specialists and providers so they can provide comprehensive assessments in all Iowa communities

Cross-cutting Findings

Overview of Health Status for Cross-cutting Population Needs

Oral health, insurance coverage, and tobacco use all have cross-cutting effects for the MCH population. Oral health care presents unique challenges both in terms of dental insurance coverage and access to care. Iowa's Medicaid program provides comprehensive care for adults, yet dentists may choose not to participate in Medicaid or limit their practices regarding the number of Medicaid-enrolled children they will see. Dental visits for children enrolled in Medicaid have been on the rise since 2005.

Access to health care is intertwined with insurance coverage that meets an individual's needs. Fortunately, most Iowa women do have health insurance at rates higher than the national averages, except for Hispanic women. Iowa also has the highest income eligibility for pregnant women to enroll in Medicaid. The vast majority of children (97%) are medically insured and dental coverage for children has increased since 2005. Further, despite the majority of CYSHCN having insurance coverage, over one-third of families report that their coverage does not meet their needs.

Tobacco use among women of reproductive age continues to be a challenge. While the number of women who are currently smoking has declined, it is still about 20%. Children in low-income families are more likely to live in a household where someone smokes. Further, tobacco use is relatively common among Iowa adolescents. However, Iowa high school students report smoking at the same rate as the national average (18%).

Summary of Cross-cutting Strengths and Needs

Strengths

Most Iowa women report having insurance coverage at rates higher than national averages. Additionally, Iowa is the most inclusive state in the US in terms of Medicaid income eligibility for pregnant women and infants. Iowa's presumptive eligibility allows pregnant women to receive services while their Medicaid eligibility is determined, which helps women gain a point of entry into prenatal and perinatal services.

Medicaid provides comprehensive oral health care for eligible adults in Iowa. Children in Iowa have better access to dental care than 10 years ago. Through the I-Smile™ program, dental visits are 61% higher in 2013 compared to 2005 for Medicaid-enrolled children.

The percentage of women of reproductive age who report smoking has decreased by about 3% from 2011 to 2013. There has been an increase in efforts to increase awareness of the availability of Iowa's Quitline. Iowans can access Quitline either by telephone or through web-based counseling.

Needs

While Iowa has made progress in assuring access to insurance coverage for women, undocumented women rely on Emergency Medicaid for Non-Qualified Immigrants to cover the costs of delivery when their presumptive eligibility expires. This coverage lasts for the length of the woman's labor and delivery only. While her newborn will be eligible for Medicaid, the woman is no longer eligible for services.

Additionally, women who were on Medicaid for the duration of their pregnancy are no longer eligible for Medicaid coverage 60 days postpartum. These women are often left with gaps in coverage and have difficulty enrolling in a suitable plan once they are off of Medicaid.

There is a lack of access to oral health care in Iowa. While 97% of children ages 0 to 18 years are covered by an insurance plan, 18% do not have dental coverage. While dental visits have increased for Medicaid-enrolled children, just 18% of all Iowa children younger than 3 years old saw a dentist in 2013.

Fewer women of reproductive age are smoking in Iowa. Non-Hispanic White women have higher rates of smoking than other women. Twelve percent of Iowa adolescents report ever using tobacco, and 7% report having used tobacco in the last 30 days. Children in low-income families are more likely to live in a household where someone smokes. Just over 18% of children living in households earning less than 100% of the FPL are exposed to secondhand smoke at home compared to 2.3% of children living in households at 200-399% of the FPL.

Detailed Description of Cross-cutting Findings

Oral Health - Women

According to the 2013 BRFSS data, 75.2% of Iowa women ages 18-44 had a visited a dentist in the past year, with a wide range based on household income. Nearly 71% of women in households earning less than \$15,000 had visited the dentist, compared to 95% of women in household earning more than \$75,000. Many women enrolled in the

Title V maternal health program in Iowa receive oral screenings, fluoride applications, education, counseling, and dental referrals as an integral component of their comprehensive prenatal health services. They also receive assistance making appointments with dentists for routine and restorative dental care. Yet data continues to show that a very limited number of Medicaid-enrolled MH clients are receiving dental cleanings or treatment for periodontal disease, indicating a lack of access to routine dental care.

Iowa's Medicaid program provides comprehensive care for adults, yet dentists may choose not to participate in Medicaid or limit their practices regarding the number of Medicaid-enrolled who they will see.

Related National Performance Measures:

Dental visit during pregnancy

State Priority Areas:

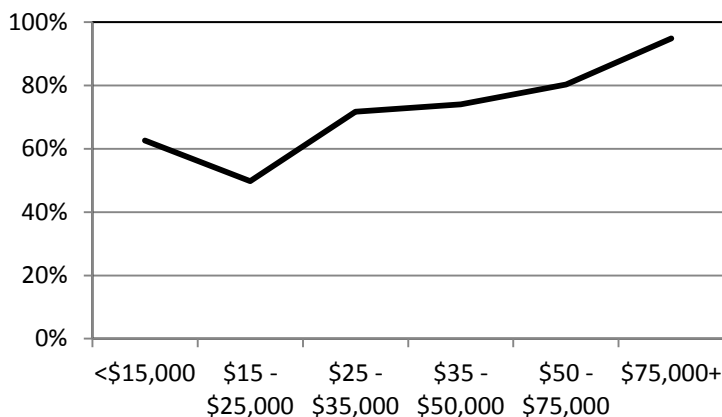
Adequacy of insurance coverage for women of reproductive age

Related National Outcome Measure:

Receipt of prenatal care

Severe maternal morbidity

Percent of women ages 18-44 with a dental visit in past 12 months by household income, BRFSS 2013



Although Iowa benefits from a large number of dentists who are enrolled as Medicaid providers, in 2009, only 331 dentists cared for 50 or more Medicaid-enrolled adults in their practices, out of 1,867 dentists licensed in the state. Less than 200 dentists cared for 100 or more Medicaid-enrolled adults. Low reimbursement is cited as the main reason to not accept patients on Medicaid; Iowa's reimbursement is less than 50% of commercial insurance rates. In 2011, 56% of women had a preventive dental visit during their last pregnancy; however, only 19% of Medicaid-enrolled women did.

In addition to dentists limiting the number of Medicaid-enrolled patients they will see, many Iowa communities may not have enough dentists available to care for the number of residents in the area. There are 42 Dental Health Professional Shortage Areas (HPSAs) across 40 counties in Iowa.

Oral Health – Children and Children with Special Health Care Needs

Parents/guardians of Iowa children believe that their children have mostly good oral health, yet they also believe that their oral health is not as good as their children's physical health.

Disparities are reported for Iowa children from lower income families, with parents/guardians living in households at less than 134% of the FPL more likely to report poorer oral health status. The 2010 IHHS found that nine out of ten children had one main place where they receive dental care.

The survey also reported that 95% of families of CYSHCN had a regular source of dental care. Children from low-income families also indicated that they were more likely to receive dental care in public health settings such as WIC clinics or at Head Start centers. The survey also found that African American and Hispanic children were more likely to experience delays accessing dental care.

Related National Performance Measures:

Preventative dental visit for infants and children

Related National Outcome Measure:

Children with special health care needs

CSHCH receiving care in a well-functioning system

Children with decayed teeth or cavities

Child and adolescent mortality

Children in excellent/very good health

Data from Iowa's I-Smile™ dental home initiative indicate improvements in the number of Medicaid-enrolled children seeing a dentist since the program began (61% increase for children ages birth to 12 years in 2013 than in 2005). Yet the number of children younger than 3 years of age who see a dentist is still lagging; just 18% of Medicaid-enrolled younger than 3 saw a dentist in 2013.

The IDPH school-based sealant program (for children in grades 2 to 8) reports that 18% of children have untreated decay. The rate is even higher for children on Medicaid (21%).

Many Iowa children, although likely to have medical coverage, do not have dental coverage (18%). Parents are more likely to report a regular source of dental care for children when their children have dental coverage. I-Smile™ data shows a 45% increase in the number of children receiving Medicaid coverage since 2005, which is beneficial since Medicaid provides comprehensive dental coverage. This benefit is weakened, however, due to low reimbursement rates and its impact on dentists' willingness to accept Medicaid-enrolled patients. The **hawk-i** Dental Only program currently has over 3,300 children

enrolled. Iowa's 19 and 20 year olds enrolled in the Iowa Health and Wellness Plan also receive dental coverage.

In 2013, 55 fewer dentists saw Medicaid-enrolled children than in the previous year. This trend is of particular concern due to the chance that those who do accept Medicaid-enrolled patients are seeing a disproportionate number, which can result in provider weariness and potentially choosing to stop seeing Medicaid-enrolled altogether. The I-Smile™/Title V program provides preventive services for many at-risk children, particularly those younger than age 5. Services are often provided by dental hygienists, as well as some registered nurses. Over 28,000 Medicaid-enrolled children (ages 0 to 12) received preventive services in 2013.

Data for Iowa's children receiving a dental screening prior to entry into kindergarten and ninth grade shows a need for additional providers in order for all children to meet this school requirement. In 2012 and 2013, dentists provided 64% of the exams, dental hygienists provided 30% (screenings), and nurses 6% (screenings).

CYSHCN may have unique challenges in accessing dental care. Approximately 64% of CYSHCN are covered by Medicaid, which may lead to difficulties in scheduling appointments with dental providers who limit the number of children with Medicaid they serve.

CYSHCN may have conditions that increase the risk for oral health problems. Children with ASD or intellectual disabilities may have anxiety or difficulty communicating their needs. Dental providers must be aware of how special health care needs influence oral health and may benefit from additional training. The University of Iowa College of Dentistry operates a dental clinic allowing dental students to gain first-hand experience in working with families with special health care needs. This clinic uses a multi-disciplinary health care team approach to meet the needs of CYSHCN and their families.

Tobacco Use - Women

In 2013, 21.7% of women of reproductive age in Iowa reported currently smoking cigarettes, down from 24% in 2011. Non-Hispanic White women are more likely to smoke cigarettes in Iowa than Non-White or Hispanic women (22.6% vs. 16.6%). In Iowa, 37.4% of WIC-enrolled women smoked in the 3 months prior to becoming pregnant. This is much higher than the national level of 23% for this population. Iowa participated in a CMS/Medicaid Quality Improvement Project (QIP) focusing on smoking cessation. Iowa's Quitline is made available through either telephone or web-based counseling. Additionally, the IDPH has a web-based training for providers on brief screening and intervention for tobacco cessation and Iowa Medicaid covers smoking cessation counseling and nicotine replacement therapy. However, through the QIP, the research team discovered that one of the largest clinics included in the project was unaware of the availability of Quitline and other tobacco cessation options. Further, policies around smoking cessation were inconsistent at the project sites.

Related National Performance Measures:

*Well-woman visit
Cesarean deliveries among low-risk first births
Smoking during pregnancy
Children in households where someone smokes*

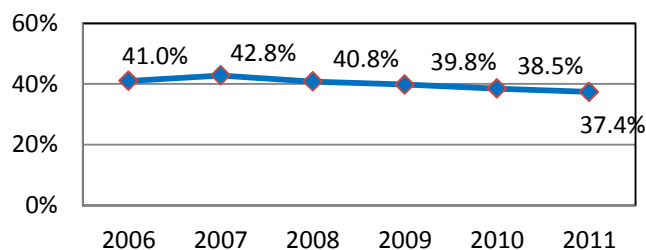
State Priority Areas:

Physical activity among women of reproductive age

Related National Outcome Measures:

*Receipt of prenatal care
Severe maternal morbidity
Maternal mortality rate
Low, very, and moderately low birth weight deliveries
Early and late preterm births
Early term births
Non-medically indicated early elective deliveries
Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates
Sleep-related SUID rate
Fetal alcohol exposure*

Percent of WIC-Enrolled Women in Iowa who Smoked 3 Months Prior to Pregnancy, 2006-2011



Tobacco Use - Children and Youth

According to the NSCH 2012, although less than the national average (9.4%), 6.7% of Iowa children live in a home where someone smokes in the home. From the NSCH 2012, 11.3% of Iowa's CYSHCN lived in a home where at least one person smokes inside the home, which is higher than the national average for CYSHCN of 7.7%. There is significant disparity in smoking exposure by FPL status in Iowa – 18.4% of children in families less than 100% of the FPL are exposed to smoke in the home. Just 2.3% are exposed to smoke in families at 200-399% of the FPL. In Iowa, prevalence of smoking in the home environment is not distinct based upon race.

Related National Performance Measures:

*Smoking during pregnancy
Children in households where someone smokes*

Related National Outcome Measure:

*Child mortality
Children in excellent/very good health*

Tobacco use is relatively common among Iowa high school students. According to the 2011 Youth Risk Behavior Survey 18.1% of Iowa's High school students have smoked in the last 30 days, equal to the percent of high school students in the country as a whole.

Insurance coverage – Women

According to the 2013 American Community Survey, almost 12% of 15-44 year old women in Iowa reported having no health insurance, compared to almost 20% for the US average. Coverage was higher for non-Hispanic women than for minority women in Iowa, which is true of the US as a whole. Almost 90% of non-Hispanic White women reported having health insurance, compared to 79% of African American and 74% of Hispanic women in Iowa.

Iowa is one of 32 states with presumptive eligibility for pregnant women applying to Medicaid, which helps to ensure that pregnant women receive early prenatal care. Iowa is the most inclusive state in the US in terms of Medicaid income eligibility for pregnant women – women living in households up to 375% of the FPL are eligible for Medicaid assistance while pregnant and for 60 days postpartum. Eligible infants are covered until one year of age. In FY2013, over 3,000 pregnant Iowa women were granted presumptive eligibility, with nearly 30% of those women going on to some type of Medicaid after the presumptive period ended. Medicaid coverage ends 60 days postpartum, and many women report not knowing where or how to enroll in health coverage after this period.

Related National Performance Measures:

Well-woman visit

State Priority Areas:

Adequacy of insurance coverage for women of reproductive age

Related National Outcome Measure:

Receipt of prenatal care

Severe maternal morbidity

Maternal mortality rate

Low, very, and moderately low birth weight deliveries

Early and late preterm births

Early term births

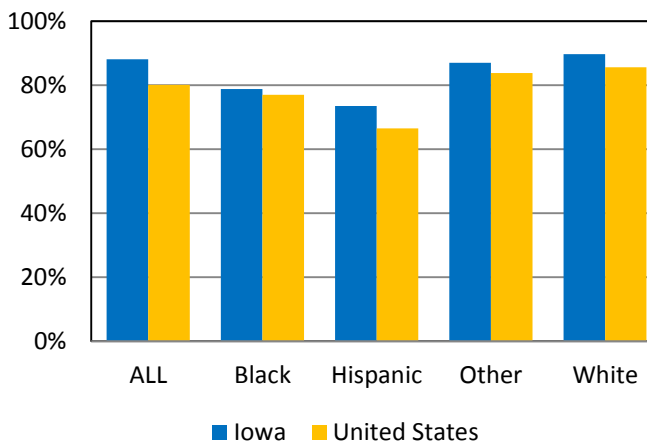
Non-medically indicated early elective deliveries

Perinatal, infant, neonatal, post-neonatal and preterm-related mortality rates

Fetal alcohol exposure

Neonatal abstinence syndrome

Insurance coverage among women, ages 15-44, by race/ethnicity, ACS 2013



Women who are undocumented have limited options for health care coverage. They may apply for presumptive Medicaid, which can provide Medicaid coverage for up to 60 days and may assist them in obtaining a medical home but they will not be eligible for Medicaid coverage once the presumptive period expires. Nearly 1,000 women per year in Iowa have a delivery that is reimbursed by Emergency Medicaid for Non-Qualified Immigrants (also known as 3-day Emergency).

