

American Academy of Pediatrics

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**Alliance for Innovation on Maternal and Child Health
Learning Collaborative on Improving Quality and Access to
Care in Maternal and Child Health
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SOUTH DAKOTA STATE REPORT

AIM Expanding Access to Care for Maternal and Child Health Populations Learning Collaborative Cohort 2 – South Dakota

INTRODUCTION/BACKGROUND

As part of the Alliance for Innovation on Maternal and Child Health (AIM) program, the American Academy of Pediatrics (AAP) gathered background information to better understand access to care and coverage issues from the patient/family and provider perspectives. In addition, the AAP reviewed current state EPSDT programs to compare the services offered with the services recommended within the Bright Futures Guidelines for Health Supervision. This was accomplished through several different mechanisms: telephone interviews with pediatrician leaders, a survey of patients/families, telephone interviews with families to capture their stories, internet searches about state EPSDT programs, and discussions with state EPSDT coordinators. This data collection and analysis took place in April and May 2016. The intent of this information is to outline challenges and opportunities in each Cohort 2 state, and help to inform state team discussions during the Learning Collaborative meeting. Below is a summary of the findings.

PHYSICIAN INTERVIEW FINDINGS

A phone interview was held between AAP staff and two pediatrician leaders from the AAP South Dakota Chapter. The goal of the interview was to obtain pediatrician insight into the health care financing environment in the state, including information about access, coverage, and payment for maternal and child health-related services. The interview highlights are documented below.

Pediatric Care Challenges	
Behavioral Health	<ul style="list-style-type: none"> • Counseling services are often not covered or have limited coverage • Pediatricians are prescribing more antidepressants in past 5 years due to lack of access and payment to mental health specialists
Bright Futures / EPSDT	<ul style="list-style-type: none"> • Some plans do not cover developmental screening (state employee health benefits, 12 and 15 month visits or universal cholesterol screening - Avera)
Medicaid	<ul style="list-style-type: none"> • Practices in some communities have stopped taking new Medicaid patients
Provider Distribution / Specialty Care	<ul style="list-style-type: none"> • The two largest cities (Sioux Falls and Rapid City) have 25% of the state's pediatricians and 90% of the pediatric subspecialists • Smaller cities have 1-3 pediatricians and rarely any subspecialists • Limited pediatric specialists across the state (Ex: no pediatric rheumatologists) • Some insurance plans encourage PCPs to refer patients out of state
Substance Abuse	<ul style="list-style-type: none"> • Increased use of amphetamines by teens and mothers, with limited treatment options • Up to 80% of babies born exposed to amphetamines, opiates or meth
Maternal Care Challenges	
Access to Specialty Care	<ul style="list-style-type: none"> • Limited access to high risk OB specialists • Common for very long travel times for even general OB visits

Pediatric Care Successes	
Access	<ul style="list-style-type: none"> • Larger hospitals have opened outreach clinic for some specialties
Medicaid	<ul style="list-style-type: none"> • Most who are eligible apply (covers about 25% of the population)
Maternal Care Successes	
Access	<ul style="list-style-type: none"> • Bringing perinatologists to some smaller communities on a monthly basis

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Opportunities
<ul style="list-style-type: none"> • Utilize telehealth to increase access to specialty care • Increase practice supports for pediatricians practicing in rural areas • Improve Medicaid pediatric reimbursement rates

FAMILY SURVEY RESULTS

In an effort to better understand what patients and families were experiencing at the community level, the AAP partnered with Family Voices to create a survey to explore this topic in greater depth. The survey was disseminated through the Family-to-Family Health Information Center in each of the Cohort 2 states, as well as via other AAP information dissemination mechanisms. The survey explored whether patients/families had specific challenges in accessing care from providers, whether there were gaps in insurance coverage, and whether out of pocket costs were prohibitive. Respondents were also given the opportunity to provide additional information in an open-ended response.

