

American Academy of Pediatrics

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Maternal and Child Health Bureau

**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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NORTH DAKOTA STATE REPORT

**AIM Expanding Access to Care for Maternal and Child Health Populations
Learning Collaborative Cohort 2 – North 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 a leader within the AAP North 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	
Access	<ul style="list-style-type: none"> • Long travel times to receive care for people in rural areas • Access is especially challenging for impoverished patients without transportation • Few subspecialists in the state – only two pediatric neurologists
Bright Futures / EPSDT	<ul style="list-style-type: none"> • Hospital systems' Epic EHRs use templates that do not follow Bright Futures making it challenging to remember all recommended screenings
Marketplace Insurance Plans	<ul style="list-style-type: none"> • Often very high deductibles causing families to skip or reduce recommended rehabilitative services or needed drugs • Some plans limit the number of covered rehabilitative visits
Medicaid	<ul style="list-style-type: none"> • Often does not pay for children to receive care at the children's hospital in Minneapolis – require kids to go to Fargo despite the better care available at the hospital • Recently implemented a 47% payment cut – resulting in some physicians reducing Medicaid patients and furthering physician recruitment challenges
Maternal Care Challenges	
Access	<ul style="list-style-type: none"> • Frequently must travel to receive prenatal care which is especially difficult for patients without reliable transportation • High rate of maternal drug abuse and addiction

Pediatric Care Successes	
Access	<ul style="list-style-type: none"> • Specialists rotate through Bismarck
Medicaid	<ul style="list-style-type: none"> • Very low uninsured rate (2.3-2.8%)

Opportunities	
<ul style="list-style-type: none"> • Expand telehealth services to include tertiary children's hospital systems • Reverse the Medicaid payment cut • Improve EHRs so that the templates follow Bright Futures 	

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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 state Family-to-Family Health Information Center in each of the Learning Collaborative 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 22 complete responses were received from patients/families in North 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 – no access issues (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."
 - "Therapy was delayed due to insurance not covering therapies and couldn't afford to pay out of pocket. We waited for almost 2 months."

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- *“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 North 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

Complex Needs Require Communication across Systems - ND

Married to an amazing man, Beth and her husband had two wonderful children. They had secure jobs, friends, and family members who loved them. A year into their marriage, Beth's husband became very sick. Through testing, procedures, and visits to numerous doctors he was diagnosed with hereditary pancreatitis (PRSS1). A week later at age one, Beth's daughter was also diagnosed with the same disease. Later on, her son was also diagnosed.

Hereditary Pancreatitis (PRSS1) is an extremely painful disease. Many doctors indicate that pancreatitis as well as pancreatic cancer are two of the most painful diseases one can have. In pancreatitis, the pancreas actually "eats" itself causing extreme pain. Along with pain, other symptoms of this disease are malabsorption, malnutrition, diabetes, and pancreatic cancer. Beth's daughter was in and out of the hospital for many years. At six months when Beth witnessed her son screaming and arching his back she was convinced that he also had the disease, but no one believed her, and told her that it was psychological.

There is no treatment for this disease. One of the treatment options for this disease is a relatively new surgery for individuals called an Auto-islet Transplant Total Pancreatectomy (AIT TP). In this surgery, the pancreas, spleen, gall bladder and half of the stomach are removed. The islet cells from the pancreas are harvested and placed into the liver. The hope is that this will provide a better quality of life for people with this disease. At age 9, Beth's daughter was one of the first to have this procedure at the University of Minnesota Children's Hospital when they just opened their transplant center for children. Due to this, she had a few more surgeries as they were "refining" the procedure (AIT TP).

The last four years, their lives have been a daily struggle. Beth's husband's pancreatitis advanced to pancreatic cancer and after a three year battle he succumbed to the side effects of treatment rather than pancreas cancer. A month after Beth's husband's death, her son had his transplant. He too was diagnosed with hereditary pancreatitis after long battles with misdiagnoses. Her son did not get better after the surgery. He was diagnosed with c-diff 6 weeks after his transplant and they struggled for 2.5 years to get control of the disease.

