

THE NATIONAL STANDARDS FOR CHILDREN AND YOUTH WITH
SPECIAL HEALTH CARE NEEDS: A COMPENDIUM OF NATIONAL
DATA AND QUALITY MEASURE SETS

National Academy for State Health Policy (NASHP)

Background

Creating a comprehensive, high quality system of care for children and youth with special health care needs (CYSHCN) is a key priority for many state health policy leaders. Key national stakeholders participating in the *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* project identified optimal capacity and performance for systems of care serving CYSHCN, resulting in the [National Standards for Systems of Care for CYSHCN](#), to help state leaders transform and improve systems of care for CYSHCN and their families. Since its publication in 2014, the National Standards have been used by national, state, and local stakeholder groups, including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children’s hospitals, insurers, health services researchers, families, consumers, and others.

Nearly 20 percent of all US children up to 18 years (more than 14 million) have chronic and/or complex health care needs (e.g., asthma, diabetes, spina bifida) requiring health care services and supports beyond what children require normally.¹ Among them, about 3 million children have complex health care needs (representing about 0.5 percent of all US children and their numbers are growing) and require the highest levels of need.²

Quality measurement is a critical component of many state programs, including Medicaid, the Children’s Health Insurance Program (CHIP), and state Title V CYSHCN programs. The federal Title V MCH Services Block Grant program requires states to report annually on a set of [Title V National Performance Measures](#) and the Centers for Medicare & Medicaid Services asks states to voluntarily report on the [Child Core Set](#) of measures on an annual basis. In 2024, states will be required to report on all measures in the Child Core Set. Measuring the quality of care that CYSHCN receive is a growing priority for state and national health policymakers and public and private health plans and providers. As states implement health system reforms, including linking performance and quality to payment for services, interest in quality measurement for programs serving specialized populations, including children with chronic and complex health care needs, is increasing. States’ [increased use of Medicaid managed care](#) delivery systems to serve CYSHCN³ also presents an opportunity to hone and refine quality measurement strategies. Identification of data and quality measures that align with the National Standards can help states better implement the standards and evaluate how well their systems of care are serving CYSHCN.

This measures compendium is designed to provide states and other key stakeholders with a reference tool that highlights relevant quality measures aligned with key domains of the National Standards for CYSHCN. It compiles current data and quality measures – and avoids creating new measures -- given the availability of numerous existing measure sets and states’ limited capacity and infrastructure to design or test new measures.⁴ The measures listed in this compendium summarize relevant measures from the most applicable and widely used measure sets, and are not intended to be an exhaustive list of all available measures or to provide quality measures that focus on specific medical conditions.

Methodology

The National Academy for State Health Policy (NASHP), in partnership with the Association of Maternal and Child Health Programs (AMCHP), conducted an environmental scan of measures from the following sources: national data measures and quality measurement sets, regularly conducted national and health plan surveys, patient survey instruments, and National and State Title V Performance and Outcome Measures as required by the federal Title V MCH Services Block Grant program. Following a review of these sources, key measure sets that align with the National Standards were identified and relevant measures from these sets were compiled in an index of more than 250 measures. When selecting relevant measures, the goal was to cast a wide net so that states could identify the measures that most closely met their needs. The index also listed key information about each measure, including the organization who created or maintains the measure, target population, level of analysis, and data source. Each individual measure was then reviewed to determine which National Standard domain (or domains) it should be attributed to. The measure sets included in the compendium are described below.

¹ “2016 National Survey of Children’s Health,” Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health, accessed April 2018, www.childhealthdata.org.

² Turchi R and Mann M. “Building a Medical Home for Children and Youth with Special Health Care Needs,” in *Handbook of Children With Special Health Care Needs*, ed. David Hollar, (Philadelphia: Springer Publishing, 2012), 399–418.

³ Kate Honsberger and Karen VanLandeghem, *State Medicaid Managed Care Enrollment and Design for Children and Youth with Special Health Care Needs: A 50-state Review of Medicaid Managed Care Contracts* (Washington, DC: National Academy for State Health Policy, October 2017).

