# **ADPH Executive Summary**

2015 Title V Maternal and Child Health Needs Assessment

Report of Findings for Alabama's Women, Children, Teens, and Families Alabama Department of Public Health, Bureau of Family Health Services Completed by UAB School of Public Health, Department of Health Care Organization and Policy May 2015







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#### I. Introduction

As part of the 2015 Title V Maternal and Child Health (MCH) Needs Assessment, the Alabama Department of Public Health (ADPH), Bureau of Family Health Services (Bureau) entered into an agreement with the UAB School of Public Health, Department of Health Care Organization and Policy (UAB) to develop, analyze, and report on data collected from Alabama families. The methods used and results obtained are summarized below. Individual, in-depth reports by method are available through the Bureau. All data collection instruments were designed through a joint effort between UAB and the Bureau. The Bureau was responsible for efforts related to marketing the needs assessment and recruitment of survey, focus group and key informant interview participants. UAB facilitated the focus groups and key informant interviews, performed all analyses, and developed final reports.

NOTE: Questions related specifically to children and youth with special health care needs (CYSHCN) and their families were not a part of the ADPH data collection effort. Perspectives of CYSHCN and their families were captured by the Title V CSHCN Program, Children's Rehabilitation Service, which is located in a separate agency from the Bureau. Separate reports are available related to this specific population. The final Alabama 2015 MCH Needs Assessment Report includes perspectives from all MCH populations in the state, including CYSHCN and their families.

#### II. Methods

Information compiled from national surveys, census data, vital statistics, and previous needs assessments were also considered by the Bureau and are reported elsewhere. The data described in this report were collected specifically to capture the perceptions of consumers, families, teens/young adults, and providers across the state to add to the knowledge base and to assist in identifying maternal and child health needs. Bringing the two sources of data together allows the Bureau to consider the issues identified and the general findings across broad cultural and socioeconomic groups. All methods were based on previous instruments, past experience, best practice in instrument development and data collection, the new guidance document for the MCH Block Grant/Needs Assessment, and areas of interest identified by an internal needs assessment leadership team at ADPH. Each method is described briefly below.

#### A. The Family Survey was disseminated as an online survey in English.

- i. There were 389 responses from 59 of 67 counties.
- *ii.* Respondents were mostly female; white, non-Hispanic; married; highly educated; mean age 40.5 years; 18.8% reported having a disability.
- iii. For child-specific questions: 0-5 years, n=96; 6-18 years, n=126; 19-25 years, n=14.
- iv. Strengths:
  - Demographics largely suggested that respondents were representative of the population across Alabama counties, rural versus urban areas, and public health areas
  - Income distribution was broad.
  - Responses provided extensive and powerful information to guide the identification of needs and potential solutions.
- v. Limitations:
  - Sample size was small.
  - Compared with Census data for Alabama, the respondent group consisted of a higher percentage white, Non-Hispanic, female, highly educated participants.
  - Results may not be generalizable to the Alabama MCH population.
- B. The Provider Survey was disseminated in online and hard copy formats in English, focusing on health care providers for women and children in the state.
  - i. There were 32 respondents from 15 of 67 counties.
  - ii. Provider type: OB/GYN = 10; Pediatrician = 19; Other = 3

#### iii. Strengths:

• Findings are most-appropriately considered trends that contribute to the identification of needs and potential solutions.

#### iv. Limitations:

- Sample size was too small for any advanced statistical analyses.
- Results are not generalizable to the Alabama MCH providers.

# C. Key Informant Interviews were facilitated with individuals identified as having expert knowledge of one or more of these MCH populations or about specific issues of importance to the MCH population in the state.

- *i.* Fifteen individuals were identified by the Bureau; nine consented to participate in an interview with UAB faculty, staff, or doctoral students.
- ii. Participants represented health and health-related service providers, state agencies, partner organizations, and a private advocacy group.

#### iii. Strengths:

- There was active participation in key informant interviews. Participants engaged with the interviewer and added richness to the discussion of maternal and child health issues in the state.
- Respondents provided keen insights and information to guide the identification of needs and potential solutions.

#### iv. Limitations:

• As is true of all qualitative interview data, results are not generalizable to members of the population or to other states/regions.

# D. Focus Groups were facilitated with representatives of Alabama's maternal and child health population.

- i. A total of 83 participants attended 11 focus groups addressing women of child bearing age, parents of children (birth to age 12 years), parents of children (age 13-18 years), teens and young adults, Poarch Band of Creek Indians, and Latinas.
- *ii.* Focus groups were conducted in Birmingham, Mobile, Anniston, Montgomery, Tuscaloosa, Troy, Huntsville, and Atmore.