The survey was available in both English and Spanish, and 77 complete responses were received from patients/families in South Dakota. The three most common issues reported for access, coverage and payment are listed below:

Access	<ul style="list-style-type: none"> • The recommended doctor or service is not available in my area (62%) • The wait time to get an appointment is too long (48%) • None (24%)
Coverage	<ul style="list-style-type: none"> • A recommended service is not covered by my insurance plan (52%) • My insurance takes a long time to tell me whether I'm covered for specific things (48%) • Recommended services were limited (43%)
Payment	<ul style="list-style-type: none"> • My child's health plan does not cover all the cost of care such as specific medications, therapy services, equipment, in-home services, etc (50%) • I quit work or cut back on my hours to care for my child (46%) • Out of pocket (deductibles / co-pays) costs are too high (37%)

*% reflects the respondents that selected the listed option. Respondents were able to select more than one response for each survey question.

Common Themes:

Several sections of the survey invited respondents to provide additional comments. Many took the opportunity to offer information about their experience; and several recurring themes emerged:

- Behavioral Health: Poor access, poor coverage, little to no covered autism services, not enough providers, long wait time for appointments
 - "The behavioral health was too expensive for us and there were not enough providers in our area, so that care was not received."
 - "We need more autism specialists in our area, especially some geared towards helping older kids with social skills, self-regulation, etc."
 - "Need more ABA therapists to stay in our state. Maybe through loan forgiveness?"

- Inadequate Coverage: Necessary services, supplies and therapies not covered, under-covered or take a long time for approval, inadequate number of in-network physicians
 - "DME took over 7 months for approval after submitting all necessary paperwork."
 - "We are currently not receiving the services we need because of lack of funding."
 - "My child has not received recommended services because they are not covered."

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- *“Therapy was delayed due to insurance not covering therapies and couldn't afford to pay out of pocket. We waited for almost 2 months.”*
- *“Our insurance has a therapy cap max number of therapy visits. This is all visits combined instead of separated by discipline.”*
- *“Our private insurance has limited the number of speech services to 30 per calendar year.”*
- *“There needs to be regulation of Medicaid to pay for medically necessary coverages that are determined by a doctor.”*

- Lack of Specialists: Many do not accept public plans, very long wait time for appointments, high co-pay, some not accepting new patients
 - *“My son sees a specialist who only comes to our area once a month. It takes several months to get on his schedule. This is the only specialist in our area.”*
 - *“It would be nice if the specialists would be enticed in some way to stay in this area.”*

- Support Networks: Access to other families in similar situations for information and support
 - *“Connecting with other families and experienced parents would be very helpful.”*

Conclusion:

Parents in South Dakota are encountering many access, coverage and payment issues, and expressed frustration with the lack of available assistance based on AAP/Family Voices survey results. Many survey respondents were parents of CYSHCN, and several reported that they were unable to obtain recommended care due to issues coordinating care and unmanageable out-of-pocket expenses. There are opportunities to make meaningful improvements in the health care of maternal and child health populations in the state.

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FAMILY STORIES

Family Story #1

Anne's son Ethan is 12 years old, and has cerebral palsy, intellectual delays, fine and gross motor skill delays, and processing issues, caused by injuries at birth and what was later shown to be medical negligence. Her struggle to get care and proper diagnoses for Ethan is somewhat unique—doctors who are aware of his birth story have not been very forthcoming in providing a diagnosis, despite Anne's repeated questions about issues she felt were obvious with Ethan's development.

In addition to the circumstances that caused Ethan's problems, Anne suffered serious complications from the birth, including renal failure, and spent time in the ICU while her newborn was in the NICU. "We were both recovering—and my family came close to losing both of us." Anne came home, still quite ill, and her husband took over care for her and Ethan until she was strong enough to do so a few months later. Because of everything her husband went through during that time, it is still hard for him to talk about it at all. He credits the neonatologists and the nurses in the NICU for saving their son's life.

The pediatric neurologist that treated Ethan in the NICU would not even discuss brain injury as a possibility. When Ethan was 12 months old this same neurologist told Anne that her son had autism, and that he would never know the difference between her and a chair and that unless the seizures he had been having returned, there was no reason to see him again.

Anne was essentially on her own to find care and resources for her son. Through an online parent Facebook group, a few years ago she found the name of a forensic perinatologist, who studied Ethan's records and was able to interpret what had likely happened to him at birth. Unfortunately, key data had been lost by the hospital—the fetal monitoring strips were not available. These strips would be necessary if Anne had tried to pursue the medical negligence angle legally. Anne would have at least appreciated an official apology from the hospital and doctors involved, but that did not happen.