"They denied her insurance because she's non-citizen. She's bringing a citizen into this country; I think they should take care of her and her baby. I don't think it's very fair. They leave pregnant women kind of high and dry. That really upsets me."

- Title V Maternal Health Client, through an interpreter

In 2006, Iowa was awarded a Medicaid Family Planning Waiver to extend the provision of family planning services to low income women who would otherwise not be eligible for coverage. For 1-year post-partum, women who deliver within the Medicaid program are automatically eligible for services. Over 65,000 women accessed the waiver from 2006 to 2013, which is estimated to have averted anywhere from 6,000 to 15,000 repeat births over this time period and decreased Medicaid costs by over \$50 million.

Insurance Coverage – Children and Children with Special Health Care Needs

Ninety-seven percent of all children ages 0 to 18 years in Iowa are covered with either private or public medical coverage. In 2011, the majority (75%) of Iowa children ages 0 to 18 years were covered by private medical insurance, 22% were covered by public insurance (i.e. Medicaid or **hawk-i**), and 3% were uninsured. The 2010 IHHS estimated that 60% of uninsured children in Iowa are eligible for Medicaid or **hawk-i**.

In 2010, 18% of children ages 0 to 18 years did not have dental coverage. While this has decreased since 2005 (25%), it is still significantly higher than the percentage of Iowa children who do not have medical coverage (3%). Most of the children without dental coverage (88%) have medical coverage, and 84% of those children have private medical coverage. Twenty percent of parents of dentally uninsured children reported an unmet dental need for their child, primarily check-ups and cleaning (95%), with a smaller percentage needing other treatments (24%) or emergency care (3%).

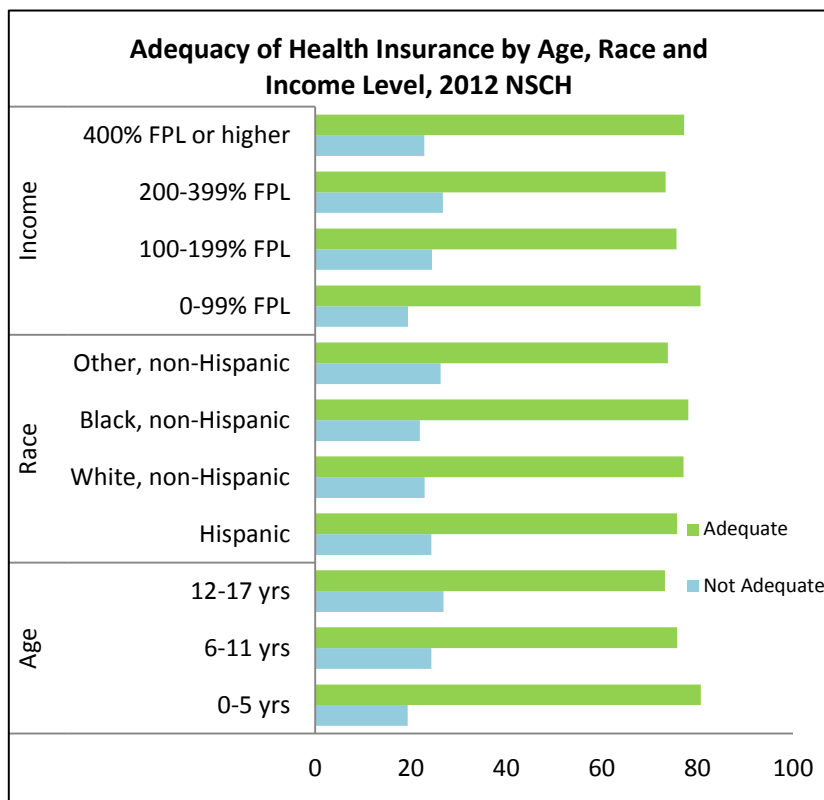
Related National Performance Measures:

Selected as a State Priority Area
Adequate insurance coverage

Related National Outcome Measure:

Child and adolescent mortality
Adolescent suicide
Children with special health care needs
CSHCH receiving care in a well-functioning system
Autism spectrum disorder diagnosis
ADD/ADHD diagnosis
Children treated/counseled for a mental/behavioral condition
Children in excellent/very good health
Children and adolescents overweight/obese
Children without health insurance
Received routine vaccines
Received influenza, HPV, Tdap and meningococcal conjugate vaccines

Medicaid offers comprehensive dental benefits for children, although reimbursement rates are estimated to be less than 50% of commercial insurance rates. Children enrolled in **hawk-i** have dental coverage provided via Delta Dental of Iowa. Dental insurance can also be provided via a dental rider, **hawk-i** Dental Only, which is for children who have private medical coverage but insufficient dental coverage. Iowa is the only state that offers this program.



Since 2010, children eligible for **hawk-i** and Medicaid have been able to obtain immediate, temporary Medicaid coverage through the Presumptive Eligibility for Children program. Between 2010 and 2013, over 6,000 children were approved for Presumptive Eligibility.

According to the 2009-10 NS-CSHCN, the majority of CYSHCN have insurance coverage, but over one-third of families with insurance report that their coverage does not meet their needs. In one example, Applied Behavioral Analysis (ABA) therapy is an evidence-based service for children with Autism Spectrum Disorder, however not all insurance programs in Iowa provide coverage. Age limits and restrictions may also apply. If families must bear the full cost of ABA, some families may not be able to afford the cost and forego ABA treatment.

Iowa families also incur higher out of pocket costs for health care than the national average. According to Iowa's State Health Improvement Plan from 2013, the average out of pocket spending among Iowa's families, including for those with special health care needs, was \$3,513 in 2010-2011, compared to a national average of \$3,456 in the same time period. As medical costs continue to rise and consume an increasing share of income, more families may delay or not seek needed care.

Through the HCBS Waiver program, the most medically complex children automatically qualify for Medicaid and additional services, though these waivers have a complicated application process and may not meet a family's needs. As of March 2014, there are 3,929 children on the waiting list for Iowa's HCBS waivers.

According to key informants, reimbursement policies for some health care plans may create financial disincentives for providers to deliver comprehensive, high-quality care to CYSHCN. This may disproportionately affect PCPs serving CYSHCN in rural and low-income areas across Iowa.

Iowa Medicaid and one major health plan provide health care coverage to 70% of all Iowans, including most CYSHCN. Iowa is exploring the potential to use this ‘critical mass’ of covered individuals to develop value-based payment methods to support integration across systems. This effort will align with the federally funded State Innovation Model to help transform Iowa’s health care system.

Iowa’s Patient-Centered Health Advisory Council and the Office of Health Care Transformation encourages partnerships between community health care partners working on system-level models to provide better health care at lower costs by shifting from volume to value based health care.

Cross-cutting Programmatic Approaches

Reaching additional underserved and minority populations will require new and innovative partnerships with faith-based and community-based programs. Organizations within Iowa’s System of Care will need to adapt approaches based on the health beliefs and concerns among members of diverse populations.

Oral Health Activities

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, and be reimbursed. Oral health activities are a required piece of the Request for Proposals issued by the IDPH. This partnership between oral health care and other maternal and child health activities continues to be a central part of Title V activities.

I-Smile™ continues to promote access to preventive oral health care to prevent tooth decay in children, in addition to building networks with dentists to accept referrals. This network helps to increase the number of children with established dental homes and increases access to oral health care.

Insurance Activities

Iowa is entering into an expanded managed care environment within proposed state-level initiatives through the Iowa Medicaid program. This will provide Iowa’s Title V program with opportunities to work with contracted Medicaid Managed Care Organizations to enhance their program of services for the MCH population. The new managed care initiatives include individuals who are covered by Medicaid as well as *hawk-i*, Iowa’s SCHIP program, and includes children whose coverage is provided through all of Iowa’s HCBS waiver programs.

While the majority of children in Iowa have insurance coverage, efforts are needed to maintain this high level of coverage. *hawk-i* (SCHIP) outreach continues to ensure children have access to healthcare coverage. This supports access to regular, preventive healthcare services for children as they age and grow.

Postpartum insurance coverage is an area of opportunity for Iowa, in particular for women who were enrolled in Medicaid for a pregnancy. While Title V maternal health agencies include education on IFPN to all clients, IFPN only provides access to family planning services and birth control methods. Women

needing management of chronic conditions are left without a source of care once their Medicaid eligibility expires.

Tobacco Activities

According to the National Scientific Council on the Developing Child (2006), preventing tobacco exposures is of paramount importance. The IDPH continues to investigate how the Quitline is being promoted and accessed by at-risk populations. Quitline provides quit aids (nicotine replacement therapy) and personalized coaching to support the client. The recent QIP with Medicaid has resulted in renewed efforts to train providers in accessing Quitline for their patients. It is anticipated that with greater awareness regarding Medicaid's reimbursement policies for tobacco cessation, the Title V program, through local maternal health agencies, can increase the number of women using Quitline for tobacco cessation. Iowa is also anticipating the release of PRAMS data which contains detailed information regarding the methods women choose to utilize to quit smoking and use of other tobacco products.

The Adolescent Health Collaborative is an intra-agency collaborative, consisting of programs and services offered to Iowa's youth. One of the aims of this collaborative includes the prevention of tobacco use. Since the beginning of 2014, the collaborative has come together to educate one another about intra-agency adolescent health services, to reduce service duplication, and to share and leverage resources.

Title V Program Capacity

Organizational Structure

The Iowa legislature designated the Iowa Department of Public Health (IDPH), a cabinet level agency, as the administrator for Title V and maternal and child health (MCH) services. The legislature also directs the IDPH to contract with Child Health Specialty Clinics (CHSC) within the University of Iowa Division of Child and Community Health (UI-DCCH) as the state's Title V service provider for children and youth with special health care needs (CYSHCN) 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 the IDPH and CHSC outline the responsibilities of both agencies for fulfilling the mandate for maternal and child health services. Copies of the contracts are available upon request.

The IDPH Division of Health Promotion and Chronic Disease Prevention (DHPCDP) includes the Bureau of Family Health (BFH), the primary MCH unit within the state. Responsibility for the administration of the Title V Block Grant lies within the BFH. Tables of organization illustrating the relationship of the division and the bureau within the IDPH can be found in Appendix M.

UI-DCCH delivers Iowa's Title V program for CYSHCN. Systems building, enabling services, and direct services occur throughout the state. UI-DCCH also has 15 community-based regional centers. UI-DCCH includes clinical staff, family navigators (FNs) and public health professionals who work together to assure Iowa's system of care for CYSHCN and their families, advanced registered nurse practitioners, registered nurses, family navigators, registered dietitians and social workers. A map of UI-DCCH's locations and other program information is located at www.chsciowa.org.

Bureau of Family Health

Public health functions relating to the health of mothers, children, and families are centered in the BFH. The organizational structure within the BFH includes four work units: Women/Reproductive Health, Child Health, Early Childhood and Home Visiting/Family Support. The BFH and Title V program provide support for the department's Office of Multicultural Health, co-located within the DHPCDP, to support integration of cultural competence into program development. Areas of work for these teams include system planning, standards of care development, contract management, and coordination of health-related services. Both teams collaborate with the Iowa Department of Human Services (DHS), the Iowa Department of Education (DE), and the Iowa Regents Universities. The BFH contracts with 24 local child health and maternal health agencies and health care providers to manage MCH programs at the local level. A list of all current contractors is located in Appendix N.

The BFH collaborates with the Bureau of Oral and Health Delivery Systems (also within the DHPCDP at the IDPH) to issue a joint Request for Proposal (RFP). The RFP is issued to community-based organizations interested in providing public health services for MCH and Family Planning. The RFP requires contractors to link with the Bureau of Local Public Health Services, Bureau of Immunization and

TB, Early ACCESS (IDEA, Part C), Healthy Child Care Iowa, *hawk-i* (S-CHIP) and the Lead Poisoning Prevention Program. Selection is based on applicant's ability to meet criteria in the areas of access, management, quality, coordination, and cost.

Administration of Programs Funded by Block Grant Partnership Budget

The IDPH is responsible for the administration of all programs carried out with allotments under Title V. A genetics coordinator of the Center of Congenital and Inherited Disorders (CCID) is housed in the BFH and coordinates with the Early Hearing Detection and Intervention program.

The lead program, housed in the Division of Environmental Health, partners with the BFH and local MCH agencies on reducing the incidence of lead poisoning among young children. The lead coordinator collaborates with the BFH to improve system integration of child health programs.

The immunization program is part of the Bureau of Immunization and TB and partners with the BFH and local maternal and child health agencies on improving immunization rates. Local contractors are required to develop activities that advance children receiving the full schedule of age appropriate immunizations per the Advisory Committee for Immunization Practices (ACIP) Childhood Immunization Schedule. Activities may address coordination of immunizations with local practitioners, promoting the use of Immunization Registry Information System (IRIS), strengthening referral relationships with providers, and/or developing public education campaigns that promote children's immunizations. Activities may involve administering immunizations and providing related assessment, education, anticipatory guidance, and follow-up.

As part of the maternal health program, there is support for the Statewide Perinatal Care Program to help improve the perinatal infrastructure. The Statewide Perinatal Care Program provides professional training, development of standards/guidelines of care, consultation to regional and primary providers and evaluation of the quality of care delivered to reduce the mortality and morbidity of infants. Through a contract with the University of Iowa Hospitals and Clinics, these services are provided to all hospitals that perform deliveries. More intensive services are directed toward regional centers, including two tertiary care centers, and 10 secondary centers.

Iowa's 1st Five Healthy Mental Development Initiative began as a state funded program in 2007, and was the result of a successful pilot ABCD II project funded by the Commonwealth Fund (2003-2006). The purpose of the 1st Five Healthy Development Initiative is to support and enhance models of service delivery that promote high quality well-child care, supporting healthy mental development for all children ages birth to five years. The primary focus of 1st Five is on children with less intense needs. For example, those who may only need preventive care, those who are identified as at-risk or in need of "low-level" interventions, and to assure that appropriate referrals, interventions, and follow-up will occur.

1st Five programs, administered through local Title V CH agencies, work with providers to ensure the three levels of developmental care through Iowa Medicaid's Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program become standard practice. This relationship includes regular

communication with medical providers on referral status and program maintenance. Visit www.iowaepsdt.org for more detailed information on the three levels of developmental care.

1st Five serves as a community utility, playing a crucial role in assisting primary care providers to deliver coordinated, comprehensive and family-centered care. Care coordination requires personal contact with families and providers that allows for individualization of care and family-centered decision making to meet the needs of each family. This communication may be carried out through face-to-face visits, telephone contacts, or written correspondence. UI-DCCH is collaborating to develop system level metrics to measure the impact of the 1st Five program.

At the individual level, care coordination may involve providing information about available services, assisting clients in making health care appointments, coordinating access to needed support services, coordinating access to health care services and following up to ensure that services were accessed. In addition, successful applicants will serve as messengers about the importance of young children's healthy mental development to community stakeholders.

The IDPH contracts with UI-DCCH to provide medical consultation for primary care practice transformation to increase the number of practices that are conducting developmental screenings using evidence-based screening tools. UI-DCCH also assists in developing system level metrics to measure the impact of the 1st Five program.

Agency Capacity

In Iowa, Title V administration is the joint responsibility of the BFH at the IDPH and UI-DCCH. Iowa's MCH programs promote the development of systems of health care for children ages 0 to 21 years, pregnant women, and their families. Iowa strives for services that are collaborative, comprehensive, flexible, coordinated, culturally competent, developmentally appropriate, family-centered and community-based. The core public health functions of assessment, policy development and assurance are promoted.