Currently both kids struggle with on-going health issues due to complications from their surgeries. They also deal with significant mental health issues related to the trauma of all the hospitalizations, mismanagement of care and pain, as well as the death of their father. Beth's daughter has diabetes and chronic abdominal and back pain. Beth's son also has chronic abdominal and back pain. Both struggle with chronic c-diff. They are susceptible to illnesses due to the lack of spleen. They take many medications for their medical issues as well as mental health issues. Both are medically non-compliant because as Beth says, they have in ways "given up" on their health and life. Beth's son often talks about wanting to die because he can't deal with his pain and he feels that he has nothing to live for. Beth struggles getting him to school and appointments. Beth's daughter is tired of doctors, medications, and hospitalizations.

Adding to their complex medical conditions, the family is feeling the brunt of the system's lack of preparedness to successfully deal with medically and behaviorally complex children and youth. Beth's son requires involved

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behavioral support, and she has tried to access in-patient behavioral health facilities only to be turned away because they are not equipped to handle his complex medical needs. She is now considering placement in Virginia and North Carolina, across the country because no one in the area will take them.

Additionally, there have been severe misunderstandings and risky lack of communication among providers about the administration of pain medication. Providers swing between withholding pain medications to address behavior, and prescribing it. While they do this, they do not communicate with the other agencies that are involved, and Beth ends up being accused of unilaterally withholding her son's meds. This has left Beth on the receiving end of several abuse and neglect complaints, some reaching her hands during critical procedures for both children, adding an almost insurmountable amount of distress. For example, Beth was accused of giving her son marijuana after she brought him to the hospital. He was having hallucinations. The doctors blamed her, only to find out that her son was sneaking his sister's pain medications to self-medicate his unbearable pain. On a different occasion, his provider directed Beth to withhold pain medications in an attempt to control his behavior. When the behavioral institution that was evaluating him found out that he was not taking his pain medications, they filed yet another abuse and neglect claim against Beth. Beth explained that she was withholding it following strict orders from her son's providers. If they had communicated, they would have known, and would have been able to coordinate her son's care, and avoided one more instance of stress and suffering for Beth. She is still mitigating the consequences of that abuse and neglect allegation.

The inappropriateness of North Dakota's behavioral health system has caused Beth's son's and daughter's behavioral issues to spill onto the justice system. Beth has had to enlist the help of the police to get her son to school and to resolve escalating disputes between her two children. Likewise, Beth's daughter was "kicked out" of an eating disorder clinic the day before her graduation, and Beth was afraid to take her home. Beth explained both to the clinic personnel and the county police that she was afraid that her daughter would become physical with her, and asked for help. The clinic gave Beth's daughter a shot to chemically restrain her, and asked Beth to pick her up. The county police were non-responsive to her request for help.

In addition to the tremendous psychological burden on Beth, she worries about the family's finances. In Beth's own words, "Currently, there are times when my take home monthly pay from my job does not cover their necessary care. As a single parent I am attempting to keep my job, attend necessary appointments, coordinate care, and find options for care for my children." The family has private insurance through Beth's job, but they don't know for how long. They currently have no waiver coverage. Beth's daughter was kicked off the waiver "for lack of use." Her son did not qualify for the waiver in the first place. There is a waiting list, and if children don't meet the narrow waiver classification, they are not considered for the waiting list. Their condition is not well understood, especially the complications that arise during and after care. The complications are both behavioral and physical. The chronic pain needs a multi-pronged approach, instead of just addressing it medically.

The ND medically fragile waiver is very narrow, and it fails to take into consideration many of the needs that children with complex medical conditions in conjunction with behavioral conditions have. Beth's daughter was denied coverage because she had to travel out of state to receive the specialty care necessary for her conditions. The waiver has no provisions for behavioral care.

In addition to not being able to qualify for the waiver, the children's income from their dad's death benefit disqualifies them when applying for medical assistance, so they can't receive any.

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Many agencies in the county and the state have been engaged in one way or another in Beth's cases, across many systems of care. However, because there is no apparent interagency communication infrastructure, Beth and her children are living in a kind of limbo. Beth feels alone and antagonized in her quest to take care of her children while facing the consequences of tremendous personal loss.