It was only recently that Anne discovered a pediatric neurologist had moved into her area—one who did not know Ethan's history. She asked why Ethan had not been diagnosed with cerebral palsy years ago, and said there was no doubt that he had this condition. She sent him to a physiatrist, another newcomer to the area with no knowledge of Ethan's history. These two doctors have been more helpful than any Anne had worked with to date.

Anne said her biggest struggle was just trying to get the health care professionals to be open with her and help her figure out the right path to take, and the right people to help her. She initiated requests for referrals to specialists from Ethan's pediatrician, noting that she did not have to have the referral, but having one made the difference in getting an appointment sooner rather than later.

She was also frustrated by the lack of communication between the specialists, therapists, and other providers her son was seeing—even though their offices were in the same medical building. Each specialist took care of only their own specialty. There was no care coordination to help link all the pieces of the medical puzzle. The Medical Home concept is new in South Dakota, as is care coordination. Anne has been her son's care coordinator out of necessity. South Dakota, like many of the western states, is large, with a few large population centers, and the rest of the state is rural and frontier. Anne said, "I have the benefit of living in Sioux Falls, and because I had worked in the system before, I was familiar with the system. Other families don't even know where to begin."

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Another issue for Anne and other parents is the perception that the doctor always knows best—she knew something was wrong with Ethan, and assumed that the doctors would take care of her child. She heard multiple times statements like, “Let’s not worry about that right now. We’ll just keep doing what we’re doing.” This attitude often leads to delays in care and therapies that are best initiated when a child is very young.

“I want to be the one who makes decisions. I don’t want to turn everything over to the health care professionals—I’ll lead the care for my child, working together as a team. Ethan won’t get better—as he gets older, the gaps in his development get wider, and that will continue into adulthood. I want him to be able to participate in his own care. As little as he says, if he wants to give input, I’ll do everything to see that he gets that opportunity.” Anne also notes that communication is not always verbal, and she wants physicians to understand and seek ways to engage those other forms of communication.

It’s not about curing or “fixing” Ethan, but providing the best support to help him lead as full a life as possible.

Anne’s story illustrates key issues for the state of health care in South Dakota:

- **Lack of care coordination:** Parents, like Anne, are left to seek out the care their children need. Many do not know where to start, or what resources are available to them.
- **Lack of Medical Home:** There is a great need for health care in the state to be seen as teamwork, especially for children like Ethan with complex needs. The team should include the doctors, specialists, therapists, educators, and especially the parents and the child (as appropriate).
- **Delays in diagnoses and treatments:** Children with conditions such as Ethan’s or autism benefit greatly from early recognition of problems and early intervention. This often means working with the parents who can often identify worrisome issues that might lead to a diagnosis much sooner.

“I just want families coming along behind us to get the help they need. For the most part Ethan gets his needs met, and overall he is doing pretty well. Some families don’t know where to begin. They have a notion that something is wrong, but where to go? My personal goal is to find the barriers and families overcome them.”

*Names have been changed to protect confidentiality

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Family Story #2

Musheera's story illustrates the challenges that foreign visitors to this country face when a child is born here with special health care needs. Her story also illustrates the need for engaging parents in partnership with providers to ensure the best care, as well as the need for open discussions around complementary and alternative medicine.

Musheera and her husband are from Egypt, here in South Dakota on student visas. Their third child was born in the U.S. and therefore a U.S. citizen. Eman was born in 2012 in a small hospital after a long delivery that included some scary moments during birth. "Something made me ask the doctor to look for Down's syndrome," but the doctor said Eman looked fine. The next day, because Eman was showing a characteristic tongue action, he had doubts. Tests showed a couple of holes in the heart, very high blood pressure, and Eman was diagnosed with Down's syndrome. She was admitted to the NICU for 6 days.

The official diagnosis came from a phone call from the geneticist, whom Musheera described as "cold." She had to tell her husband, wishing that the hospital had been the one to deliver the news to him.

The hospital staff did a great job in bringing in people with personal stories about having a child with Down's. Musheera was given a packet of material from the Parent Connection (South Dakota's Family-to-Family Health Information Center), and while the packet had a lot of information, it was overwhelming at the time, and she was on her own to read and digest the resources.