#### iii. Strengths:

- There was active participation and attendance for the focus groups.
- Participants readily engaged in conversations and added a great deal of richness to the discussion of maternal and child health issues in the state; findings are likely to represent broad viewpoints that exist in Alabama's MCH population.
- Respondents provided extensive and powerful information to guide the identification of needs and potential solutions.

#### iv. Limitations:

- As with all qualitative focus group data, findings are not generalizable to all members of the population or to other states/regions.
- There was low participation by males/fathers in the focus groups.
- Most of the participants were likely a convenience sample of clients of specific organizations, as funding and time limitations precluded broad community recruitment. However, participants were recruited from groups served by Alabama's MCH program and were not limited to those who received services directly through a local health department.

#### III. Needs Identified Across All Methods

Data from across all methods were analyzed and compared to identify needs that emerged for Alabama's maternal and child health population (with the exception of those for CYSHCN which were identified through a separate process). The following chart displays needs that emerged from across all data sources. These needs are not presented in any particular order, but are organized by MCH population group. A plus sign

(+) indicates data sources that specifically addressed the issue and where results confirmed the need. While other Bureau data sources support these needs, these data are not presented in the chart.

Needs by population domain and data source

	Data Source			
Priority Need/Issue	Family Survey	Provider Survey	Focus Groups	Key Informant Interviews
Population Domain: Women's/Maternal Health				
Lack of or inadequate access to comprehensive reproductive and well women health care		+	+	+
Lack of or inadequate access to family planning services and education		+	+	+
High obesity/overweight levels among adults	+	+	+	+
Lack of access to smoking cessation services among pregnant and pre- conception women		+		+
Lack of or inadequate comprehensive postpartum depression services			+	
Lack of or inadequate substance abuse treatment		+		+
Lack of or inadequate access to dental care and oral health services		+	+	+
Perinatal/Infant's Health				•
High infant mortality rates for those without private insurance*				
Lack of support and acceptance of breastfeeding	+	+	+	
Lack of awareness of and trust in safe sleep recommendations	+	+		
Higher than national rates for infant mortality, especially among African Americans*				
Unacceptable rate of preterm births*		+		
Lack of anticipatory guidance in safe sleep recommendations	+	+		
Lack of awareness about risks of early elective delivery	+	+	+	+
Unacceptable rate of early elective deliveries*				
Desire to maintain and strengthen regionalized perinatal care*				
Child Health				
Perceived lack of resources and supports to promote parenting skills and child development among new parents and parents of young children		+	+	
Concern over bullying			+	
Low rates of preventive health and developmental screening for children	+	+		
Inadequate follow-up and treatment for identified health and developmental issues in children		+	+	
Inadequacy of insurance/lack of insurance		+	+	+
Lack of access to a medical home*				
High rates of asthma among children and youth*				
Adolescent Health				
Youth risky behaviors and decision-making, including driving safety			+	
Lack of or inadequate access to mental health services	+	+	+	+
Low rates of preventive health and developmental screening for adolescents	+	+		
Inadequate and insufficient health and sexual health education	+	+	+	+
Concern over youth violence, including bullying	+		+	
Inadequate follow-up and treatment for identified health and developmental issues in adolescents		+	+	
Teen and young parents unprepared to raise their children		+	+	

	Data Source			
Priority Need/Issue	Family Survey	Provider Survey	Focus Groups	Key Informant Interviews
Life Course / Cross-cutting				
Primary care not perceived as comprehensive, family-centered, and culturally-competent across all Title V populations	+	+	+	+
Inadequate health and dental insurance for all Title V populations	+	+	+	+
Lack of or inadequate access to obesity prevention and treatment services for all Title V populations		+	+	+
Inadequate nutrition and physical activity education and awareness for all Title V populations	+	+	+	+
Insufficient care coordination for all Title V populations	+	+		
Title V populations not meeting established guidelines for nutrition and physical activity	+	+		
Inadequate and insufficient health education and outreach	+	+	+	+
Insufficient means for health department patients to provide feedback on services and experiences*				
Lack of or inadequate access to mental health services for all Title V populations		+	+	+
Inadequate levels of family and consumer involvement in policy-making, evaluation, and partnering with providers*				
Inadequate transportation		+	+	+
*Need supported by other data sources available to the Rureau	,			

<sup>\*</sup>Need supported by other data sources available to the Bureau

#### IV. Prioritized Maternal and Child Health Needs

In February 2015, ADPH convened a statewide meeting of key constituents and consumers to serve as an advisory committee and to assist with the prioritization of identified maternal and child health needs. In addition to other quantitative data available to the Bureau, data from each of the collection methods described in this report were presented to the group. The entire list of needs was also presented for consideration and participants were divided into small groups according to their areas of expertise related to the MCH population groups. Each group discussed needs and issues identified for their specific population and in addition, all groups considered the life course/cross-cutting needs.