Lack of Comprehensive Care for Children with Complex medical and Behavioral Conditions: Beth has been unable to find appropriate care and support to care for both of her children at home or even locally in ND. Behavioral institutions do not have the ability to support their critical health needs, and hospitals don't have the resources to deal with the children's intense behavioral challenges.

Lack of Knowledge of Complex Medical Needs: Doctors in ND have limited knowledge of complex procedures needed for children with complex medical needs. This leaves Beth having to travel out of state to access knowledgeable specialists, which presents yet another expense for a family whose resources are already tapped out.

Lack of Care Coordination: Beth has had no assistance in coordinating care for her children. The after care for the children's surgeries is very complex, involving both medical and behavioral components. Beth has had to do everything by herself, often facing the dire consequences of the lack of communication between behavioral and medical providers. This lack of communication has been the cause of several abuse and neglect complaints being filed against Beth.

Narrow Waiver: Waiver requirements reflect a poor understanding of complex medical and behavioral needs, often neglecting behavioral needs.

Lack of Local Behavioral Resources: Beth is having to consider out-of-state options for placing her son, as ND does not have clinics that are capable of handling both behaviorally and medically complex children and youth.

Lack of Communication and Coordination across Systems of Care: The challenges that Beth's family is facing respond in great part to the silo approach that ND seems to display when it comes to addressing the needs of medically complex children.

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Family Story #2

Long-term Care for a Child with High Needs: The Story of a Native American Family from North Dakota

Kelly is the mother of four children, and this story will focus on Cash, her 4 year old boy who began his extended stays at the hospital early on in his life. Their story exemplifies the difficulties that a family faces in ND when they need access to long term critical care. The consequences of not having specialized providers in the state are far reaching, and add unnecessary hardship to circumstances that are already dire.

When Cash was 1 month old, he was found unresponsive, and the doctors did not know why his airway had collapsed. He was in the hospital for three weeks, where he received several blood transfusions and was put on life support. As his condition worsened, his doctors in North Dakota began calling children's hospitals in other states to see where Cash could receive the specialized care that he needed.

The Children's Hospital of Minneapolis decided to take Cash, and he was flown in while on life support. When Kelly arrived at the hospital, she was met by nurses with hopeless prospects. The nurses greeted her by telling her that they were sorry, as babies like Cash usually died. Kelly had Cash receive the last rites. But Kelly was not about to lose hope because she had seen Cash's toe move while still in the North Dakota hospital. Even though the nurses and doctors periodically checked in with Kelly about how she felt regarding discontinuing life support for Cash, Kelly never lost hope. Things improved and Cash survived, but he had a long road ahead of him and required extensive medical treatment.

Kelly and Cash had to move to Minnesota for two years, while Cash went from the NICU to the PICU. She lived at the hospital for the first month or so, and then she moved into the Ronald McDonald house with her toddler so she could be close to him and Cash. Her 3-year-old started preschool while living in Minnesota. She was also able to qualify for Medicaid in Minnesota without having to establish residency, and this assistance paid for Kelly to stay at the Ronald McDonald House. Kelly is very grateful for all the help that she received from the supportive group of parents and staff at the Ronald McDonald House.

Meanwhile, her husband stayed back in North Dakota working with her other two children. Her family life suffered greatly. Kelly says that her oldest child's father used Kelly's absence to claim abandonment, and she lost custody of her.

After a year at the children's hospital in MN, Cash was ready to go home on a ventilator. However, he would only be able to go home if it could be established that support for the ventilator would be available within a 50 mile radius, and her local North Dakota hospital did not want to buy the equipment necessary to support it. Therefore, Kelly would have to keep Cash in Minnesota until this became an option.