Musheera wanted to breastfeed Eman, and had a lactation consultant help her with latching on in the hospital. The hospital staff did not wake Musheera for feedings, however, and gave Eman formula. "I didn't feel like I had a choice." Later the pediatrician suggested pumping and fortifying the milk with formula. Eman gained weight, and at six months Musheera was able to stop supplementing her milk.

Musheera asked if there were other things they could do for their daughter, including alternative therapies, but she was told to just "go home and enjoy your baby."

Based on connections she made with other parents on Facebook, Musheera found a naturopath therapist who was able to help Eman, though her services were not covered by insurance because they are not evidence-based interventions. The therapist changed her medications, and they saw a big difference in Eman. Musheera noted that while her pediatrician is a "great guy," his approach is always about the lab work numbers, and not necessarily looking at the child and the symptoms she presents.

Eman received "amazing" physical and occupational therapies, but Musheera was not impressed with the speech therapy her daughter was getting. Eman did not seem to enjoy the speech therapy, and Musheera noted that the therapist did the same thing each time, and nothing that seemed fun or interesting to her daughter. At two years of age, Eman did not use words, and Musheera began paying out of pocket for a speech therapist, and Eman has made progress. Her insurance only covers up to 12 sessions and then they must pay out of pocket.

Early Intervention and school system therapists were great, but Musheera said there seemed to be a big disconnect between home and school. Therapists saw Eman once a week, but never suggested activities that her parents could do with her at home.

Musheera applied for SSI shortly after Eman's birth, and while she has a qualifying disability, the application was rejected. The family application for Medicaid was also denied. It isn't clear why this was denied for Eman, who is a U.S. citizen by birth, and should qualify for it. If Eman had SSI, she would have Medicaid coverage. The Parent

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Connection staff are currently working to find out why this application might have been denied. Musheera noted that there are other people she knows in similar positions (foreign parents who have children here in the U.S. and those children are denied services).

Musheera's story illustrates key issues for the state of health care in South Dakota:

- **Children born in the U.S. to foreign parents may struggle to get the services they are entitled to as U.S.-born citizens.**
- **Doctors and other health care providers don't necessarily engage families as partners in their own health care.** Decisions are made for, rather than with, families, and the input from the family is not valued.
- **Complementary and Alternative Medicine therapies are dismissed rather than openly discussed—both the plusses and the minuses—as possibilities.** These therapies are not likely to be covered by insurance.
- **Insurance coverage of speech, physical, and occupational therapy is restrictive and limited.**

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EPSDT AND BRIGHT FUTURES – SOUTH DAKOTA REPORT

Bright Futures is a national health promotion and prevention initiative led by the American Academy of Pediatrics (AAP). It consists of a recommended set of health supervision services starting prenatally and continuing through age 21ⁱ and is recognized as the standard for pediatric preventive health insurance coverage under the Affordable Care Act.ⁱⁱ The Centers for Medicare and Medicaid Services (CMS) encourages state Medicaid agencies to use this nationally recognized pediatric periodicity schedule or consult with recognized medical organizations involved in child health care in developing their EPSDT schedules, which refers to Medicaid's coverage for children, known as the Early and Periodic Screening, Diagnostic and Treatment benefit.^{iii,iv} The following analysis of the South Dakota EPSDT program was conducted by the AAP, with funding support from the federal Maternal and Child Health Bureau, to promote the use of Bright Futures as the professional standard for pediatric preventive care.

South Dakota's profile compares the state's EPSDT Program with the Bright Futures periodicity schedule and screening recommendations. The state profile also contains information about South Dakota's pediatric preventive care quality measures and performance, financial incentives, medical necessity definition, and best practices. Information was obtained from telephone interviews and/or email queries with the state EPSDT director; reviews of the Medicaid website, provider manual, and other referenced state documents; and analysis of CMS reports on child health quality. Additional information regarding Bright Futures and EPSDT in the seven states participating in the June 2016 "Learning Collaborative on Improving Quality and Access to Care in Maternal and Child Health" (Colorado, Minnesota, Montana, North Dakota, South Dakota, Utah, and Wyoming) is available on request.^v