#### A. Process to Obtain Need Rankings

- Individual group members rated each need according to three separate criteria:
  - o "Importance" refers to the size, scope, and urgency of the need/issue.
  - o "Feasibility" refers to a level based on these questions: Is there a solution? Can we realistically make progress? Have we been making progress (and need to continue efforts)?
  - o "Resources" refers to the level of expertise, time, and funding to address the need, either at ADPH and/or through partnerships with other agencies and organizations.
- Scoring Scale for rating needs:
  - o 1 = Low 2 = Low-Medium 3 = Medium 4 = Medium-High 5 = High
- Individual ratings for criteria scores were summed to yield a total score for each need.
- Total scores were summed for entire group to assign rank order for needs.
- Ties were broken by total scores for individual criterion in the following order:
  - o 1. Feasibility 2. Importance 3. Resources

The following tables show rank-ordered needs for each population group as rated and ranked by participants at the statewide advisory meeting.

### B. Ranked Needs by Population Domain

i. Population Domain: Women's/Maternal Health

Overall Rank	Priority Need/Issue		
1	Lack of or inadequate access to comprehensive reproductive and well women health care	120	
2	Lack of or inadequate access to family planning services and education	118	
3	High obesity/overweight levels among adults	113	
4	Lack of access to smoking cessation services among pregnant and preconception women	112	
5	Lack of or inadequate comprehensive postpartum depression services	107	
6	Lack of or inadequate substance abuse treatment	96	
7	Lack of or inadequate access to dental care and oral health services	94	

## ii. Population Domain: Perinatal/Infant's Health

Overall Rank	Priority Need/Issue		
1	High infant mortality rates for those without private insurance	131	
2	Lack of support and acceptance of breastfeeding	130	
3	Lack of awareness of and trust in safe sleep recommendations	128	
4	Higher than national rates for infant mortality, especially among African Americans	124	
5	Unacceptable rate of preterm births	122	
6	Lack of anticipatory guidance in safe sleep recommendations	121	
7	Lack of awareness about risks of early elective delivery	117	
8	Unacceptable rate of early elective deliveries	116	
9	Desire to maintain and strengthen regionalized perinatal care	109	

## iii. Population Domain: Child Health

Overall Rank	Priority Need/Issue		
1	Perceived lack of resources and supports to promote parenting skills and child development among new parents and parents of young children	151	
2	Concern over bullying	144	
3	Low rates of preventive health and developmental screening for children	136	
4	Inadequate follow-up and treatment for identified health and developmental issues in children	134	
5	Inadequacy of insurance/lack of insurance	127	
6	Lack of access to a medical home	115	
7	High rates of asthma among children and youth	113	

#### iv. Population Domain: Adolescent Health

Overall Rank	Priority Need/Issue		
1	Youth risky behaviors and decision-making, including driving safety	95	
2	Lack of or inadequate access to mental health services	92	
3	Low rates of preventive health and developmental screening for adolescents	89	
4	Inadequate and insufficient health and sexual health education	82	
5	Concern over youth violence, including bullying	80	
6	Inadequate follow-up and treatment for identified health and developmental issues in adolescents	74	
7	Teen and young parents unprepared to raise their children	71	

### v. Population Domain: Life Course / Cross-cutting - Overall

Overall Rank	Priority Need/Issue	
1	Primary care not perceived as comprehensive, family-centered, and culturally-competent across all Title V populations	481
2	Inadequate health and dental insurance for all Title V populations	444
3	Lack of or inadequate access to obesity prevention and treatment services for all Title V populations	
4	Inadequate nutrition and physical activity education and awareness for all Title V populations	433 (F=150)
5	Insufficient care coordination for all Title V populations	433 (F=145)
6	Title V populations not meeting established guidelines for nutrition and physical activity	430
7	Inadequate and insufficient health education and outreach	427
8	Insufficient means for health department patients to provide feedback on services and experiences	418
9	Lack of or inadequate access to mental health services for all Title V populations	410
10	*Inadequate levels of family and consumer involvement in policy-making, evaluation, and part- nering with providers	120
11	*Inadequate transportation	37

<sup>\*</sup>Added by one group only; voted on by more than one member of the group

#### V. Results Summary

The remainder of this executive summary provides a general overview of results across methods, ordered by MCH population group. For more detailed results and more in-depth reporting by method, please refer to the method-specific reports which are also available through the Bureau.