At this point, Family Voices of North Dakota became involved to help Kelly and Cash come home. When Family Voices of North Dakota realized that the problem was larger, they engaged the help of Julie Beckett and Trish Thomas from Family Voices National on behalf of Cash and Kelly. They brought in the insurance commissioner and called the insurance company to inquire about why coverage had been denied three consecutive times. The appeals process bought Cash some more time at the hospital because the hospital could not take action against Kelly during the appeal. However, the Minnesota hospital used this time to try to intimidate Kelly into dropping the complaint. They said that she was going to lose, and that if she lost, she would be liable to pay all the charges that Cash had been incurring for all that time. Intimidations came accompanied by periodic "reminders"

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that life support could be discontinued to end Cash's life. Kelly has always seen meaning in having Cash, and those suggestions made her feel that Cash was only seen as a number by the administrators at the hospital.

After months of investigations and the insurance commissioner intervention, the appeals resulted in a judgement in favor of Kelly. By the time that Cash and Kelly returned home to North Dakota, Cash had spent the first two years of his life in a hospital in Minnesota. Cash was able to come back to North Dakota because the North Dakota hospital agreed to support Cash's ventilator. Cash was on the waiver and on Blue Cross Blue Shield upon their return home, and ready to start a new life at home.

Coming home was a short lived victory. When Cash came home he had to be admitted overnight to the hospital. Shortly thereafter, Kelly got a letter from the hospital stating that the North Dakota hospital would not provide home care for Kelly. This felt like a discriminatory action because the hospital was equipped to do so. At the same time, Blue Cross Blue Shield said that they would only pay for 8 hours of nursing care per day even though Cash had to be on a ventilator overnight, requiring round the clock care every day.

Family Voices became involved again to help Kelly when they saw an open letter that Kelly had posted on Facebook detailing her situation with Cash. Family Voices helped Kelly to find a home nursing care provider, though their charges were very high, sending the insurance company into another denial of payment cycle. At this point, the Family Voices director reached out to the DD manager and medical directors to let them know that there was no care coordination taking place in cases like Kelly's, in addition to all the difficulties in trying to obtain coverage for home based nursing care for Cash. Finally, with the help and guidance of Family Voices, Kelly obtained coverage through the waiver.

Today, the North Dakota hospital still does the maintenance for Cash's ventilator. Kelly has since purchased a backup ventilator as recommended and required by her doctors, but inexplicably, the people from the hospital that did the maintenance, took that backup ventilator without an explanation to Kelly. Kelly says that the backup ventilator is her property because she paid for it. Cash's back up ventilator has not been returned, and Kelly remains without an explanation or answers to her inquiries.

Kelly has become a savvy advocate. Her experiences with Cash and the support that she received from Family Voices have empowered her to become an important advocate for Indian Health. She notes that Native Americans go through tremendous discrimination when accessing healthcare. She recounted many instances of discrimination during her already difficult ordeal with Cash. For example, Kelly was often by-passed and is still seldom asked for her input by providers. When the hospital employees come in to do the maintenance on the ventilator, they never talk to her. She says that it feels as if she is invisible.

While Cash was in the hospital, Kelly was also bypassed, and she says that they even took Cash off the ventilator once without her consent or previous knowledge. Kelly is an incredibly resilient individual, but that doesn't keep her from noticing how children in white communities are treated versus Native American children. During her two year stay at the hospital, she noticed how the community would pull together around white children, organizing fundraisers for a two week stay, while Cash's issues went ignored for two years. She felt forgotten, a feeling that many in the Native American community have. The trust in hospitals is eroded among tribal people, and they feel like they are being left to die.

Many Native American leaders echo the feelings that Kelly expressed. They feel that Indian youth are forgotten, and the neighboring white communities seldom come in contact with them, and "they never cross." Kelly's advocacy has had some positive effects and she sees that there has been positive attention brought on to Native

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American health. There is still much work to be done because the Indian Health Service is not appropriate for children with special needs. Additionally, much work remains to be done to gain the trust of the Native American community, and Kelly says that the most effective way to do so effectively is to use cultural brokers. She says that Native Americans are much more likely to be open and trusting of one of their own, versus a well-meaning outsider. Similarly, Native Americans have a personal understanding of the great role that spirituality plays in the care of their family members. Kelly says that if her spirituality had been taken into consideration during her ordeal with Cash, her experience would have been very different.