Women's/Maternal Health

The Reproductive/Maternal/Women's Health Team is headed by Denise Wheeler, a Certified Nurse Midwife, who has worked with the IDPH's family planning services for 8 years. The Team includes 5.5 other FTEs.

Women's Health: The Reproductive Health Team provides direction, oversight and monitoring for the 21 local MH and 8 family planning (FP) agencies. Systems development activities are coordinated with the IDPH FP Program, the Family Planning Council of Iowa, hospitals, schools, local boards of health, providers of adolescent health programs, and statewide women's health initiatives. Technical support is provided to local MH and FP agencies. Contracts are managed with the University of Iowa Hospitals and Clinics (UIHC), Department of Pediatrics.

Maternal Health (MH) agencies: Local MH contract agencies are charged with developing programs that are responsive to the needs of the community. Contractors for the FFY 2011-2015 project period were selected through a competitive request for proposals (RFP) process.

The goal of the MH program is to improve health outcomes for pregnant women and infants. Local MH contract agencies provide prenatal and postpartum care to low-income women and other women in need. Services include risk assessment, psychosocial screening, referrals, care coordination, education, delivery planning, oral health screening, postpartum visits and presumptive eligibility for Title XIX. Performance standards were developed to ensure the provision of quality MH service throughout the state. Local MH contract agencies also complete an annual direct care audit and semiannual review of the service documentation in WHIS.

Perinatal/Infant Health

Perinatal/Infant Health is embedded within the Child Health, Maternal Health, Early Childhood and Home Visiting Teams.

Iowa's Perinatal Team: The Statewide Perinatal Care Program provides training of health care professionals, development of care guidelines, consultation for regional and primary providers, and evaluation of quality of care through the state's approximately 79 hospital facilities providing obstetrical and newborn services. The team consists of a neonatologist, a perinatologist, a dietitian, an obstetrics nurse, and a neonatal intensive care nurse. Through a contract with the UI, Department of Pediatrics, these services are provided to all birthing hospitals and more intensive services are directed toward Iowa's three tertiary care centers and 19 secondary care centers.

Preventing Shaken Baby Syndrome (SBS): Representatives from the IDPH, Prevent Child Abuse Iowa, the Iowa Department of Management and Blank Children's Hospital, collaborated as the Iowa Prevent SBS team to plan and implement a statewide program to prevent SBS. The team attended the PREVENT Institute for Child Maltreatment at University of North Carolina which provided education and coaching toward the development of a plan for Shaken Baby Prevention.

Efforts by child abuse prevention advocates led to the passage and signing of a bill during the 2009 legislative session, directing the IDPH to develop and implement a statewide SBS prevention plan. The foundation plan from PREVENT was used to further refine a plan and pilot implementation phase. Funds received have allowed this pilot to serve birthing hospitals in a 12-county region in central Iowa. Currently, 58 of the 78 birthing hospitals implement the Period of PURPLE Crying curriculum. The IDPH plans to target education to emergency room nurses to reinforce that crying in normal and to never shake a baby.

Child Health

The Child Health Team is headed by Janet Beaman who has worked within the Child Health program for 19 years. There are 6.5 other FTEs within the Team.

Medical Home/EPSDT Work Team: For the child health (CH) program, the work team includes a focus on both the Medical Home Project and the EPSDT program. The Medical Home Project features a Medical Home System Advisory Council to make recommendations to the IDPH on the plan for implementing a statewide, patient-centered medical home system. The initial phase will focus on providing a patient-centered medical home for children who are eligible for Medicaid. Included in a later phase is a focus on providing a patient-centered medical home to children covered by the *hawk-i* program.

This work team also focuses on quality improvement to promote effectiveness of the CH/EPSDT program. It addresses policy and practice to promote access to preventive health care services provided by CH contract agencies. Representatives on the team include those from CH, adolescent health, EPSDT, *hawk-i* outreach, oral health, and Medicaid fee-for-service, and quality assurance. Consultation is available from other key programs in the BFH and throughout the IDPH.

Local Child Health (CH) Agencies: Local CH contract agencies are charged with developing programs that are responsive to the needs of the community. Contractors for the FFY 2011-2015 project period were selected through an integrated competitive RFP process for MCH and FP.

A CH Logic Model provides the framework for CH programs to implement services that impact key performance measures. The goal of the CH program is to improve health outcomes for children. CH contract agencies provide infrastructure building, population-based, and enabling services to assure that children have access to comprehensive well child-screening services including oral health services, based upon guidelines established under the EPSDT program. Agencies provide outreach to uninsured children, education on the importance of preventive health care, and access to medical and dental care. They promote linkage to medical and dental homes and referral to needed services. Service coordination under Early ACCESS (IDEA, Part C) is provided for children with blood lead levels of 20µg/dL or greater. Gap-filling direct care services are provided where access is limited.

Adolescent Health

The Adolescent Health Team is embedded within the Reproductive Health Team in the BFH. This is intended to provide cohesiveness and partnerships spanning the programs involved with both teams.

Personal Responsibility Education Program (PREP): Iowa's PREP program provides comprehensive sexuality education to adolescents with medically accurate, culturally and age-appropriate, and evidence-based programming in order to assist them to reduce their risk of unintended pregnancy, HIV/AIDS, and other sexually transmitted infections (STIs). PREP programs will also address life skills to assist Iowa teens in making responsible, informed decisions and lead safe and healthy lives. Iowa has identified three priority programs for implementation. Awards were based on a competitive application process. The vision of PREP is: Iowa youth will be empowered to make positive decisions and healthy choices regarding sexual behavior as they prepare for a successful adulthood.

Abstinence Education Grant Program: The purpose of the Abstinence Education Grant Program is to support decisions to abstain from sexual activity by providing abstinence education, along with

mentoring, counseling and adult supervision. The program focuses on those groups that are most likely to bear children out-of-wedlock, such as youth who are in foster care, aftercare or an out of home care setting and youth who reside in a county with a high teen birth rate.

The State Abstinence Program in Iowa currently has five local contractors, consisting of local school districts, private non-profits and a local board of health, delivering programming in seven counties. These contractors are implementing evidence-based or promising practice teen pregnancy prevention programs to youth through a mix of school and community-based settings.

Children and Youth with Special Health Care Needs

UI-DCCH administers Iowa's Title V program for CYSHCN. Through UI-DCCH's partnerships and 15 regional centers located across Iowa, UI-DCCH provides public health and systems-building services, enabling services and direct services. UI-DCCH's capacity for serving CYSHCN and their families is enhanced by additional programs it administers that are supported by funding sources separate from MCH Title V. UI-DCCH includes clinical staff, FNs, and public health professionals who work together to assure Iowa's system of care for CYSHCN and their families.

Public Health Services and Systems: UI-DCCH leverages its MCH Title V funds to advance a seamless and comprehensive system of care (SOC) for CYSHCN. The Iowa system embraces the standards developed by a national workgroup organized by the Lucile Packard (LP) Foundation for Children's Health and the Association of Maternal and Child Health Programs. UI-DCCH's recent HRSA-funded systems integration project for CYSHCN is detailed in the "Partnerships, Collaboration and Coordination" section.

UI-DCCH provides infrastructure for policy development and public education campaigns to support the needs of Iowa's CYSHCN and their families. UI-DCCH's statewide regional centers provide physical infrastructure for telehealth services and a statewide delivery system for its programs.

UI-DCCH is in the process of developing several trainings and tools for workforce development. UI-DCCH is partnering with national, state, and family organizations to implement an enhanced FN training program. UI-DCCH is piloting an enhanced care coordination algorithm to help child health agencies identify CYSHCN who would benefit from UI-DCCH's care coordination and family support program. UI-DCCH piloted tools to assist youth, families, and care coordinators for planning the transition to adulthood for CYSHCN and is coordinating a statewide coalition of organizations to address transition. UI-DCCH also collaborates with Iowa's Disability Services Bureau to train health care professionals in the appropriate documentation needed for disability determination to help CYSHCN qualify for Home and Community Based Services Waiver programs.

Enabling Services: UI-DCCH staff are experts in assuring a family-centered, community-based approach to the effective and efficient use of services, resources, and natural supports. The UI-DCCH Family Navigator Network is comprised of 41 FNs who provide emotional support, education, and care coordination to Iowa families of CYSHCN. FNs complete 40 hours of core competency training and receive ongoing peer mentoring and continuing education. The care coordination provided by UI-DCCH fosters productive relationships with medical homes and other providers for CYSHCN, including referral

to subspecialists as needed. UI-DCCH tracks the number of children receiving care coordination and analyzes care coordination data quarterly.

Iowa's Title V definition of rehabilitative services for CYSHCN includes a detailed consultation with each family of a child determined eligible for Supplemental Security Income (SSI). The consultation offers a connection between SSI beneficiary families and Title V services. When working with CYSHCN and their families to complete applications for the Health and Disease Management Medicaid waiver, UI-DCCH staff also provide consultations to approximately 90% of families that have CYSHCN younger than age 16 years who are approved for SSI. UI-DCCH doesn't provide 100% of the consultations because a small percentage of children with SSI reside in foster homes or other out-of-home placements and already receive rehabilitative services from Iowa's Department of Human Services.

Direct Services: Gap-filling services through CHSC's 15 regional centers include evaluations and recommendations, child psychiatry consultation, and telehealth nutrition services. Collaboration occurs with medical homes, Area Education Agencies, mental and behavioral health providers, speech and hearing professional(s), and other community providers as needed.

All ARNPs in the regional centers are trained to screen children for Autism Spectrum Disorder (ASD), allowing children needing a diagnostic assessment for ASD to receive it in their community. ARNPs, RNs and targeted FNs are also trained in the use of evidence-based developmental/ behavioral screening tools. For children in the early childhood system, the regional centers provide developmental screening, assessment and follow-up for young children at-risk for developmental delay and referrals to Early ACCESS (IDEA Part C).

Cross-cutting

Oral Health Center (OHC): The OHC, within the IDPH Bureau of Oral and Health Delivery Systems, works to protect the health and wellness of Iowans through prevention and early detection of dental disease and through the promotion of optimal oral health and improved access to care. OHC staff offer consultation and assistance to local MCH contract agencies in assuring good oral health for the women and children they serve. An agreement with the DHS supports the I-Smile™ dental home initiative. I-Smile™ is the result of a state mandate that all Medicaid-enrolled children ages 0 to 12 have a dental home. The I-Smile™ program plan developed by the OHC requires each CH agency to have a dental hygienist serving as I-Smile™ coordinator, who work to build support systems for families through work with dental providers, medical providers and community organizations. In addition to building local oral health infrastructure, the coordinators and other CH agency staff provide oral health promotion and education, care coordination and preventive dental services to ensure optimal oral health for children. OHC staff also provide consultation to MH contractors to work toward better access to oral health care for pregnant women.

Maternal and Child Health Advisory Council: The main responsibility of the Maternal and Child Health Advisory Council is to advise the Director of Public Health regarding health and nutrition services for women and children in Iowa. The Council also assists the Iowa Department of Public Health in the design

and implementation of MCH Services, Family Planning Services, Child Health Specialty Clinics, and the Special Supplemental Food Program for Women, Infants, and Children (WIC).

The MCH Advisory Council meets on a quarterly basis (typically the second Thursday in September, January, March, and June). Terms are for three years (June 2012 through June 2015) and members can serve two terms.

The MCH Advisory Council's membership includes representatives from professional groups, agency representatives, legislators, and parents with an interest in promoting health services for women and children. Specifically, required members are appointed by the Director of the Iowa Department of Public Health. The Chair or designee from the Perinatal Guidelines Committee and Center for Congenital and Inherited Disorders Advisory Committee also serve as required members. Discretionary members are also appointed by the Director of the IDPH. Ex-Officio members are not voting members, though they have the right to attend the meetings of the MCH Advisory Council, be heard upon any questions or matter under consideration, and provide feedback to help the Council achieve its mission and functions.

MCH Workforce Development and Capacity

Iowa Workforce Development estimates that Iowa's workforce of health care practitioners and support workers will grow by approximately 2% by 2020. While the increase in health care providers is encouraging for the MCH population, CYSHCN and their families, Iowa struggles in the recruitment and retention of these professionals, especially in rural areas. Of Iowa's 99 counties, 79 are designated rural with no large metropolitan area. This results in a shortage and unequal distribution of both primary care and specialty providers. Iowa's low Medicaid reimbursement rates may contribute to the departure of providers trained in Iowa's excellent health professional training programs that leave the state.

Iowa's Title V Maternal and Child Health 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 the BFH there are 35 professional staff and 4 support staff that work (directly and indirectly) on behalf of the Title V program (see Appendix M). Iowa has 24 local MCH agencies spanning our 99 counties (see Appendix N and O). Local MCH agencies are chosen through a competitive request for proposal application process every five years. Local and state MCH partners focus on fostering integration within the public health system and across organizational boundaries and sectors, including primary care providers, mental health providers and family- serving community organizations. These 24 agencies have a combined workforce of 156.12 FTEs, funded through the federal/state/local partnership. Iowa's Title V workforce is competent in delivering core services, understanding the needs and issues of the vulnerable population they serve and developing partnerships with other community service providers.

Iowa strives to implement a comprehensive system of care through public and private partnerships to address the needs of children, women and families and will positively impact their lives. Iowa's maternal and child health agencies are in a state of transition due to the evolving health care reform environment and changing demands triggered by the implementation of the ACA. This transformation of the health

care system has generated questions as to where MCH agencies will fit in this new integrated delivery model. More specifically, what changes will be required of MCH agencies so they will be able to successfully fulfill the new demands placed on them. Additionally, Iowa will continue to determine how children and women fit in these newly developing programs and models of health care reform. State and local MCH partners are working together to identify and prioritize the core services of Iowa's MCH program. The BFH has been working to align efforts in Iowa with the MCH transformation at the federal level. Much of the focus of these programs is to reduce cost by looking at "high utilizers" and those with multiple chronic diseases. Children especially do not frequently fit under these priorities.

A strengthened workforce will lead to improved collaborative relationships and will drive organizational change while enhancing staff competencies, both at a state and local level, related to quality improvement methods, performance management, data system development and building leaders to ensure new skills are implemented and sustained in MCH operations.

Key MCH Leadership Staff

Marcus Johnson-Miller 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 13 years. Along with the Title V Block Grant, Marcus provides leadership for over 25 programs related to maternal and child health. He has extensive experience in working with local partners implementing the Title V MCH program, 1st Five Healthy Mental Development and other early childhood programs. Marcus has built strong relationships with the Departments of Human Services, , Education, Human Rights, Workforce Development and Economic Development, as well as with Iowa Medicaid Enterprise. Marcus has a BS in Child and Family Services and master's level coursework in public administration from Iowa State University.

Bob Russell, DDS, MPH has been the Public Health Dental Director at the Iowa Department of Public Health for 10 years. In his role he has collaborated with all aspects of the Title V MCH program. Oral health is a crucial piece to in every human's life and Dr. Russell and his staff works hard to make sure the Title V program is infusing oral health within all aspects of the programs. Dr. Russell received his MPH in 2002 from The University of Michigan School of Public Health.

Debra Kane, PhD, an MCH epidemiologist assigned to the IDPH through a contractual agreement with the Centers for Disease Control and Prevention. Kane has a background in public health nursing and a doctoral degree in community health sciences with a focus in MCH epidemiology. She has served in this capacity since January 2005. Her key roles include: linkage of Medicaid claims data to the birth certificate for the Title V program, promotion of data to action using these data, to build data capacity within the BFH, and to provide leadership to promote data to action activities using other data sources such as the inpatient data file. In addition to her role of building data capacity and conducting data analyses, she has been instrumental in recruiting graduate level interns to the IDPH to support and extend the BFH data analyses and data capacity.