### A. Population: Women's and Maternal Health

- i. Top Five Unmet Needs for Pregnant Women (identified by providers)
  - 1. Treatment for other mental or social problems
  - 2. Treatment for abuse of/dependence on other drugs
  - 3. Treatment for alcohol abuse/dependence
  - 4. Dental examination or treatment
  - 5. Measures to avoid domestic violence

- ii. Top Five Unmet Needs for Non-pregnant Women of Child-Bearing Age (identified by providers )
  - 1. Treatment for other mental or social problems
  - 2. Treatment for nicotine dependence
  - 3. Treatment for abuse of/dependence on alcohol and other drugs
  - 4. Treatment for obesity or overweight
  - 5. Measures to avoid domestic violence
- iii. Focus group participants discussed a lack of emphasis on preventive health care and difficulties with prioritizing and supporting healthy nutrition and physical activity engagement. Participants mentioned a lack of health education information, especially about reproductive health and birth control methods, and difficulty accessing a variety of health and health-related services.
- *iv.* Key informants discussed similar issues and there was overlap with survey results. Commonly-mentioned needs included:
  - Mental health services not available or inadequate;
  - Dental health access
  - Access to treatment for substance abuse, especially for pregnant women

"I think women aren't given enough credit for wanting to make those decisions for themselves and be able to handle all the information to come to our own conclusion. I think sometimes they dumb it down for us a little too much."

Focus group participant
 [speaking about needing information about family planning options]

#### B. Population: Perinatal / Infant's Health

- i. Infant Mortality
  - a. More Family Survey respondents indicated infant mortality was decreasing rather than increasing or staying the same.
  - b. Provider Survey respondents identified the following issues as related to infant mortality rates in Alabama:
    - Substance abuse
    - Poverty
    - Single and teen pregnancy
    - Unprepared to parent
    - Co-sleeping
    - Lack of education
    - Inadequate access to prenatal care/women's health
    - Obesity
    - Lack of mental health care in rural and inner city
    - Rural residence and transportation issues
    - L&D units closing
  - c. Key Informants offered the following issues as related to high infant mortality rates:
    - Substance abuse
    - Poverty
    - Age of mothers
    - Genetics
    - Lack of nutrition
    - Inadequate access to prenatal care

#### ii. Early Elective Delivery (EED)

- a. Respondents to Family and Provider surveys were asked why mothers or providers might schedule deliveries before 39 weeks when there is no medical need for the baby or mother that would indicate early delivery. Though there was some overlap, there were also differences between provider and family perceptions of why an EED might be scheduled.
  - Top four reasons identified by Family Survey respondents:
    - 1. Pregnant mother had C-section delivery previously
    - 2. Doctor wants to schedule delivery of baby because of his/her travel or work schedule
    - 3. Pregnant mother is physically uncomfortable at the end of the pregnancy
    - 4. Pregnant mother wants to schedule delivery of baby because of her family schedule
  - Top four reasons identified by Provider Survey respondents:
    - 1. Pregnant mother is physically uncomfortable at the end of pregnancy
    - 2. Pregnant mother is concerned she may deliver too quickly or not make it to the hospital because of location and travel time
    - 3. Pregnant mother and/or doctor is concerned the baby will be too big
    - 4. Pregnant mother wants to schedule delivery of baby because of her family schedule
- b. Focus group participants indicated that EED rates are fueled by higher reimbursement rates for C-sections and convenience of the mother and the provider. They also noted that many women do not consider a scheduled C-section an EED if it is scheduled at 39 or 40 weeks exactly, even if it is not medically indicated for the mother or baby.

#### iii. Safe Sleep

- a. Respondents to the Family Surveys were presented with the safe sleep recommendations and were asked their opinions on why some families may have trouble following them.
- b. Top four reasons identified by Family Survey respondents:
  - 1. Baby in bed makes night-time feedings easier
  - 2. Prefer a "family bed" or to have baby sleep in the bed with family
  - 3. Other people in the family haven't done all these things
  - 4. Baby will be safer in the bed with family
- c. Other reasons included distrust or disbelief of "experts" and/or recommendations, recommendations keep changing, comfort of baby, and parental choice
- d. Almost all respondents reported that their health provider had discussed safe sleep with them.
- e. Most, but not all providers, reported that they advise parents about safe sleep all or most of the time.