Summary of Findings

- South Dakota reports a very high rate of provider participation in Medicaid, which results in great access to and choice for families. Another strength mentioned was that South Dakota extends EPSDT coverage to children enrolled in its separate CHIP program.
- South Dakota's EPSDT program has adopted the AAP's Bright Futures periodicity schedule and screening recommendations, although the provider manual references 2014 AAP recommendations and their member handbook has a different schedule for preventive visits. In addition, the state's description of interperiodic preventive care screening (visits that may occur between scheduled preventive care visits) in its recipient handbook will need to be updated.
- The state's medical necessity definition for EPSDT does not address coverage for preventive purposes. It does not specifically refer to Bright Futures as its professional standard for pediatric care.
 - To be medically necessary, the covered service must meet the following conditions: (1) It is consistent with the recipient's symptoms, diagnosis, condition, or injury; (2) It is recognized as the prevailing standard and is consistent with generally accepted professional medical standards of the provider's peer group; (3) It is provided in response to a life-threatening condition; to treat pain, injury, illness, or infection; to treat a condition that could result in physical or mental disability; or to achieve a level of physical or mental function consistent with prevailing community standards for diagnosis or condition; (4) It is not furnished primarily for the convenience of the recipient or the provider; and (5) There is no other equally effective course of treatment available or suitable for the recipient requesting the service which is more conservative or substantially less costly.
- According to CMS, in 2014, South Dakota selected 1 of the 11 pediatric preventive care measures: preventive dental visits.
- According to a report from the federal Department of Health and Human Services (DHHS), South Dakota's quality performance rate for preventive dental visits was lower than the national average.^{vi} See below.

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- No preventive care improvement projects were identified by the individuals interviewed in South Dakota.

Opportunities to Consider

1. Ensure that all of the state's communications to providers and consumers consistently reference the pediatric preventive care schedule and recommendations aligned with Bright Futures and also the availability of interperiodic visits.
2. Consider linking guidance on health education/anticipatory guidance to Bright Futures.
3. Consider lessons learned from other rural states that rely on primary care case management programs and fee-for-service arrangements in selecting pediatric preventive care quality measures and implementing related improvement projects.
4. Consider reviewing the state's medical necessity definition for EPSDT in terms of incorporating a preventive focus and referencing Bright Futures as its pediatric preventive care standard.
5. Consider strategies for increasing use of child and adolescent primary care visits, including financial incentives. In addition, examine options for increase adolescent preventive care visits aligned with CMS' recommendations and addressing transitions of care and coverage when youth are no longer eligible for EPSDT.

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EPSDT RECOMMENDATIONS AND SELECTED PEDIATRIC QUALITY PERFORMANCE MEASURES

EPSDT Periodicity Schedule, 2016 (# of well child visits)	SD	Bright Futures
- Prenatal period	1	1
- Birth through 9 months	7	7
- 1 through 4 years	7	7
- 5-10 years	6	6
- 11 through 14 years	4	4
- 15 through 20 years	6	6

Pediatric Preventive Care Quality Measures and Performance, 2014	SD	US
- % of children with primary care visit	NA	95.8
o Ages 12-24 months in past year	NA	87.1
o Ages 25 months-6 years in past year	NA	88.9
o Ages 7-11 years in past 2 years	NA	88.0
o Ages 12-19 in past 2 years	NA	61.7
- % of children by 15 months receiving 6 or more visits	NA	67.1
- % of children ages 3-6 with one or more well child visits	NA	45.5
- % of adolescents ages 12-21 receiving 1 well visit	NA	62.1
- % of children up to date on recommended immunizations (combination 3) by 2 nd birthday	NA	64.9
- % of adolescents up to date on recommended immunizations (combination 1) by 13 th birthday	NA	64.9
- % of sexually active women ages 16-20 screened for Chlamydia	NA	48.8
- % of female adolescents receiving 3 vaccine doses of HPV before age 13	NA	17.2
- % of children ages 3-17 whose weight was documented based on BMI percentile	NA	41.7
- % of children ages 1-20 with at least 1 preventive dental visit	39.6	47.5

Pediatric Preventive Care Financial Incentives, 2016	SD	US
- Use of preventive incentive for consumers	No	NA
- Use of performance incentives for providers	No	NA