Brenda Dobson, MS, RDN, LD has been serving as the Interim Director for the Division of Health Promotion and Chronic Disease Prevention since July 2014. She is also continuing in her role as the

Bureau Chief for the Bureau of Nutrition and Health Promotion, a position she has held since September 2010. Brenda has a long history working for the state WIC program office as a regional consultant, the state WIC Nutrition Services Coordinator and the state WIC Director. In these roles and as bureau chief, she has collaborated with numerous internal and external partners providing services and support to maternal and child health populations and successfully competed for funding from a variety of state and federal sources. As bureau chief, she managed the CDC Nutrition, Physical Activity and Obesity Grant until it ended in December 2013 and the CDC Community Transformation Grant that ended prematurely in September 2014. She currently provides leadership to the state WIC Program, the Iowa Nutrition Network (SNAP-Ed), and co-directs the CDC State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Grant (basic, enhanced and supplemental funded components).

CYSHCN Workforce Development and Capacity

The Division of Child and Community Health (UI-DCCH) within the Stead Family Department of Pediatrics at the University of Iowa Carver College of Medicine administers Iowa's Title V program for CYSHCN. UI-DCCH delivers its public health, systems building, enabling and direct services through 15 community based regional centers located across Iowa. The total number of UI-DCCH employees is 117, with full-time equivalents (FTEs) of 93.4. MCHB Title V funds support 89 employees and 24.8 FTEs.

UI-DCCH has a long history of employing family to family support workers, originally called Parent Consultants (now known as Family Navigators). The first Family Navigator (FN), hired in 1984, was Julie Beckett. Ms. Beckett worked with state and federal officials to develop the "Katie Beckett Waiver," which was passed into federal law in 1982 and into Iowa law in 1984. Subsequent FNs follow Ms. Beckett's commitment to promoting parent-professional partnerships, developing family leadership and strengthening family centered care.

UI-DCCH employs 41 family members of CYSHCN, most of them as FNs. FNs work in UI-DCCH's regional centers and contribute to both MCHB Title V activities and other UI-DCCH programs, such as the Pediatric Integrated Health program and Part C of the Individuals with Disabilities Education Act. FNs provide peer support, care coordination, resource-and-referral information, and advocacy training. They are instrumental in facilitating communication among agencies and service providers. FNs ensure that services are family-centered; they provide leadership to promote the needs and well-being of CYSHCN and their families. Iowa's FNs are frequently represented in the Association of Maternal and Child Health Programs (AMCHP) Family Scholar Program.

FNs complete a 40-hour core competency training and receive ongoing continuing education and peer mentoring. UI-DCCH has built a network to provide ongoing support and training to FNs that uses virtual meeting technology. The monthly meetings build FN competencies, provide updates on current events affecting Iowa families of CYSHCN, and foster collaboration among FNs.

UI-DCCH expanded its partnership with CYSHCN and their families by launching a Family Advisory Council (FAC) in September 2014. Consisting of 14 diverse family members of CYSHCN and two youth

representatives, the FAC assists UI-DCCH with planning, development, and evaluation of programs and policies that impact the System of Care for CYSHCN in Iowa. Members receive training on MCH core competencies, mentoring, and reimbursement for their time and travel expenses. FAC members participated in the MCHB Title V Needs Assessment, providing firsthand knowledge about gaps in services and suggestions for improvement.

Since 2004, UI-DCCH has pioneered the use of telehealth to connect families of CYSHCN with providers they might not otherwise access due to transportation problems or lack of pediatric specialists in their community. Specialists who routinely serve CYSHCN and their families via telehealth include psychiatrists, psychologists, and UI-DCCH staff, including registered dietitians. FNs have been trained to work with autism professionals via telehealth to provide access to Applied Behavior Analysis (ABA).

UI-DCCH's Center for Child Health Improvement and Innovation (CCHII) helps prepare Iowa's workforce to partner with CYSHCN and their families. The CCHII has trained over 6,600 individuals on a range of curricula including Quality Improvement, Family support, Systems of Care, Practice Transformation, Mental Health First Aid, Trauma Informed Care, and Bridges Out of Poverty among others. The CCHII helped Iowa to become first in the nation for the number of people per capita trained in Mental Health First Aid in 2012-13 by training 1,749 individuals. In all trainings delivered to Iowa's workforce, FNs serve as partners in planning and presenting and play a key role in educating policymakers on key issues affecting CYSHCN.

One special program offered through telehealth in 17 Iowa counties is the Child and Youth Consultation Service of Iowa (CYC-I). CYC-I targets Primary Care Providers (PCPs) who care for children and youth 0-21 years with mild or moderate behavioral health needs. Services include real time consultation between a University of Iowa Child Psychiatrist and PCP, mental and behavioral health focused training for the PCP, web-based resources for the PCP and families, and care coordination.

One of the major challenges with Iowa's workforce is a shortage of pediatricians and pediatric specialists. As of 2012, the American Medical Association reported that Iowa was 44th in the nation in pediatricians per capita, 42nd in child and adolescent psychiatrists per capita, and 46th in psychiatrists per capita. There is a lack of developmental specialists in Iowa, and there is a specific and severe shortage of providers to assess, diagnose, and treat CYSHCN with Autism Spectrum Disorder (ASD) and Serious Emotional Disturbance. Although Iowa's Autism Support Program, legislatively created in 2013, provides access to funding for Applied Behavioral Analysis therapy for those who are living at or under 400% of the FPL and who would not otherwise have access, the waitlist for this therapy is 6-9 months, and therapy is not available in some areas.

A second major workforce challenge is facilitating access to care for the one-third of the population that lives in rural areas. There are very few pediatricians and fewer pediatric subspecialists working in rural areas of the state, and 80% of psychiatrists are concentrated in Iowa's three most populated cities. Many families lack financial resources, or do not have the ability to take time off from work to travel to urban areas for appointments. As a result, rural families depend on local PCPs who may lack training in

diagnosing and treating CYSHCN. Most rural PCPs do not have access to locally-based clinics with pediatric specialists.

Telehealth has been successful in reducing some access barriers, but its availability has been limited. Expansion of telehealth services would help address provider shortages and geographic disparities in access to care for CYSHCN and their families.

Developing a workforce that is skilled in coordinating care and collaborating across agencies is the top need in Iowa for CYSHCN. CYSHCN often have multiple care coordinators or case managers that coordinate care within the clinic or agency, but they rarely collaborate or even communicate with each other. The lack of coordination causes duplication and/or gaps in services. When agencies and other providers fail to cooperate, parents of CYSHCN bear the burden of trying to get accurate information and appropriate services. Many of Iowa's communities do not have an adequate workforce to provide sufficient resources and holistic, family-centered support to CYSHCN. The shortage is most acute in rural areas. For example, there is a shortage of paraprofessionals and direct care workers with the skills and experience necessary to serve children with ASD. Child care facilities serving CYSHCN often have waitlists of at least one year, and few are located in rural areas.

When workforce members collaborate, they are sometimes restricted by rigid program requirements and conflicting program objectives. To enable improved coordination in all of Iowa's programs, UI-DCCH works with the Systems Integration Grant (SIG) Advisory Council, which was formed in 2014 through the HRSA funded Iowa's Systems Integration Grant "Enhancing a System of Care for Iowa's Children and Youth with Special Health Care Needs." The SIG Advisory Council includes two family members of CYSHCN. Members of the SIG Advisory Council represent diverse groups that are stakeholders in systems integration and have a vested interest in improved CYSHCN health outcomes and receipt of care.

Many members of Iowa's workforce have a desire to improve cultural competency skills to work with families of CYSHCN whose preferred language is not English. Concurrent with racial and demographic changes, the percentage of Iowans that speak a language other than English has more than doubled since 1990, to 7.4%. There is a need for family leaders from all cultures served and the availability of cultural brokers and translators to assure effective family and professional partnerships.

A state workgroup tasked with redesigning Iowa's mental health system reported a need for practice transformation across all types of providers. Health care providers need assistance in developing and implementing health homes in clinical practices, as well as information on the unique needs of CYSHCN. Specific areas for practice transformation include: collaboration, family partnering skills, shared decision making, development of high functioning teams, System of Care principles, population health concepts, Life Course, cultural competency, continuous quality improvement, and care coordination. In addition, clinicians reported a lack of knowledge on appropriate surveillance and screening methods and referral processes for CYSHCN.

Implementing changes from the state level, such as expansion of telehealth and use of electronic health records, will require targeted training for the provider workforce. The SIG Advisory Council plans to collaborate with another statewide coalition to build the Iowa Health Information Network (IHIN) and encourage Iowa providers to use electronic health records. IHIN will be a “hub” that facilitates the sharing of electronic patient health information between authorized users. As health care and other providers adopt the utilization of electronic health records, technical support is needed to ensure that the electronic registries can share data and interact meaningfully across organizations.

Health care providers serving CYSHCN and adults may benefit from training to assist them in partnering and serving young adults, such as shared decision-making, addressing the developmental stages of youth and young adults, and involving legal guardians in the plan of care. Many of Iowa’s health care providers and educators also need training on the impact of trauma and in trauma informed care.

UI-DCCH staff would benefit from formal training in quality improvement methodology to assist providers with practice transformation. Staff need training in the effective use of social media to create new initiatives to provide resources and support to CYSHCN and their families. Other areas that need development in UI-DCCH staff include collecting data from electronic medical records, developing universal care plans, understanding the social determinants of health, and establishing effective community partnership models.

CYSHCN and their families need support and resources to help them receive the care and assistance they need. UI-DCCH will help champion the family-professional partnerships by providing CYSHCN and their families with training on shared decision making, Life Course, and advocacy. One of the goals of the SIG is to develop a web-based portal that is a single point of access to available services and supports for families with CYSHCN. The portal will include up-to-date information regarding services available in different geographic areas in Iowa and real-time, on-line chat capabilities to support families as they navigate the portal. The website will also include resources for workforce development related to care coordination, quality improvement, family to family support, integrated systems and treatment interventions.

Key CYSHCN Leadership Staff

Debra Waldron, MD, MPH, FAAP is Professor of Pediatrics at the University of Iowa Colleges of Medicine and Public Health, Director of the UI-DCCH and Vice Chair of Child Health Policy at the University of Iowa Children’s Hospital. She is a board certified pediatrician specializing in children with developmental disabilities and chronic conditions. She has extensive experience in public health and clinical systems development, quality improvement methodology, medical home building, and health equity.

Dr. Waldron directs a number of federal grants and state contracts that are related to state systems building, including: the Title V Block grant for CYSHCN; the (2014-2017) MCHB State Implementation Grant for CYSHCN; Iowa’s Regional Autism Assistance Program (RAP); 1st Five Healthy Development

Technical Assistance project; and Iowa's Pediatric Integrated Health Home Technical Assistance, Training, and Quality Improvement project.

Dr. Waldron is involved with many projects and committees for the American Academy of Pediatrics (AAP) at both the state and national level. She is Immediate Past President of the IA chapter of the AAP and a member of the AAP Medical Home Implementation Project Advisory Committee. She also serves on AMCHP's Executive Committee as Treasurer and is a member of the AMCHP National Consensus Framework for Improving Quality Systems of Care for CYSHCN Work Group.

Dr. Waldron currently leads efforts in Iowa to integrate concepts of the social determinants of health and health equity into the Title V program. She provides vital linkages to multiple entities that are stakeholders in improving Iowa's system of care for CYSHCN.

Mary Larew, MD is Clinical Associate Professor of Pediatrics at the University of Iowa Carver College of Medicine, Medical Director for UI-DCCH, and a board-certified pediatrician specializing in adolescent medicine. She has extensive experience in delivering clinical care and in working with interagency partners to conduct learning collaboratives within medical homes. She supervises all clinical functions at CHSC Regional Health Centers and was previously the Director of the Adolescent Clinic within the Stead Family Department of Pediatrics at the University of Iowa Hospitals and Clinics.

Doris E. Montag, MHA is the UI-DCCH Associate Director. She has over 35 years of progressive responsibility in academic department administration. For the past 17 years she served as the Department of Pediatric administrator within the University of Iowa Carver College of Medicine. In this role she was the liaison and financial manager for numerous contracts held by the Department of Pediatrics with the Iowa Department of Public Health, the Department of Education and the Department of Human Services. These have included the medical contract for Iowa's Newborn Screening Program, the Statewide Perinatal Services, a large Medicaid Administrative Claiming agreement, the Neuromuscular and Related Genetics Disorders and the Regional Genetics Consultation Service agreement. Ms. Montag provided strategic guidance and oversight, participated in MCHB Title V Grant reviews and program planning, and recently joined the UI-DCCH as a full time Associate Director responsible for Finances, Human Resources, Operations and oversight of numerous programs/contracts. She contributes to analysis of program data, strategic planning and feasibility assessments.

Vickie Miene, MS, MA, LMHC is the Executive Director of the UI-CCHII. She is a licensed mental health therapist in Iowa and has experience managing many large programs including the Integrated Health Home Technical Assistance, Training and Quality Improvement Project and the Peer Support and Family Peer Support Training and Mentoring program. Vickie oversees training, quality improvement, telehealth and CYC-I programming. She has experience managing multiple contracts, including sub-contractors, as well as developing, implementing and evaluating a variety of programs. Vickie has over 25 years of experience in the child welfare and mental health service industry as a therapist, supervisor, manager, and administrator. Vickie was previously an adjunct faculty member for Loras College teaching Ethics and Child Development for graduate students in the Department of Psychology, and adjunct

faculty for the American Institutes for Research at Georgetown where she taught System of Care Values and Principles and Capacity Building for Family and Youth Partnerships.

Sharon Rettinger is a CHSC Family Navigator and Coordinator of Iowa's Family Navigator Network (FNN). Sharon has provided family to family support for CHSC for 9 years and coordinated the FNN for 8 years. As a Family Navigator, she has provided family to family support for the Health and Disease Management HCBS Waiver program. She serves on CHSC's Leadership Advisory Council, Advocacy Committee, and MCH Needs Assessment and Care Coordination teams. She provides family/consumer input for the AMCHP Action Learning Collaborative and the State Implementation Grant for System Integration for CYSHCN. Ms. Rettinger partnered to develop and implement CHSC's Family Advisory Council, which provides family and consumer input for CHSC.

Ms. Rettinger is the parent of a child with a metabolic genetic disorder, and she has served as an AMCHP Family Scholar. Her trainings include University of Chicago Leadership Development and Coaching for Maternal and Child Health Professionals, Community Circle of Care Parent Consultant Training, Family to Family Iowa Navigator Training and 1-2-3 Magic Train the Trainer.

Martha Hanley, MA, has been a CHSC Family Navigator since 2010. The mother of a young adult with a Serious Emotional Disturbance (SED), she currently works with families of children with SEDs for the Pediatric Integrated Health program, connecting them with community-based services and supports. She has provided the National Alliance on Mental Illness (NAMI) Family to Family education course to numerous families in Iowa. She has also received training in RESPECT, Mental Health First Aid, facilitating, and Family Team Meeting techniques. She has participated in AMCHP activities as a Family Scholar and Family Mentor and is currently Iowa's MCH Title V Family Delegate. Martha is a trainer for the Family Peer Support Specialist Training Program, and she is a family faculty member with Iowa's Leadership in Education of Neurodevelopmental Disabilities (ILEND) program.