#### iv. Breastfeeding

- a. Focus group participants reported broad acceptance of the positive impacts of breastfeeding among participants, but perceived a lack of support and encouragement for breastfeeding, especially in some cultures and among teen parents.
- b. Participants discussed the importance of WIC (Women, Infants and Children) as a support for breastfeeding.

"I don't know what doctor you are talking to, but that's a broad overgeneralization and is NOT what I have been told by my (provider)."

<sup>&</sup>quot;Recent studies have shown that bed sharing is safer and does not cause SIDS."

"Women have slept safely with their babies since the dawn of time. As long as you know the risks of 'impaired' co-sleeping and do what you can to minimize them you are at LESS risk for SIDS when co-sleeping."

- Family survey written comments [speaking about safe sleep recommendations]

#### C. Population: Child Health

- i. Preventive Health and Developmental Screenings
  - Family Survey respondents who had children were asked about whether their child had received the following screenings in the previous year. These are family perceptions of whether their child received these health and developmental screenings. Responses were unable to be verified to determine actual receipt due to the anonymous nature of the survey.

Screening	Children 0-5 years (% Received)	Children/Youth 6-18 years (% Received)
Cholesterol	-	13.8
Blood sugar	22.3	14.6
Blood pressure	54.2	71.1
Vision	55.2	71.3
Hearing	54.5	38.5
Developmental	52.2	23.3

- ii. Top Five Unmet Service Needs For Children and Adolescents (identified by providers)
  - Treatment for other mental or social problems
  - Treatment for obesity or overweight
  - Speech and language assessment or therapy
  - Screening or treatment for developmental delay
  - Transportation to health care appointments
- iii. Most Commonly-Identified Barriers to Services For Children (identified by providers)
  - Insurance issues
  - Lack of providers
  - Long wait lists
- iv. Focus group participants noted concerns about child safety, including bullying, particularly on school buses and social media. Participants also reported unmet needs related to access to services and medications related to autism & ADHD, as well as a lack of support for new parents and parents of young children (parenting skills, child development).

"It's been a really big issue... I'm not that old but when I was in school it wasn't that big of an issue. I remember I would see kids being picked on but not trying to commit suicide."

Focus group participant [speaking about bullying]

#### D. Population: Adolescent Health

- i. Family Survey respondents were presented a list of issues that may be considered problems for youth and teens. Respondents were asked to rate each issue according to how much of a problem they perceived the issue to be for teens in their community. The top six issues identified were:
  - Driving safety (seat belt usage, texting while driving)

- Bullying
- Smoking or using smokeless tobacco
- Not having an adult role model or trusted adult they can talk to about their problems
- Alcohol use and abuse
- Drug use
- ii. Focus group participants, including parents of teens and teens/young adults separately, identified the following issues and needs:
  - Lack of information regarding sexual education, sexually-transmitted infection and pregnancy prevention, and maintaining healthy sexual relationships
  - Lack of education and treatment for drug and alcohol abuse and smoking cessation
  - Concerns over confidentiality when receiving health services
  - Young parents reported they were perceived as lacking the skills to be a parent
- iii. Provider Survey respondents were asked about their provision of sexual health education and specific vaccinations. Nearly three-fourths of respondents reported offering abstinence counseling and information on the risks of sexually transmitted infections. More than 80.0% reported offering HPV vaccine (Gardasil) to female patients (aged 12-21). Nearly two-thirds reported offering the meningitis vaccine (Menactra) to adolescents. In write-in comments, providers noted concerns that young parents are often not prepared to be a parent.

"They're [teens] doing grown-up things, having sex, things like that. So they should be able to get grown-up information."

"Most of the doctors say 'you young, you don't know nothing'."

- Focus group participants

"The younger the mother, the less educated they are. And by them being so young, they have no desire to learn proper techniques for baby care and well-being."

- Provider survey written comment

#### F. Cross-Cutting /Life Course Issues

A number of issues and concerns applied to all or several population groups and were reported in more than one data source.