Kelly's dream for her community is that Congress will pass legislation to fund health care for tribes separately. The need on the tribal reservations is often much larger than the funding. She will continue to advocate for her child and for her community, and hope that government will see the importance of developing solutions that are initiated by native people themselves, instead of imposed by outsiders.

Cash's and Kelly's story is a vivid reminder of the difficulties that many people in North Dakota experience when accessing care for their loved ones, emphasizing the importance of culturally appropriate and respectful care at every step of the way.

Lack of Specialty Providers: North Dakota lacks specialty providers for critical, long term cases. Had North Dakota had the resources necessary to help Cash from the beginning, Kelly would not have to live away from the rest of her family for two years.

Lack of Care Coordination: Kelly has been left to do most of the care coordination for Cash. This places extremely high demands on a family that is already taxed by the gravity of having a child who needs round-the-clock care.

Indian Health Service is Under-funded: Kelly mentioned that there is an epidemic of cancer among Native Americans, but "we're being left to die." Additionally, IHS is not funded to take care of the specific needs of children with special health care needs.

Need for more Native American Cultural brokers: There is a severe lack of trust in white institutions. Therefore, solutions need to come from native people. If there are more native advocates, tribal people are more likely to believe in service providers.

Need for Cultural Reciprocity Training: Kelly expressed feeling discounted because of her cultural and ethnic background. Providers and hospitals need to be committed to training their staff and administrators to be respectful of the needs of Native Americans.

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EPSDT AND BRIGHT FUTURES – NORTH 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 North 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.

North 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 North 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

- North Dakota's EPSDT program has adopted the AAP's Bright Futures periodicity schedule and screening recommendations. Their provider manual, however, includes a different schedule than Bright Futures.
- The state's medical necessity definition for EPSDT does not address coverage for preventive purposes. It does not specifically refer to mental health conditions or to Bright Futures as its professional standard for pediatric care.
 - Medically necessary includes only medical or remedial services or supplies required for treatment of illness, injury, diseased condition, or impairment; consistent with the patient's diagnosis or symptoms; appropriate according to generally accepted standards of medical practice; not provided only as a convenience to the patient or provider; not investigational, experimental, or unproven; clinically appropriate in terms of scope, duration, intensity, and site; and provided at the most appropriate level of service that is safe and effective.
- According to CMS, in 2014, North Dakota selected 5 of the 11 pediatric preventive care measures: child and adolescent access to PCPs, well visits in years 3 through 6, adolescent well visits, adolescent immunization status, and preventive dental visits.
- According to a report from the federal Department of Health and Human Services (DHHS), North Dakota's quality performance rates were higher than the national average for primary care visits by adolescents and adolescent immunizations. It was lower than the national average for primary care visits made by children ages 25 months through 11, preventive visits for children ages 3 through 6 and adolescents, and for preventive dental visits.^{vi} See examples below.
- Preventive care improvements projects related to well child care, childhood immunizations, and oral health are being implemented in North Dakota.

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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.
2. Consider linking guidance on health education/anticipatory guidance to Bright Futures.
3. Examine reasons for why the primary care visit rates for younger children are not as high as the rate for adolescents.
4. Consider reviewing the state’s medical necessity definition for EPSDT in terms of incorporating a preventive focus, including mental health conditions, 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)	ND	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	ND	US
- % of children with primary care visit	#	95.8
o Ages 12-24 months in past year	79.9%	87.1
o Ages 25 months-6 years in past year	81.0	88.9
o Ages 7-11 years in past 2 years	89.4	88.0
o Ages 12-19 in past 2 years	NA	61.7
- % of children by 15 months receiving 6 or more visits	35.0	67.1
- % of children ages 3-6 with one or more well child visits	40.0	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	62.1
- % of adolescents up to date on recommended immunizations (combination 1) by 13 th birthday	71.3	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	28.9	47.5

Pediatric Preventive Care Financial Incentives, 2016	ND	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	ND	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

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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- Blood pressure	U	U	
- Vision	U/S	U/S	
- 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 *EPSDT 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.