Jean Willard, MPH is a Program Manager with CHSC. Jean has extensive experience in health measurement and policy analysis. She managed the Iowa Child and Family Household Survey from 2000-2013, including data analysis, reporting, and oversight of the data collection process. Jean has significant experience translating data results for policy makers and health planners. She has been a co-author on over 30 monographs along with numerous peer-reviewed articles in journals, including Medical Care, Ambulatory Pediatrics, Journal of Dental Research, Pediatric Dentistry, and General Hospital Psychiatry. In 1995 she earned an MPH in Public Health Policy and Administration, with emphasis in Family and Child Health, from the School of Public Health at the University of Michigan.

Kathryn Dorsey, MBA is a CHSC Program Manager with over 18 years of experience in health policy. Her experience includes writing reports for the Congressional Budget Office, directing Medicare demonstration projects, and implementing an online nurse residency program. She earned a MS in Economics in 1996 and a MBA in 2009. Her role at CHSC is to oversee MCH Title V services for CYSHCN and assure that MCH Title V resources and other grants and projects are coordinated to achieve maximum benefit to CYSHCN.

Promoting and Providing Culturally Competent Delivery of Services

Although Iowa is less racially diverse than some states, this diversity is increasing rapidly. Iowa's Asian and Hispanic communities are the quickest growing population groups.²⁵ Key informants noted that there has been an increase in immigrant and refugee populations, resulting in small groups of people from several different countries, such as Burmese and Sudanese populations, residing within a single community. Providers in Iowa may find it challenging to tailor programs to meet the needs of small numbers of diverse populations.

The IDPH has an Office of Minority and Multicultural Health (OMMH). This office is charged with developing, improving and implementing effective methods to increase access to culturally and linguistically competent health care for all racial/ethnic populations across the state of Iowa. The OMMH utilizes a vast array of data collection sites for race, ethnicity and linguistic needs for the diverse populations within the state. These sources include but are not limited to: BRFSS, Title V program data, University of Northern Iowa Center on Health Disparities, division of health promotion and chronic disease prevention programming data, and state library data resource centers. The OMMH also utilizes the DHHS Office of Minority Health Culturally and Linguistically Appropriate (CLAS) Think Cultural Health web site for resources in the delivery of CLAS trainings, workshops and outreach strategic planning.

In accordance with the IDPH and MCH employment and orientation policies, OMMH provide new employee professional development in-service training sessions targeting culturally and linguistically appropriate service delivery and inclusion. CLAS standards training was provided to all MCH state staff in FFY2014. OMMH participates in yearly regional and bi-yearly MCH conference workshops on cultural awareness and sensitivity, changing demographics of the state, as well as cultural and linguistically appropriate service delivery. These workshops range in attendance from 30 to 125 participants. OMMH staff provides individual and clinic staff workshops on topics which are inclusive to the needs of the specific targeted populations of that service delivery area. An average of 50 workshops/trainings and technical assistance are provided yearly. OMMH staff serves on PRAMS, Adolescent Health, and MCH committees specifically targeting special populations and is lead staff for the previous SPM #3 *"The degree to which Iowa's state MCH Title V program addresses health equity in MCH programs measured through the MCH Title V index"*. OMMH staff is available to any community and faith-based organization, public and not for profit entities, state and local health contractors and organizations, as well as subcontractors, for technical assistance, workshops, summits to address specific needs of the agencies in the area of racial/ethnically and linguistically appropriate services.

OMMH currently has a partnership of over 80 organizations to provide on-going collaborations in the areas of needs/asset assessments, program planning, service delivery and evaluation/monitoring/quality

²⁵ Miller, V. (2014, March 28). Iowa sees surge in Asian populace, Hispanic growth remains strong. The Gazette. Retrieved from <http://thegazette.com/2013/06/13/iowa-sees-surge-in-asian-populace-hispanic-growth-remains-strong/>
University of Iowa Public Policy Center (2012). The 2010 Iowa Child and Family Household Health Survey: Statewide results.

improvement activities. For example, in 2014 OMMH provided CLAS standards training and served on the systems of care planning initiative in collaboration with DHS specifically targeting mental health in diverse populations. OMMH provided in-service training for all MCH contractors in developing a toolbox for health equity/health disparities within their MCH/FP plans. The faith-based community has received technical assistance in community collaboration and sustainability efforts through such programs as Body and Soul and summits which target specific health disparities such as nutrition, health life style choices and chronic diseases. Through the DHHS OMH National Partnership for Action OMMH continues to use these tools and resources to direct service delivery, especially in decreasing health disparities. OMMH works with the IDPH communications division to ensure that up to date listings and resources in media (radio, TV, written) for diverse communities are maintained within this central informational base.

OMMH continues to work with HPCDP grant coordinators to access funding streams to enhance service delivery to diverse communities. OMMH continues to provide services via partnerships within MCH and other programs, in networking and assurance in possible allocations to community partners. OMMH works with MCH contractors specifically addressing services that can be provided through collaboration and partnerships with community based service delivery agents and faith-based health initiatives. OMMH works to ensure that performance standards, for state staff and local contractors, incorporate cultural competence practices and policies thru education, instruction and infusion of the CLAS standards within strategic plans, goals and objectives of the agencies/contractors. Technical assistance is provided to MCH programs in the development of these standards.

Policies and guidelines used to support the above identified activities and approaches above include: Title VI of the civil rights act, Culturally and Linguistically Appropriate Services (CLAS) standards, the Persons with Disabilities Act, the IDPH Operational Plan, the Title V Block Grant and the Needs Assessment all provide direction in addressing disparity issues pertaining to racial and ethnic diverse populations.

UI-DCCH collected baseline race and ethnicity data for CYSHCN receiving clinical services or care coordination through UI-DCCH regional centers during FFY14. CHSC recognizes that the regular collection, analysis, and dissemination of data related to health disparities and greater outreach to minority and underserved populations are essential to this goal and will continue these efforts. Several state and community organizations provide qualitative and quantitative data on minority and underserved populations in Iowa. These organizations include the Iowa Department of Education, Iowa Center on Health Disparities, Ethnic Minorities of Burma Advocacy and Resource Center (EMBARC) and the University of Iowa College of Public Health.

UI-DCCH collaborates with several informal community leaders and groups, including CHSC's Family Advisory Council, Access for Special Kids (ASK) Resource Center, National Alliance of Mental Illness – Iowa Chapter, and EMBARC. At the local level, staff refer families to faith-based and other community organizations that offer assistance with unmet needs. Regional Center staff serve on community coalitions that monitor and address child health issues at the local level.

All UI-DCCH staff complete a web-based Diversity and Limited English Proficiency training as a condition of employment. A UI-DCCH staff member further promotes cultural competence and health literacy trainings within MCH Navigator as a continued resource. The UI uses a web-based program known as CultureVision to provide frontline health care professionals with information needed to provide culturally competent patient care. Staff receive updates on the health of diverse populations of CYSHCN and relevant resources through a monthly newsletter. A UI-DCCH staff member sends position announcements for circulation among community-based groups representing diverse populations. UI DCCH recognizes that a diverse workforce is a key element to delivering culturally competent care and will continue to strive to increase diversity among the workforce.

The Regional Autism Assistance Program (RAP) and Pediatric Integrated Health (PIH) programs provide comprehensive, whole-person care. An integral part of these programs is the development of a care coordination plan that includes information about the child's and family's strengths, dynamics, traditions, and culture, along with areas of need. PIH program activities are strengths-based and individualized, building on each family's informal and natural supports while connecting them to available community resources.

UI-DCCH uses a telephone interpreting service for families requiring an interpreter. This service provides prompt access to interpreters fluent in over 200. UI-DCCH translates written materials into Spanish or other languages as necessitated by the population served. UI-DCCH translated ASD materials into six languages for families and shared them with other states as requested.

The UI Hospitals and Clinics has a policy requiring materials for families to be written at 6th grade level or below. UI-DCCH uses a software program to review documents and assure they meet this standard. They are readability tested by the Family Advisory Council.

The UI Center for Excellence in Developmental Disabilities (UCEDD) offers technical assistance to state and local agencies to improve services, as well as policy analysis to identify emerging best practices. The UCEDD coordinates the Iowa Leadership Education in Neurodevelopmental and related Disabilities (ILEND) program, which is a one year interdisciplinary leadership training program for graduate students that promotes culturally competent and family-centered, coordinated systems of care for CYSHCN and their families. A UI-DCCH Family Navigator is an ILEND Family Faculty member, and UI-DCCH collaborates with ILEND to provide work experiences for trainees on topics important to CYSHCN.

Partnerships

The Iowa Department of Public Health (IDPH) and the University of Iowa Division of Child and Community Health (UI-DCCH) maintain many formal and informal partnerships to plan and implement Maternal and Child Health (MCH) programming. This leveraging of resources results in a strong statewide network, benefiting Iowa families.

i. MCHB Investments

State System Development Initiative (SSDI) Grant	The purpose of SSDI grants are to develop, enhance, and expand the state's Title V MCH data capacity to allow for informed decision making and resource allocation that supports effective, efficient and quality programming for women, infants, children and youth, including children and youth with special health care needs. Historically, Iowa has obtained maximum benefit from using its SSDI resources to direct the state's ongoing Title V needs assessment activities. Assessment of Iowa's MCH population was strengthened by an innovative SSDI-funded initiative, the Iowa Child and Family Household Health Survey (IHHS). The survey, which began in 2000 and was replicated in 2005 and 2010, was the first comprehensive statewide evaluation of the health status, access to health care and social environment of children living within families in Iowa. Due to the change in goals of the SSDI project, the IDPH is retiring the IHHS and focusing attention on use of data sources that support the newly developed Title V performance measures and the Iowa Collaborative Improvement and Innovation Network (CoIIN) to Reduce Infant Mortality.
Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Grant	The IDPH contracts with local implementing agencies to expand evidence-based home visiting services in targeted communities identified in the 2010 home visiting needs assessment. Currently, MIECHV services are available in 18 counties and serve 1,124 families with young children. In addition, the IDPH has invested in numerous infrastructure building projects to meet the priorities of the MIECHV funds.
Healthy Start Grant	The director of Iowa's Healthy Start grant partners with the IDPH on the CoIIN to reduce Infant Mortality. This partnership shares the cost of training staff about screening pregnant and postpartum women for depression and also Listening Visits. The IDPH staff also serves on the Healthy Start Advisory Board.
Early Childhood Systems of Care (ECCS) Grants	The IDPH is the state's ECCS grantee. Iowa is working to integrate developmental screenings within child care and home care centers. ECCS activities are conducted in three pilot communities, administered through the local Title V contractors of these communities.

MCH Public Health Leadership Institute	<p>One staff member from the IDPH Bureau of Family Health participated in the <i>MCH-Public Health Leadership Institute</i>, a focused, yearlong, intensive leadership development for both MCH program and family leaders in the US and territories. The yearlong program seeks to significantly expand self-awareness and quickly build practical skills for effectively leading and managing people and building partnerships to advocate for and create the MCH systems of tomorrow. This unique program improves leadership capacity, teaching how to create the kind of organizational culture that engages and motivates others.</p> <p>The UI-DCCCCH Family Navigator Network Coordinator participated in a six month Leadership Development and Coaching for MCH Professionals presented by the Maternal and Child Health Program at the University of Illinois at Chicago School of Public Health. The online training provided professional leadership development to 25 MCH leaders. Monthly group calls and bi-monthly individual coaching sessions worked on personal leadership objectives, leadership lessons learned, and engaging and improving MCH in your organization.</p>
Improving Services for Iowa's Children with Autism Spectrum Disorders	<p>To maintain the Regional Autism Assistance Program (RAP), UI-DCCH uses funding from the Health Resources and Services Administration (HRSA), the State of Iowa, Iowa Department of Education (DE), Iowa Department of Human Services (DHS), and the IDPH. The RAP program has teams in 15 regional sites to provide care coordination with the medical home and other providers, family to family support, mid-level screenings for Autism Spectrum Disorder (ASD), and connections to Applied Behavioral Analysis (ABA) therapy.</p> <p>In 2014, UI-DCCH received a two-year MCHB-funded grant entitled, "Improving Services for Iowa's Young Children with Autism Spectrum Disorder and Other Developmental Disabilities." RAP has an Advisory Committee that convenes quarterly and is comprised of family members, services providers, stakeholders and state agencies. RAP has established protocols for early identification, referral, and diagnostic services. RAP will create a dynamic web-based resource portal that will be available for families, educators, medical and service providers and will offer additional opportunities for collaboration for workforce development opportunities. (More information provided in section vi. "Other Governmental Activities.")</p>
MCHB efforts relating to developmental disabilities	IDPH - NA
MCHB efforts relating to adolescent health	See "PREP" and "AEGP"

MCHB efforts relating to workforce development	<p>Iowa was selected to participate in the National MCH Workforce Development Center’s first cohort. The aim of the project was to identify the most appropriate role for Iowa’s state and local MCH programs in the health reform era, especially in regard to Iowa’s emerging public health insurance model. Using the Center’s tools, including the Health Reform State Assessment Tool and the Title V Value Proposition Tool, the team systematically explored the possibility for Iowa’s local MCH agencies to serve as providers in the emerging health care networks, including ACOs. They also learned and applied tools related to systems mapping, leadership, and fostering public-private partnerships that increase the MCH workforce’s capacity to effectively respond to new demands placed on MCH professionals as a result of health reform in Iowa.</p> <p>The University of Iowa Center for Excellence in Developmental Disabilities coordinates the Iowa Leadership in Neurodevelopmental Disabilities (ILEND) program, which is a one-year interdisciplinary leadership training program for graduate students. The program promotes cultural competency and family-centered, coordinated systems of care for CYSHCN and their families. A UI-DCCH Family Navigator is a family faculty member for the ILEND program, and other UI-DCCH leaders serve as MCH Title V faculty.</p> <p>In 2009, UI-DCCH received an MCHB grant called “Iowa Family to Family Health Information Center” (F2F HIC) to promote collaboration between existing family support groups. F2F HIC (known as Family to Family Iowa) has united over 25 family advocacy groups and grown into a leading stakeholder group to assure that all families have access to the supports and services they need. Over 70 Family Navigators (FNs) have been trained according to standards adopted by Family to Family Iowa. Access for Special Kids (ASK) Resource Center currently administers the program. ASK Resource Center also provides statewide trainings for FNs on system of care principles and requesting accommodations within schools. UI-DCCH received MCHB-funded technical assistance from the Missouri Family to Family Resource Center to train staff in shared decision making (SDM) in October 2014. SDM is a collaborative process that allows patients, families, and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the family’s values and preferences. SDM honors both the provider’s expert knowledge and the family’s right to be fully informed of all care options and the potential harms and benefits. Families are valued as engaged members of the team and providers are able to feel confident in the care they prescribe.</p> <p>UI-DCCH received technical assistance, funded by AMCHP and provided by the Florida Health and Transition Services program, to provide expert consultation in developing tools and procedures to facilitate the transition from pediatric to adult health care for youth with special health care needs.</p>
--	--

Enhancing a System of Care for Children and Youth with Special Health Care Needs (SIG)	UI-DCCH administers a MCHB funded Systems Implementation Grant to Enhance Systems Integration (SIG) for CYSHCN to increase the proportion of CYSHCN who receive integrated care through a medical or health home approach. The SIG is led by an advisory council formed through partnerships with agencies, organizations, and programs who serve Iowa's CYSHCN. The duties of the council are to lend expertise and knowledge on how to enhance Iowa's system of care. Through the SIG, a revised state plan will be developed that will assure a system of care for CYSHCN through evidence-based practices and nationally recognized best-practice policies. The SIG will also develop a comprehensive web-based information, resource, and referral website for CYSHCN and their families.
Coordinating Adolescent Emotional Health through Community Child Health Teams (CAEH-CCHT)	UI-DCCH administered a MCHB-funded Innovative Evidence Based Models for Improving System Services for CYSHCN grant from September 1, 2011 to August 31, 2014. CHSC partnered with the University of Iowa Hospitals and Clinics and Blank Children's Hospital to promote and spread a family centered, community utility model for underserved Iowa youth with behavioral, emotional, and mental health concerns (BEHMC). CAEH-CCHT focused on increasing the percentage of youth with BEHMC who received coordinated, ongoing, comprehensive care within a medical home. UI-DCCH continues to promote this model for CYSHCN.

ii. Other Federal Investments

Head Start The Head Start (HS) State Collaboration Office within the Department of Education and the Iowa Head Start Association work closely with the IDPH and local MCH programs. Linkages include partnering on state oral health policy development and program improvements and offering preventive dental services and education to nearly all Head Start centers through local I-Smile™ programs within Title V. An annual “oral health networking” session is held for HS health and I-Smile™ coordinators to facilitate program collaboration.