- i. Adequate Insurance Health & Dental (Provider Survey; Family Survey; Focus Groups)
  - Providers for women of child bearing age (both pregnant and not) reported issues with health insurance not covering needed services.
  - Providers for children and youth reported barriers to receiving services as no insurance, providers not accepting Medicaid, patient could not pay, and insurance does not pay.
  - Most Family Survey respondents had health and dental insurance.
    - o More respondents had health than dental coverage.
    - o Lack of insurance was more of a problem for adults than for children.
    - o People with disabilities were significantly less likely to have health and dental insurance compared to people without disabilities.
    - o Cost, unemployment/lost job, and employer did not offer were the most common reasons cited for lack of insurance coverage.
  - Focus group participants reported concerns about health insurance not covering

needed services; the lack of dental coverage, especially for adults; and the lack of coverage for orthodontic treatment for children and adolescents.

- ii. Availability of Health Services & Adequacy of Providers (Family Survey; Focus Groups)
  - Family Survey respondents were generally satisfied with availability and adequacy in their county.
  - People with disabilities and rural residents were more likely to be dissatisfied with avail ability.
  - People with disabilities were more likely to be dissatisfied with the adequacy of providers' abilities to meet their needs.

# iii. Primary Care Access-Related Issues (Family Survey; Provider Survey; Focus Groups)

- Lack of convenience (hours, wait times, and short amount of time spent with providers) was reported as an issue among focus group participants, particularly for working families.
- Providers were more likely to report their practice offered 24/7 telephone access & night/weekend emergency care than families were to report experiencing this.
- Both providers and families reported that weekday evening and Saturday morning appointments were rarely or never offered.
- Access issues led to emergency department usage for some Family Survey respondents.

#### iv. Cultural Competency (Provider Survey; Focus Groups)

- Issues related to cultural competency were not limited to race and ethnicity, but also included age and income.
- Provider Survey respondents addressed questions about cultural competencyrelated services in their practices.
  - o Half of respondents reported "rarely" or "never" providing a translator or interpreter for patients for whom English is a second language.
  - o Just over 53.0% reported "sometimes" providing materials translated into the primary language used by patients.
  - o About 60.0% reported "always" or "nearly always" attempting to incorporate a patient's or family's beliefs and requests for alternative treatments.
- Latina focus group participants reported experiencing language and interpretation issues at their providers' offices.
- African-Americans, Latinas, and Native Americans all reported experiences of being treated differently from others in health care settings.
- Similar experiences of being treated differently from others were reported by teen/ young parents and people who received public insurance.

#### v. Obesity (Family Survey; Key Informants; Focus Groups)

- About two-thirds of respondents reported that someone in the household had been told by a health provider that he or she needed to lose weight.
- More than half of respondents (53.2%) had been told by a health provider that they themselves needed to lose weight.
- Key Informants suggested the following contributing factors:
  - o Poor dietary habits and food choices, fast food, food insecurity hunger, access to unhealthy foods at school, inadequate physical activity, and too much technology.
- Focus Group participants suggested the following contributing factors:
  - o Nutrition and lack of physical activity, poor food choices at home and school, culture, and high cost to eat healthy.
- vi. Nutrition and Physical Activity (Family Survey)

- Physical activity questions were based on national recommendations for adults and children.
- Fewer than 25% of adults reported exercising for at least 30 minutes, five or more days in the past week.
- Just over 15% of children (6-18 years) met the recommendation for physical activity (60 minutes each day).
- The most commonly reported daily serving amount for fruits and vegetables for both adults and children was one to two servings per day.

#### vii. Care Coordination (Family Survey; Provider Survey; Focus Groups)

- Most family and provider survey respondents identified having a primary coordinator of medical care in the health care practice.
- Discrepancies existed between provider and family perceptions of how often certain services were provided, providers reported that they occur more frequently than did families.
  - o Scheduled time to discuss results of specialist visits.
  - o Someone in practice discusses related service needs (financial services, respite care, equipment, and transportation).
- Nearly half of providers reported that someone in their practice serves as care coordinator for children/youth with special health care needs.

#### viii. Transportation (Provider Survey; Focus Groups; Key Informant Interviews)

- Transportation was top barrier to receipt of assessment at perinatal center by highrisk pregnant woman as reported by providers who provide delivery services.
- According to providers, focus group participants, and key informants, transportation is a particularly difficult issue for people who live in rural areas, where there is unreliable or no public transportation.

# ix. Health Education, Awareness, and Outreach (Provider Survey; Family Survey; Focus Groups; Key Informant Interviews)

- There was broad support across all methods for increasing and improving health education and educational materials.
- Focus group participants discussed the potential for using social media to distribute health education materials.
- Teens/young adults expressed a strong preference for receiving health information through alternative methods to traditional brochures and fact sheets, especially formats such as YouTube videos, social media platforms, and public service announcements.