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EPSDT Universal (U) and Selected (S) Screening Requirements, 2015	SD	Bright Futures
<i>Infancy (Prenatal-9 months)</i>		
- Length/height & weight	U	U
- Head circumference	U	U
- Weight for length	U	U
- Blood pressure	S	S
- Vision	S	S
- Hearing	U/S	U/S
- Developmental surveillance/screening	U	U
- Psychological/behavioral assessment	U	U
- Newborn blood screening	U	U
- Congenital heart screening	U	U
- Hematocrit or hemoglobin	S	S
- Lead screening	S	S
- Tuberculosis testing	S	S
- Oral health	U/S	U/S
<i>Early Childhood (Ages 1-4)</i>		
- Length/height & weight	U	U
- Head Circumference	S	S
- Weight for length	S	S
- Body mass index	S	S
- Blood pressure	S	S
- Vision	U/S	U/S
- Hearing	U/S	U/S
- Developmental surveillance/screening	U	U
- Autism screening	U	U
- Psychological/behavioral assessment	U	U
- Hematocrit or hemoglobin	U/S	U/S
- Lead screening	U/S	U/S
- Tuberculosis testing	S	S
- Dyslipidemia screening	S	S
- Oral health	U/S	U/S
- Fluoride varnish	U	U
<i>Middle Childhood (Ages 5-10)</i>		
- Length/height & weight	U	U
- Body mass index	U	U
- Blood pressure	U	U
- Vision	U/S	U/S
- Hearing	U/S	U/S
- Developmental surveillance	U	U
- Psychological/behavioral assessment	U	U
- Hematocrit or hemoglobin	S	S
- Lead screening	S	S
- Tuberculosis testing	S	S
- Dyslipidemia	U/S	U/S
- Oral health	U	U
- Fluoride varnish	U	U
<i>Adolescence (Ages 11-20)</i>		
- Length/height & weight	U	U
- Body mass index	U	U
- Blood pressure	U	U
- Vision	U/S	U/S

Code:
 U= universal screening (all screened)
 S = selective screening (only those of higher risk screened)
 U/S = visits in that age group have universal and selective requirements.
See Bright Futures periodicity information for complete information.
 * = if not results for newborn screening on file, or did not pass, follow-up appropriate.
 + = if not done at 24 months
 ^ = for menstruating adolescents
 R = recommended for visit
 X = Risk assessment followed by appropriate action
 NS = not specified

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- Hearing	U/S	U/S	
- Developmental surveillance	U	U	
- Psychological/behavioral assessment	U	U	
- Alcohol & drug use assessment	S	S	
- Depression screening	U	U	
- Hematocrit or hemoglobin	S	S	
- Tuberculosis testing	S	S	
- Dyslipidemia screening	U/S	U/S	
- Cervical dysplasia screening	U	U	
- STI/HIV screening	U/S	U/S	
- Oral health	-	-	

EPSDT REFERENCES

Paving the Road to Good Health: Strategies for Increasing Medicaid Adolescent Well-Care Visits. Baltimore, MD: CMS, February 2014.

ⁱ Committee on Practice and Ambulatory Medicine. 2015 Recommendations for Preventive Pediatric Health Care. *Pediatrics*.2-15:136(3).

ⁱⁱ *FAQs about Affordable Care Act Implementation.* Washington, DC: US Department of Labor, Employee Benefits Security Administration, May 11, 2015.

ⁱⁱⁱ *ESPDT – A Guide for State: Coverage in the Medicaid Benefit for Children and Adolescents.* Baltimore, MD: Centers for Medicare and Medicaid Services, June 2014.

^{iv} *Paving the Road to Good Health: Strategies for Increasing Medicaid Adolescent Well-Care Visits.* Baltimore, MD: Centers for Medicare and Medicaid Services, February 2014.

^v To obtain a copy of *ESPDT and Bright Futures in Colorado, Minnesota, Montana, North Dakota, South Dakota, Utah, and Wyoming*, please contact jgorlewski@aap.org.

^{vi} Quality information was obtained from *DHHS 2015 Annual Report on the Quality of Care for Children in Medicaid and CHIP*, February 2016.