The IDPH provides oversight and facilitation to the Family Support Leadership Group (FSLG.) The Head Start State Collaboration Officer is a member of the FSLG. The members determine the direction and priorities for family support programming in Iowa. The group also serves as a natural venue for information sharing and collaboration. In addition, a Head Start representative serves on the IDPH’s federal home visit advisory group that provides advice and input on MIECHV programming.

MIECHV and Early ACCESS have combined efforts and funding to provide a coordinated intake system for Iowa families to access resources including Early ACCESS and home visiting services. The system has both web-based and telephone access.

National Science Foundation UI-DCCH collaborated with faculty in the Department of Occupational and Environmental Health at the UI College of Public Health for a National Science Foundation research grant called “Disaster Resilience for Rural Communities.” Trainings were given throughout Iowa, and researchers investigated the potential to increase access to emergency information and planning resources for families of CYSHCN. Opportunities to continue the research are being explored.

Personal Responsibility Education Program (PREP) The IDPH receives PREP funding which is contracted to local organizations around the state. Contractors deliver evidence-based comprehensive sexuality education to adolescents and also address life skills to assist Iowa teens in making responsible, informed decisions and lead safe and healthy lives. Information about sexually transmitted diseases and HIV/AIDS are included within the curriculum. Contractors partner with local youth-serving agencies in their community to help deliver programming to youth and offer referrals to health and related services, such as Title V MCH agencies and Title X clinics.

Abstinence Education Grant Program (AEGP) The IDPH receives AEGP funding and contracts with local agencies and school districts around the state. Contractors deliver evidence-based or promising practices education to adolescents. The AEGP contractors partner with local youth serving agencies in their community to help deliver programming to youth and offer referrals to health and related services, such as Title V MCH agencies and Title X clinics.

Centers for Disease Control and Prevention (CDC) Oral Disease Prevention	Through the CDC Oral Disease Prevention grant program, the IDPH allocates funds to Title V CH agencies to improve their school-based sealant programs (SBSP) and I-Smile™ program. With CDC funding and a newly dedicated Sealant Coordinator, SBSP expanded from six to 18 Title V agencies, began hosting annual SBSP contractor meetings, produced a SBSP manual, and is developing a statewide SBSP promotion campaign. In addition, CDC funds have been allocated to Title V CH agencies to expand promotion activities through the I-Smile™ program. Funding is also supporting a statistical analyst position, enhancing data monitoring and evaluation of oral health programs.
CDC assignee	The IDPH contracts with the CDC, Division of Reproductive Health, Field Support Branch, MCH EPI (MCHEP) Team for a field assignee. The field assignee's role is to build state-level MCH research and scientific capacity with a focus on data that informs public health programs and policies.
Council for State and Territorial Epidemiologists (CSTE)	The MCHEP partners with CSTE to support graduate level fellows in states focused on building MCH capacity. This year, Iowa successfully recruited a CSTE Fellow for a 2-year assignment. The CDC assignee serves as the CSTE Fellow's primary mentor and supervisor.
Pregnancy Risk Assessment Monitoring System (PRAMS)	The PRAMS survey asks women about their attitudes and experiences before, during, and shortly after pregnancy. The IDPH sends the PRAMS survey to mothers 2-6 months following the birth of her child. CDC has not yet released a dataset to Iowa. Iowa PRAMS intends to support the Title V Block Grant through analyses of the PRAMS data once it is released from CDC.
United States Department of Agriculture (USDA)	The University of Iowa eHealth Extension Network Project supplies 65 sites in 45 counties throughout Iowa with telehealth equipment including high quality cameras, HIPPA compliant video conferencing, and cloud-based image sharing software. Sites outlined in this project include the CHSC regional centers. This grant provides multiple approaches to address rural healthcare challenges such as access to medical specialists, and it provides opportunities for Medical students to have firsthand experience practicing care delivery in a telehealth setting specifically designed to enhance rural healthcare.
USDA Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)	The Iowa WIC program works directly with the Title V program by offering space at clinics thus providing dental preventive services to at-risk WIC children. WIC services are provided in every county in Iowa on a monthly basis and the partnership with Title V during these clinics impacts a large number of children by providing dental assessments and varnishes. In addition, the Iowa WIC program has a designated liaison at the state WIC office that communicates regularly with the IDPH Title V staff to ensure timely communication and coordination of education and services.
Fetal Alcohol Syndrome Prevention	Iowa is one of several Midwestern states who participate in the Midwest Regional Fetal Alcohol Spectrum Disorder (FASD) Training Center. The IDPH staff facilitate provider education on FASD through mentor-trained speakers to identify opportunities within their health networks to do trainings.

Title X Family Planning	IDPH contracts with seven community-based agencies to provide family planning services with a goal of improving the health of women, children, and families by helping people to voluntarily time and space pregnancies through the provision of a broad range of contraceptive methods, education, community outreach, and reproductive life planning.
Immunizations	The IDPH Title V MCH collaborates with the IDPH Bureau of Immunization regarding policy and practice for providing immunization services. Thirteen local CH contractors provide immunization services. Through the Title V MCH contract, they comply with standards established by the IDPH Immunization Program, participate in the Vaccine For Children's Program, and enter vaccines in the Iowa Immunization Registry Information System (IRIS). The MCH program follows the ACIP Immunization Schedule. Annual data reports are shared upon release from the IDPH Immunization Program.
Early Hearing Detection & Intervention (EHDI)	The Iowa Early Hearing Detection and Intervention (EHDI) program's mission is to ensure that all newborns and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, medical intervention and family support. The CDC's EHDI cooperative agreement and the Health Resources and Services Administration (HRSA) EHDI grant provides an organizing framework and core resources which are essential to advancing the state system. Under Iowa legislation regarding Universal Newborn Hearing Screening, the IDPH is designated as the entity responsible for the collection of hearing screening and diagnostic information. Local Title V child health programs assist the EHDI program by helping families schedule repeat hearing screens for their children who did not pass his/her hearing screen at birth.
Infant and Child Death Review	The IDPH collaborates with the Iowa Child Death Review Team (CDRT). Approximately 5 times a year, the team (facilitated and led by the Iowa Medical Examiner's Office) reviews circumstances and events associated with infant and child deaths in Iowa. Iowa's CDRT has representatives from many disciplines, from health care professionals to public safety officers to social service representatives. While the members of the team come from different backgrounds and locations in Iowa, there is one common goal; to reduce or minimize risk of infant and child death and injury through collection of data.

iii. Other HRSA Programs

Federally Qualified Health Centers (FQHC) and Rural Health Clinics (RHC)	FQHC and RHC are critical referral sources for local Title V contractors for medical and dental services for the MCH population. In addition, MCH programs work with FQHC and RHC to assure families are enrolled on Medicaid and CHIP and to provide clear, culturally competent health education to clients. I-Smile coordinators offer oral health training to RHC staff, and in some areas of the state, FQHC staff work with I-Smile to provide gap-filling dental services in schools and WIC clinics. Families are then linked to Title V for assistance with follow up and additional health resources. UI-DCCH partners with FQHC to provide external care coordination and family to family support for CYSHCN.
--	---

STD/HIV/AIDS	The IDPH staff with the MCH and Title X programs collaborate with staff from the IDPH Bureau of STD, HIV and Hepatitis on a variety of projects. Collaboration includes provision of expert program input for gap filling services STD screenings, treatment and referrals for treatment. The Community Based Screening Services project provides test kits and treatment medication to all Title X family planning providers for chlamydia and gonorrhea. Training and technical assistance is available for all Title V and Title X providers. The Disease Prevention Specialists from the Bureau of STD, HIV and Hepatitis are used to link clients to services and treatment for all reportable STDs in Iowa.
Behavioral Treatment through In-Home Telehealth for Young Children with Autism	UI-DCCH collaborated with researchers from the Department of Pediatrics, Psychology Division at the University of Iowa Carver College of Medicine to test methods for improving access to function-based behavioral treatment for young children with autism spectrum disorders (ASD). This research examined telehealth in the home environment from 2011-2015 and used lessons learned from the 2009-2012 study funded by the National Institute of Mental Health (NIMH) R01 that had evaluated the efficacy of conducting behavioral treatment through telehealth consultation provided at CHSC's regional centers for young children (ages 1-6 years) who reside in underserved areas of Iowa. A new autism telehealth grant from NIMH started April 2015.
iv. State and Local MCH Programs	
Local Health Departments	All local Title V MCH contractors work with each county board of health within their service area. Per Iowa Administrative Code, 'the county board of health shall have jurisdiction over public health matters within the county'. Title V MCH agencies provide input on programming and elicit feedback from each local board of health. They also participate in the county's community health needs assessment and development of the resulting health improvement plan. Thirteen Title V MCH contractors are county health departments (the remaining are private, non-profit service organizations). In addition, several Title V MCH programs subcontract services to county health departments to administer MCH and EPSDT services. MCH agencies strive to integrate services for their clients.
Private Non-Profit Organizations	Local Title V MCH contracts not held by local health departments are held by private non-profit organizations. These organizations meet the same requirements, participating in community health needs assessments, developing county health improvement plans, and sharing program input and eliciting feedback from local boards of health.

1 st Five Healthy Mental Development Initiative	<p>The IDPH contracts with local MCH agencies to implement the 1st Five program, which supports the partnership of medical practices and public service providers to enhance high quality well-child care. 1st Five also promotes the use of standardized developmental surveillance and screening tools that support healthy development for young children 0-5 years old and their families. Possible risk factors identified include: social-emotional development, family stress, parental depression and autism. Providers are able to identify those at risk for developmental concerns and link those children and their families to community resources. The local care coordinator then closes the referral loop to the provider by following up with the patient's status through a letter or a fax. This program has increased the capacity to identify children at risk for autism and link them to appropriate intervention services as early as possible.</p> <p>The IDPH contracts with UI-DCCH to provide practice transformation activities and develop metrics for 1st Five. Two University of Iowa physicians serve as medical consultants to deliver information on developmental screening and surveillance to primary care practices engaged in 1st Five. UI-DCCH is working with the IDPH and the evaluators for 1st Five, the Child and Family Policy Center, to develop and pilot metrics.</p> <p>UI-DCCH Regional Autism Assistance Program has partnered with 1st Five to promote knowledge of Autism Spectrum Disorder (ASD) and related screening/assessment tools and resources within primary care offices (see section i "Other MCHB Investments" for more information).</p>
I-Smile	<p>I-Smile™ is an IDPH-Medicaid collaboration, part of an interagency agreement. Title V CH contractors receive funding to administer the I-Smile dental home program. Each contractor employs a dental hygienist as the service area I-Smile coordinator. Coordinators are responsible for developing partnerships, creating referral systems with dentists and other health care providers, promoting oral health, training health care providers, ensuring dental care coordination services, and ensuring gap-filling preventive services are provided for families. I-Smile has been successful in significantly increasing the number of low-income children who see a dentist, in addition to reducing average costs per child per year for Medicaid.</p>
Adolescent Health	<p>The IDPH addresses adolescent health through systems and infrastructure building. The IDPH supports programming promoting youth development and provides training and technical assistance to state partners and local agencies looking to incorporate this model into existing programming. The Adolescent Health Collaborative, an IDPH intra-agency group representing many areas of adolescent health, convene and work together to share resources and data, reduce duplication of services for more coordination in the state, and promote adolescent health and youth development both at the state and local levels. Iowa was selected to participate in the Life Course Intensive TA CoIIN and the Adolescent Health Collaborative has been the central point in a project focused on developing a resource for school nurses to use when working with youth.</p>

Bullying	<p>The IDPH addresses bullying and bullying prevention with information available on different program websites. In 2012, Iowa State University extension and the IDPH launched www.iamincontrol.org which provides resources for adolescents. The IDPH also implemented <i>Your Life Iowa</i> (www.yourlifeiowa.org) to address bullying and suicide prevention. This website includes information for teens and offers resources and support also extending to parents and professionals. Personal Responsibility Education Program (PREP) grantees delivered the Signs of Suicide Prevention Program to Iowa youth. UI DCCH helps health care providers and other partners recognize the high risk for bullying among CYSHCN. Staff members provide training for community partners in local school districts and Head Start on recognizing and responding to bullying. UI-DCCH developed lists of community resources for families of CYSHCN who experience bullying.</p>
Siouxland District Health Department	<p>One UI-DCCH regional center is co-located in the Siouxland District Health Department. Exploration continues for additional co-location opportunities.</p>
Child and Youth Consultation Service of Iowa (CYC-I)	<p>The Child and Youth Consultation Service of Iowa (CYC-I) targets primary care providers (PCP) who care for children and youth ages 0-21 years with mild or moderate behavioral health needs. Services include real-time consultation between a University of Iowa Child Psychiatrist and PCP, mental and behavioral health-focused training for the PCP, web-based resources for the PCP and families, and care coordination.</p>
v. Other Programs within the State Department of Health	
Prevention and Health Promotion	<p>Through the CDC Health Promotion and Chronic Disease Control and Prevention (HPCDCP) program, the IDPH is implementing an initiative impacting early childhood. The Nutrition and Physical Activity Self-Assessment in Child Care (NAPSACC) training and resources have been provided to some Head Start and licensed child care centers to improve the nutrition and physical activity environment. Participating centers conduct the assessment, train staff, write an action plan for improvement, implement the action plan, and then reassess.</p>
Chronic Disease	<p>Bureau of Oral and Health Delivery Systems staff manages a chronic disease project with the Bureau of Chronic Disease Prevention and Management, targeting local dental offices. A training developed in conjunction with the University of Iowa College of Dentistry is used for local public health nurses and I-Smile coordinators. They are then used to train dental office staff on blood pressure and tobacco use screening and referrals.</p>
Immunization	<p>The MCH program works closely with the IDPH Bureau of Immunization regarding policy and practice for providing immunization services.</p>
Oral Health	<p>Staff in the Bureau of Oral and Health Delivery Systems provides the technical support and program and policy development for the oral health components of the MCH program, including the I-Smile™ dental home and school-based dental sealant programs. The bureau also promotes community water fluoridation.</p>
Vital Records and Health Statistics	<p>The Bureau of Health Statistics within the IDPH works with the MCH program through the sharing of data used to report Iowa's key MCH indicators, as well as other ad hoc requests.</p>

Office of Disability, Injury & Violence Prevention	The IDPH receives funds from the Rape Prevention Education grant program and the Violence Against Women Act. This funding supports state and local efforts to improve public health services to victims of domestic and sexual violence (especially in Title V and Title X programs) and implement evidence-based or promising practices in communities to prevent sexual violence prevention. Local subcontractors partner with local youth serving agencies in their community to help deliver programming to youth and offer referrals to health and related services.
Substance Abuse Prevention & Treatment	<p>The IDPH receives federal and state substance abuse prevention and treatment funds to support these services in communities. They work with local prevention coalitions to reduce alcohol and drug use among teens, offer substance abuse treatment for individuals who do not have insurance or other 3rd party coverage, offer services that support participation in treatment, and equip health care providers to offer a brief screen for substance use into primary health care settings. Locally, they collaborate with other public health programs/clinics to coordinate services.</p> <p>MCH collaborates with the IDPH Bureau of Substance Abuse on screening for alcohol and substance abuse. Staff has provided training and technical assistance for MCH contract agencies on the implementation of SBIRT (Screening, Brief Intervention, and Referral to Treatment).</p>
vi. Other Governmental Agencies	
Department of Human Services (Child Care Nurse Consultants)	<p>Iowa's local Title V MCH programs and the IDPH work with the Departments of Management and Human Services to provide Child Care Nurse Consultants (CCNCs) to work with early care and education (ECE) providers. CCNCs provide onsite consultation, training, and technical assistance on health and safety in ECE settings, and assist providers in improving care quality through Iowa's Quality Rating System. Funding for CCNCs comes from collaborations at the community level primarily with Early Childhood Iowa, community based agencies (i.e. United Way), and tax levy.</p> <p>The Department of Human Services provides funding for the Healthy Child Care Iowa Campaign to the IDPH to support the development and maintenance of health and safety supports for child care providers in Iowa, regulatory staff and ECE consultants.</p>

Iowa Department of Human Services (DHS), including Medicaid and Children's Health Insurance Program (CHIP)	<p>Iowa's Title V MCH program enjoys a strong collaborative relationship with the DHS. A Medicaid Policy specialist at DHS provides on-going technical assistance and support to state and local MCH and Family Planning staff (including the Iowa Family Planning Network Waiver). The IDPH contracts with DHS to enhance several program initiatives within Title V MCH. These contracts include cooperative agreements among Iowa's Title V, Title X, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Title XIX, and Title XXI programs to:</p> <ul style="list-style-type: none"> • Support quality service provision among local Title V contractors providing CH services (as Medicaid Screening Centers), MH services (as Medicaid Maternal Health Centers), 1st Five Healthy Mental Development services, and oral health services under the I-Smile™ program; • Provide funding for local MCH contractors to provide informing and care coordination services for Medicaid-enrolled children and presumptive eligibility and care coordination for Medicaid-enrolled pregnant women; • Conduct grassroots outreach for Medicaid and CHIP through local MCH contractors and to provide Presumptive Eligibility for children to ensure all Iowa children have health care coverage; • Support the Healthy Families Line, a toll-free information and referral phone line offered statewide for Iowa's families; • Support collection of outcome data for mothers and newborns based upon a match of Vital Records (birth certificates) and Medicaid paid claims; • Provide Medicaid match for a data system to support the Newborn Screening and Early Hearing Detection and Intervention programs; and • Allow sharing of Medicaid paid claims data with the IDPH to link paid claims to the birth certificate for the purposes of: <ul style="list-style-type: none"> ○ Estimating the percentage Medicaid reimbursed deliveries, ○ Monitoring key MCH health outcomes by Medicaid status, and ○ Preparing reports to guide program and policy development on behalf of Medicaid recipients.
Department of Human Services (other programs)	<p>Iowa's Pediatric Integrated Health (PIH) program was created in 2013 through a state plan amendment through section 2703 of the Patient Protection and Affordable Care Act. The Program uses a System of Care approach, allowing CYSHCN under 19 years of age with a serious emotional disturbance (SED) and functional impairment who are eligible for Medicaid to receive coordinated, whole person care in their communities. Wraparound funding pays for services that are unavailable through other payers, such as in-home skill building. UI-DCCH administers PIH sites for 12 counties.</p> <p>UI-DCCH is currently providing technical assistance, training and practice transformation coaching to Iowa's contracted Integrated Health Home (IHH) providers. This project is also funded by Section 2703 of the Affordable Care Act, and it is designed to assist the State of Iowa in its effort to integrate and improve Iowa's children's mental health system through</p>

the implementation of the IHH program. UI-DCCH provides training to direct care staff including nurses, care coordinators, peer support specialists, and family peer support specialists, as well as to the leadership of the agencies and community partners related to the development, implementation, operation and sustainability of the IHH program. Technical assistance activities include on site Quality Improvement practice transformation coaching, specifically in areas of population health, risk stratification, developing a data driven infrastructure, and providing team based care. In addition, the project develops learning networks and disseminates best practices.

UI-DCCH received funding from DHS to provide a comprehensive training and certification program for Iowa's workforce of adults with Serious Persistent Mental Illness (SPMI) and family members of children with SED who provide peer support. Partners on the grant include the National Resource Center for Family Centered Practice at the University of Iowa School of Social Work, Access for Special Kids (ASK) Resource Center, and the National Alliance on Mental Illness (NAMI) Iowa. The partnership is called the Peer Support Training and Coordination Collective (PSTCC). The PSTCC will create a robust, inclusive and meaningful training program to prepare Peer Support Specialists to partner with children, youth, adults, and families who have experienced a SED or SPMI.

IME has launched an initiative to consolidate Medicaid services through one or more managed care organizations, and UI-DCCH is providing input to assure that the initiative adequately covers the needs of CYSHCN and their families. UI-DCCH also served an advisory role to assure that children's needs were addressed in the development of the Iowa State Health Innovation Plan.

UI DCCH RAP teams work with the Autism Support Program (ASP) that is administered by DHS. Legislation in 2013 created the Autism Support Program (ASP). ASP provides Applied Behavioral Analysis (ABA) services to children under age 9 with ASD who meet eligibility requirements. As stipulated by a contract with the IDPH, RAP provides care coordination and family to family support for at least 75% of family referrals applying to the ASP (see also Section i *Other MCH Investments*).

Department of Education, Regional Autism Assistance Program (RAP)	<p>The Iowa Department of Education (DE) contracts with the UI-DCCH to support the Regional Autism Assistance Program (RAP), which is a continuation of the Regional Autism Services Program (RASP) contract from previous years to the University of Iowa Hospitals and Clinics, CHSC. The program name RASP was changed to RAP during the FY 13-14 contract renewal to more closely align to the authorizing legislation, Iowa Code 256.35. Its purpose is to coordinate educational, medical, and other human services for persons with ASD, their parents, and providers of ASD services. Currently DE funding coordinates diagnostic and assessment services, maintains a research and resource database, coordinates in-service training opportunities, and provides technical assistance and consultation on ASD services. The DE RAP contract also provides funds for workforce development on enhanced assessments and exploring the use of telehealth for ABA service delivery. As noted in Section i “Other MCH Investments,” DE funds are now blended with the MCHB and Autism Support Fund resources to create the comprehensive Iowa RAP.</p>
Department of Education, Part C Early Intervention	<p>The lead agency for Iowa’s Part C early intervention system, known as Early ACCESS, is the Department of Education (DE). The IDPH and CHSC are two of three signatory agencies (IDPH, CHSC and DHS) that contract with the DE to ensure that Part C, early intervention, is provided to children and families age birth to three years. Iowa’s Title V MCH programs promote Early ACCESS, implement strategies (e.g. complete developmental screenings) to identify children potentially eligible for Early ACCESS, and make referrals to the Early ACCESS system. MCH programs also collaborate with Early ACCESS partners to provide developmental monitoring to infants and toddlers deemed ineligible for Early ACCESS after a full evaluation has been conducted.</p>
Department of Education (other programs)	<p>The IDPH School-based Dental Sealant program has a strong collaborative partnership with the School Nurse Consultant at DE. This allows for better communication with schools and their employees, enhancing dental services provided for Iowa children and their families.</p> <p>The IDPH Adolescent Health program also works with the School Nurse Consultant at DE to post information and resources to the school nurse listserv that goes out to school nurses around Iowa. The IDPH is also working on an AMCHP project that is analyzing a subset of the adolescent life course indicators to produce a communications resource about this data for school nurses.</p> <p>The 2013 session of the Iowa General Assembly approved legislation creating a program within the IDPH to support a requirement that parents and guardians provide evidence of a vision screening for students entering Kindergarten and third grades. The program has a strong partnership with the DE’s School Nurse Consultant. Together the IDPH and the DE collaborate to distribute information and resources to the school nurse listserv that goes out to school nurses around Iowa. The IDPH is currently enrolling school nurses and other school personnel as users in the IRIS vision screening module.</p>

Iowa Department of Management – Early Childhood Iowa Office	The Early Childhood Iowa (ECI) program is coordinated by the Department of Management. ECI was founded on the premise that communities and state government can work together to improve the well-being of our youngest children. ECI's efforts unite agencies, organizations and community partners to speak with a shared voice to support, strengthen and meet the needs of all young children and families. It is believed that individuals in local communities working together can identify and implement the best means for attaining desired results. The role of the State is to be a partner to support and facilitate growth in community responsibility; not assume the directive role that the public has come to expect of government.
---	---

ECI is funded by the state, allowing local ECI boards to: expand home visitation and parent education; create quality improvement activities for child care and preschool providers, including professional development and training; increase the availability of infant, shift care and inclusive child care; and increase access to child care and preschools for children living in low income families.

An ECI State Technical Assistance Team works with local boards to enhance the services throughout Iowa. ECI has agreements with all six state agencies involved with the State TA Team to include data sharing and allocating staff time to the team. The IDPH Title V Block Grant Coordinator serves on the TA team. ECI also provides gap-filling Professional Development funds to state agencies when needed. The IDPH has used funding for: Child Care Nurse Consultants, Adverse Childhood Experience research, Iowa Family Support Credential, and Period of Purple Crying (Shaken Baby Syndrome).

The ECI Stakeholders Alliance includes stakeholders in early care, health, and education systems that affect children age zero to five in Iowa. Members include representatives of any organization or individuals who touch the lives of children through age 5; who endorse the purpose, vision and guiding principles of the alliance; and has asked to be a member and remains actively engaged. The alliance has six component groups that address key areas of Iowa's early childhood system. These groups ensure that each component of a successful system is present and functioning as well as possible and work, as appropriate, on the implementation of specific strategies as indicated by the ECI strategic plan. Local and state Title V staff are encouraged to become involved with the ECI alliance and component groups.

vii. Tribes, Tribal Organizations, and Urban Indian Organizations

Ponca, Winnebago, Omaha, and Sac and Fox Tribe of the Mississippi in Iowa	UI DCCH plans to work with the University of Iowa College of Public Health to develop partnerships with tribal organizations to better address the needs of CYSHCN and their families who are American Indian. The University of Iowa College of Public Health has long-standing relationships with tribal elders.
---	--

viii. Public Health and Health Professional Educational Programs and Universities

University of Iowa College of Nursing (UICON)	The IDPH contracts with UICON for provision of training to Title V MH contractor staff on screening women for depression and Listening Visits, a home visit model using reflective listening and problem-solving as a treatment for women with depressive symptoms.
University of Iowa - Carver College of Medicine, College of Public Health, and College of Nursing	UI-DCCH contributes to the curriculum of health care provider training programs at the University of Iowa to assure the inclusion of content relating to CYSHCN. Debra Waldron, MD, MPH is a faculty member in the College of Public Health and Carver College of Medicine. UI-DCCH provides educational opportunities for students.
University of Iowa College of Dentistry (UICOD)	The IDPH contracts with UICOD to provide dental services for at-risk children. Services are provided at the college as well as in dental offices around the state. In addition to partnering on an annual regional dental public health meeting, UICOD's dental public health program includes the IDPH staff in monthly meetings to discuss current issues and to study current scientific methods. The IDPH relies on UICOD for topic-area expertise as needed.
Community College Dental Hygiene Programs	The IDPH offers public health training for dental hygiene students annually at each of the five state programs as a way to increase awareness of dental public health programs in Iowa and promote working within public health and the I-Smile™/MCH programs as a career option.
University of Iowa (UI)	<p>The Statewide Perinatal Program with UI provides professional training, development of standards/guidelines of care, consultation to regional and primary providers and evaluation of the quality of care delivered to reduce the mortality and morbidity of infants. Through an IDPH contract with the UI Hospitals and Clinics, these services are provided to all hospitals that perform deliveries.</p> <p>A full description of the partnership between the IDPH and Child Health Specialty Clinics is found in the <i>Capacity</i> section.</p>

University of Iowa – Child Health Specialty Clinics (CHSC)	The Iowa State Legislature appropriates state funds to UI-DCCH through the IDPH for a contract called <i>Mobile Regional Child Health Specialty Clinics</i> . The contract’s purpose is to: assure community-based clinical consultation, multidisciplinary care planning recommendations and family to family support for CYSHCN in 15 regional centers throughout Iowa; provide effective and efficient organization and utilization of resources to assure access to and use of necessary comprehensive services for CYSHCN; serve CYSHCN and technologically assisted residents and graduates of neonatal and pediatric intensive care units whose families need assistance in planning adequate home and community support systems; and to provide core public health functions.
University of Iowa Center of Excellence in Developmental Disabilities (UCEDD)	The University of Iowa Center of Excellence in Developmental Disabilities (UCEDD) offers technical assistance to state and local agencies to improve services, as well as policy analysis to identify emerging best practices. The UCEDD recently began a transition clinic for youth over age 12 with disabilities, and UI-DCCH staff are collaborating as advisors.
University of Northern Iowa (UNI)	The IDPH works with UNI to conduct the Barriers to Prenatal Care survey each year. The purpose of the project is to obtain brief, accurate information about women delivering babies in Iowa hospitals. Specifically, the project seeks to learn if women had problems getting prenatal or delivery care during their pregnancy. The project is a cooperative venture of all of Iowa's maternity hospitals, the Statewide Perinatal Care Program, the UNI Center for Social and Behavioral Research, and the IDPH. Questionnaires are distributed to all maternity hospitals in the state, and all birth mothers are approached prior to discharge and asked to complete one. Completed questionnaires are returned to UNI for data entry and analysis and then shared with the IDPH and other stakeholders to assist in program and policy development.
Des Moines University (DMU)	The IDPH staff work with staff at DMU on public health training for I-Smile™ coordinators and other Iowa-licensed dental hygienists. Over 170 hygienists have received continuing education credit for completing the 6-module training. An evaluation is being completed to consider future use and updates for the training.

ix. Family/Consumer Partnership and Leadership Programs

Maternal and Child Health Advisory Council (MCH)	The MCH advisory council provides a means for the IDPH and UI-DCCH to connect with families, consumers, and stakeholders. The council assists in the development of the state plan for MCH, including children and youth with special health care needs and family planning. The council assists with assessment of need, prioritization of services, establishment of objectives, and encouragement of public support for MCH and family planning programs. In addition, the council advises Iowa’s Title V director and advocates for health and nutrition services for women and children and supports the development of special projects and conferences. The council includes family members and/or consumers of the services provided through Title V.
--	---

MCH contractors and clients	In the past year, the IDPH worked with local MCH contractors to conduct client focus groups. The clients provided feedback regarding the services they receive, the benefit of the program, and much valuable input about their family needs. The use of focus groups will be used in the future to connect with families to ensure programs are meeting the needs of our clients and communities.
Access for Special Kids (ASK) Resource Center	ASK Resource Center is Iowa's Parent Training and Information Center. Presentations for families focus on topics such as Individualized Education Plans, 504 Plans, and how to collaborate with educators to accomplish goals. CHSC promotes a family mentoring program started by ASK. CHSC is also collaborating with ASK Resource Center on the Peer and Family Peer Support Training and Coordination grant, which is explained more in section vi Other Government Agencies.
Family Voices (FV)	FV is one of Iowa's oldest family advocacy organizations. Some CHSC Family Navigators are members of the FV state chapter and regularly participate in FV events. A member of FV serves on the F2F HIC Governance Council.

x. Other State and Local Public and Private Organizations that Serve the State's MCH Population

Delta Dental of Iowa Foundation (DDIAF)	DDIAF has been an advocate and supporter of the Title V contractors and I-Smile™ program for many years. Most recently, the foundation invested in state school-based dental sealant programs, leveraging federal funds to expand the program to nearly 75% of Iowa counties. DDIF has also pro-actively offered oral health promotion tools to local MCH contractors, including toothbrushes and children's magazines. DDIAF and the IDPH also partner for dental loan repayment. Eligible dentists must agree to provide care for underserved Iowans and link with local I-Smile™ coordinators. DDIAF has also awarded funding to the IDPH for a planned comprehensive data system, to benefit the MCH program among others.
ChildServe	ChildServe is a not-for-profit organization that offers specialized health care services to children from birth to 21 years of age. ChildServe currently provides services to nearly 2,500 children throughout central Iowa. UI-DCCH partners with ChildServe on initiatives such as expanding telehealth services through the ChildServe location, reviewing statewide policies that impact CYSHCN, and developing training opportunities for parents and caregivers of CYSHCN.

Iowa Chapter of the American Academy of Pediatrics (IA-AAP)	<p>The Iowa Chapter of the American Academy of Pediatrics (IA-AAP) has nearly 400 active members in Iowa. It is committed to developing and maintaining strong relationships with state agencies, medical institutions, children and family focused organizations, and other professional organizations to improve the health of all children in Iowa. The chapter was a key collaborator on Iowa's previous Medical Home initiative for CYSHCN. It also has expertise on the use of social media to connect with diverse audiences. UI-DCCH has partnered with the IA-AAP to develop a statewide social media presence for many programs focused on improving Iowa's system for CYSHCN.</p> <p>The IDPH contracts with IA-AAP to provide targeted trainings in the pilot sites of the Early Childhood Comprehensive Systems grant. This partnership is utilized to educate community providers on the importance of early childhood brain development and the use of developmental screenings starting at a young age.</p>
Blank Children's Hospital	<p>Blank Children's Hospital, a free-standing hospital for children in Des Moines, is an 88-bed facility designed to meet the unique health care needs of children and their families. Blank Children's Hospital is a member of UnityPoint Health, one of the nation's most integrated health systems and one of Iowa's Accountable Care Organizations. The medical staff features more than 60 pediatric subspecialists and over 150 primary care providers. Blank Children's Hospital participates in the SIG Advisory Council, and UI-DCCH collaborates with the Center for Advocacy and Outreach at Blank Children's Hospital regarding policy issues that influence CYSHCN.</p>
Iowa Primary Care Association (IAPCA)	<p>Iowa Primary Care Association (IAPCA) is a statewide network of federally qualified health centers (FQHCs) and other safety net providers that provide affordable primary and preventive health care for many of Iowa's underserved residents. IAPCA has several initiatives to improve access to health services, and IAPCA provides funding to develop community-based initiatives that assist practices in becoming patient-centered medical homes. CHSC collaborates with IAPCA to address policy and workforce issues relating to primary care. The IAPCA serves on the SIG Advisory Council.</p>
Magellan Behavioral Health	<p>UI-DCCH contracted with Magellan Behavioral Health to develop and implement training for Family Peer Support Specialists throughout Iowa. The project is funded through the Community Reinvestment fund and was a partnership of the UI-DCCH, ASK Resource Center, NAMI and the National Resource Center for Family Centered Practice. The training provided Family Peer Support Specialists with core knowledge in the areas of boundaries, engagement, wellness, empowerment and ethics. The training also focused on teaching Family and Peer Support Specialists how to identify family strengths, resiliency, and needs. A total of 90 participants were trained in this 7 day face to face model. Evaluation of the training indicated that participants were highly satisfied with each core component. (See also section vi "Other Governmental Agencies.")</p>

Meridian Health Plan of Iowa	UI-DCCH is collaborating with Meridian, a Medicaid Health Maintenance Organization, to advance the objectives of an Association of Maternal and Child Health Programs Action Learning Collaborative (ALC). The ALC focuses on integrating the Lucile Packard Standards into the state plan and assuring CYSHCN receive care through a medical home.
National Alliance on Mental Illness (NAMI) Iowa Chapter	<p>The National Alliance on Mental Illness (NAMI) Iowa is a key partner in UI-DCCH efforts to improve the System of Care for children and families faced with mental health and behavioral health challenges. NAMI has several affiliate sites throughout Iowa that provide support and linkage for families to other families who may be struggling with their child's mental health diagnosis. NAMI also makes referrals to UI-DCCH.</p> <p>UI-DCCH works with NAMI to develop and deliver Family Peer Support and Peer Support trainings as described in section vi Other Governmental Agencies. UI-DCCH staff are trained facilitators of NAMI Basics and Family to Family Education and offer NAMI trainings statewide. NAMI Iowa Children's Mental Health Committee leaders also provide trainings to the Family Navigator Network.</p>
Child and Family Policy Center (CFPC)	<p>The IDPH and UI-DCCH frequently collaborate with the Child and Family Policy Center (CFPC) to develop materials describing issues that impact children and families in Iowa. CFPC has provided evaluation for the 1st Five program, as well as support and advocacy, since the program's inception in 2006. Evaluation activities have focused on process, outcomes and lessons learned. These efforts have been maintained as practices have been added at each site and the project has expanded across the state. Currently, through their evaluation efforts and contract with the IDPH, CFPC and the University of Iowa Center for Innovation and Excellence have been collaborating to identify and pilot metrics on the 1st Five program. Through this, CFPC has focused on both family and medical practice satisfaction surveys to look at the impact the 1st Five program has been making on Iowa children. (See also section iv "State and Local MCH Programs."). Additionally, UI-DCCH works with CFPC to develop measurement systems for the IDPH 1st Five program evaluation.</p>

i. Nature and substance of the established family/consumer partnership;

UI-DCCH employs 41 family members of CYSHCN. Family Navigators (FNs) work in regional centers and contribute to both Title V activities and other programs serving CYSHCN and their families. FNs provide peer support, care coordination, resource-and-referral information and advocacy training. They are instrumental in facilitating communication among agencies and service providers. FNs ensure that services are family-centered, and they provide leadership to promote the needs and well-being of CYSHCN and their families. FNs are frequently represented in the Association of Maternal and Child Health Family Scholar Program.

UI-DCCH expanded its partnership with CYSHCN and their families by launching a Family Advisory Council (FAC) in September 2014. Consisting of 14 diverse family members of CYSHCN and 2 youth representatives, the FAC assists CHSC with planning, development, and evaluation of programs and policies that impact the

System of Care for CYSHCN in Iowa. Members receive training on MCH core competencies, mentoring, and reimbursement for their time and travel expenses. FAC members participated in the MCHB Title V Needs Assessment, providing firsthand knowledge about gaps in services and suggestions for improvement.

The IDPH maintains family partnerships through local Title V MCH contractors. Twenty-one MH and 22 CH contractor organizations work directly with families within their service areas, providing care coordination, referral assistance, and gap-filling preventive health services. Contact with families ranges from daily to several times a month, based upon each MCH family's needs. Within each MCH contractor organization, a number of staff work with families, including project directors, maternal health coordinators, child health coordinators, EPSDT coordinators, care coordinators, I-Smile™ coordinators, *hawk-i* outreach coordinators, and health care providers such as nurses and dental hygienists.

Families/consumers are members of the Title V MCH Advisory Council as well as on local health coalitions or similar types of councils (i.e. Head Start Health Advisory Councils, Parents as Teachers Councils, Child Abuse Prevention Coalition, local Community Health Needs Assessment workgroups).

ii. Diversity of members engaged in the family/consumer partnership;

Family Navigators employed by UI-DCCH are diverse in terms of age, urban or rural geographic location, military family status, and type of special health care need of their child. UI-DCCH is committed to continuing to increase this diversity at all levels. Reaching additional underserved and minority populations will require new and innovative partnerships with faith-based and community-based programs.

Members of CHSC's Family Advisory Council are diverse in terms of gender, race and ethnicity, socio-economic descriptors, and age.

Working with racial/ethnic minorities is woven into the fabric of the MCH program; contractors adjust how they work with families based on the needs identified and feedback of those families. Title V MCH contractors work with a diverse population. Child Health (CH) data for 2014 shows that 34% of CH clients were of Hispanic or Latino ethnicity and racial makeup of CH clients included 678 African-American or Black, 504 American Indian, and 452 Asian. Maternal Health (MH) data for 2014 that shows 19% of clients were of Hispanic or Latino ethnicity, and the racial makeup of MH clients included 737 African-American or Black and 239 Asian clients.

MCH contractors assure that they address the needs of their diverse population through outreach efforts that include working with faith-based churches with large numbers of minority members and participating in racial and ethnic community events.

iii. Number of families/consumers engaged in the family/consumer partnership, the degree of their engagement, the compensation that is provided to them and the number of families/consumers that were trained on MCH core competencies;

UI-DCCH employs 41 Family Navigators on a full-time, permanent part-time, or hourly part-time basis. Full-time and permanent part-time employees receive full benefits. All Family Navigators receive initial training

on MCH core competencies. Members of the Family Advisory Council receive training on MCH core competencies, are compensated for attendance at meetings and receive stipends for mileage.

The MCH Advisory Council includes three family representatives who assist in the development of the state plan for MCH, including children with special health care needs and family planning. The MCH Advisory Council assists with assessment of needs, prioritization of services, establishment of objectives, and encouragement of public support for MCH and family planning programs. All members of the Advisory Council are given resources for self-training in the MCH core competencies and are given a broad orientation to the Title V program. Representatives do not receive compensation for their participation.

MCH contractors engage a given family from weekly to quarterly to twice a year, depending on the needs of the mothers/children/family. MCH contractors are responsive to families' needs based upon the communication. Families most often advocate for improved access to and more options for transportation. Families also respond with gratitude for offering services in locations where children are located, such as child care centers and schools.

MCH contractors conduct client satisfaction surveys to evaluate not only satisfaction, but also whether program services are meeting the needs of clients and identifying changes that may be needed to improve program quality. This feedback is not typically compensated.

iv. Evidence and range of issues being addressed through the family/consumer partnership;

UI-DCCH is committed to family and consumer partnership at all levels. To individual families, UI-DCCH connects families to family to family and peer support networks, while assisting them in developing self-advocacy skills. To health care and community providers, UI-DCCH promotes the concept that the families' priorities and concerns are central to care planning and management. At the community level, UI-DCCH engages child-serving systems in building support networks that work together for the benefit of CYSHCN and their families. At the state level, UI-DCCH includes family-driven principles in the development of policies and procedures governing the care of CYSHCN in Iowa.

The IDPH works through local Title V MCH contractors to assure health services for families, which includes helping them become better consumers and navigators of the health care system. Contractors report that the majority of family issues addressed are related to medical and dental appointments, issues, and services. Contractors also work with families to identify transportation, translation, food, clothing, and housing assistance. Referral to programs such as WIC is also common.

v. Impact of family/consumer partnership on programs and policies, including the development of promising practices;

UI-DCCH values the FN perspective and is committed to supporting development of family leadership among employees and among families of CYSHCN. FNs are skilled in identifying gaps in service and barriers to the provision of care. They communicate these gaps and barriers during policy discussions to provide realistic perspectives on family life for CYSHCN. Iowa's continued commitment to family and professional

partnerships at all levels has resulted in exciting new strategies to engage and empower families in caring for their CYSHCN.

AMCHP provides a national network for learning of best practices for empowering families. Iowa FNs are regularly represented as AMCHP Family Scholars and Delegates. A UI-DCCH FN serves on the AMCHP Family and Youth Leadership Committee, which is a national effort to promote family leadership.

Most MCH contractors report to the IDPH that they seek input of families/consumers and that the input may result in new or change to programs and policies. For example, as communication methods have changed over the years, families indicated the desire and a preference to communicate with MCH contractors using text messaging. After discussions with Iowa's Medicaid program, policies were developed for inclusion of text messaging as an allowable form of care coordination for families served.

Incorporating the use of language lines is another example of responding to the changing needs of Iowa families. In the past, Spanish translators were often hired to assist with Spanish-speaking clients. However, the influx of additional language-speaking populations within several service areas has resulted in a need to transition to Language Line services rather than maintaining several different translators on staff. In response to transportation issues for families, some MCH contractors have found other local partnerships to address the problem. This includes financial support for transportation vouchers to help uninsured families travel to mental health and substance abuse treatment services.

vi. Description of the state's efforts to build and strengthen family consumer partnerships for all MCH populations, including CYSHCN.

Awareness of the importance of family consumer partnerships across MCH populations and at all levels is growing. Realizing the lessons learned from direct service to families is critical in engaging and training families to partner with professionals in all settings.

UI-DCCH has built a network to support FNs that uses virtual meetings to deliver ongoing training and support. Monthly meetings build staff competencies, provide updates on issues affecting Iowa families of CYSHCN, and foster collaboration among FNs. As described previously, Iowa has evolved its training for FNs from the models developed in 2009 to the statewide adoption of training that provides FN certification.

The University of Iowa Center on Excellence in Developmental Disabilities coordinates the Iowa Leadership Education in Neurodevelopmental and related Disabilities (ILEND) program, which is a one year interdisciplinary leadership training program for graduate students that promotes culturally competent and family-centered, coordinated systems of care for CYSHCN and their families. A UI-DCCH staff member is ILEND Family Faculty and is responsible for monitoring emerging family discipline developments. (More information about ILEND is in section i "Other MCHB Investments.")

UI-DCCH provides Iowa's child health community with the necessary knowledge, skills, and resources to help all children achieve their optimal potential. UI-DCCH partners with state agencies, non-profit organizations, child welfare, juvenile justice, education, and service providers to improve child health utilizing a framework

of assessment, assurance, and policy development. UI-DCCH assists in the development of new programming and service delivery ideas, conducts health outcomes and system research, develops and evaluates innovative models of care, creates and oversees data collection protocols, and recommends enhanced metrics to improve the quality of services for Iowa children and youth. UI-DCCH uses its statewide network and partnerships to disseminate and spread best practices.

UI-DCCH provides additional training opportunities including Mental Health First Aid, Youth Mental Health First Aid, Bridges out of Poverty, Trauma Informed Care, Behavioral Health Ethics, Ethics in the Workplace, Mindfulness, System of Care Values and Principals, Quality Improvement and other topics individualized specific to the agency request.

The work done by the IDPH staff with local Title V MCH contractors improves and strengthens program and family partnerships. The IDPH staff provides oversight and consultation for all MCH contractors. In addition to phone and email communication, the IDPH staff meet with contractors quarterly – at regional meetings and an annual meeting in Des Moines – in addition to program-specific meetings such as quarterly I-Smile™ coordinator trainings. Site visits are made annually and include technical assistance and monitoring of local and state data and trends, discussion about promising practices, and performance measures.

The annual Request for Application process includes required objectives that contractors must work toward. Applications include the activities they will undertake to achieve progress toward those objectives and are approved by the IDPH staff. This process assures family-centered approaches toward achieving the performance measures and overall program quality.