⁴ Becky Normile, et al. *State Strategies for Medicaid Quality Improvement for Children and Youth with Special Health Care Needs* (Washington, DC: National Academy for State Health Policy, November 2017).

How to Use the Compendium

The Measures Compendium categorizes critical data and quality measures in the following National Standards foundational standards and domains.

- Foundational Standard 1: Children and families of CYSHCN are active, core partners in decision making in all levels of care.
- Foundational Standard 2: All services and supports for CYSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.
- Foundational Standard 3: Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.
- Domain 1: Identification, Screening, Assessment, and Referral
- Domain 2: Eligibility and Enrollment in Health Coverage
- Domain 3: Access to Care
 - Access to specialist providers
- Domain 4: Medical Home
 - Medical Home Management
 - Preventive, Primary and Specialty Care
 - Care Coordination
- Domain 5: Community-Based Services and Supports
- Domain 6: Transition to Adulthood
- Domain 7: Health Information Technology

Each foundational standard or domain features relevant measures. Once you determine which domain or foundation standard you are most interested in, you can navigate to that tab and see a list of relevant data and quality measures. For example, the measures related to newborn screening are listed in Domain 1 under the “screening” subheading. Each individual measure features a hyperlink that leads to more information about the measure, such as the numerator and denominator measured or the populations or data to be excluded from the measure results. For survey-related measures, the hyperlink is accompanied by more information, such as the exact wording of the survey question posed, the confidence interval for the data collected, and the national trend for the question (if it is from a national survey). For composite measures, the hyperlink includes information about the measures and data that make up the composite measure.

Acknowledgments

This resource was developed by Hannah Eichner, Miara Handler, Kate Honsberger, and Becky Normile from NASHP and Paige Bussanich from AMCHP. The developers would like to acknowledge guidance and support from Karen VanLandeghem (NASHP) and Kate Taft and Cheryl Clark (AMCHP). Funded by a grant from the Lucile Packard Foundation for Children's Health, Palo Alto, California

Description of Measure Sets in the National Standards Measures Compendium

Measure Set	Description	Source	Frequency of Updates and/or Reporting
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey 5.0	A survey, developed by the Agency for Healthcare Research and Quality (AHRQ), that is commonly used by Medicaid agencies and health plans to assess health plan enrollees’ experiences, including access to appointments and care through their health plan, communication with doctors available through the plan, and customer service.	Survey data	Annually

CAHPS Survey: Children with Chronic Conditions	A supplemental CAHPS survey question set specifically assessing the experiences of children with chronic conditions with health plans and health care services.	Survey data	Annually
Family Experience with Care Coordination (FECC)	A survey developed by the Center of Excellence on Quality of Care Measures for Children with Complex Needs that assesses care coordination for children with chronic and complex conditions.	Survey data	N/A
Healthcare Effectiveness Data and Information Set (HEDIS)	A set of quality measures developed by the National Committee for Quality Assurance (NCQA) to measure health plan performance. Medicaid health plans accredited by NCQA must report on 35 select measures annually.	Administrative, hybrid, and survey data	Annually
Medicaid/CHIP Child Core Set	A set of health care quality measures identified by the Centers for Medicare & Medicaid Services (CMS). State Medicaid and Children’s Health Insurance Program (CHIP) programs currently report on these measures voluntarily but will be required to submit data on all measures by 2024.	Administrative, hybrid, and survey data	Annually
Pediatric Integrated Care Survey (PICS)	A validated survey, developed by Boston Children’s Hospital, that measures experiences of families with the integration of health care and related services for children with complex medical, behavioral, and developmental needs.	Survey data	N/A
Pediatric Quality Measures Program (PQMP)	A joint CMS and AHRQ program that is strengthening the Medicaid/CHIP Child Core Set and has developed new pediatric measures across diverse topics.	Administrative and medical records data	N/A
National Survey of Children’s Health (NSCH)	A national annual survey that measures many key topics concerning children’s health and well-being. NSCH is sponsored by the Health Resources and Services Administration, Maternal and Child Health Bureau, and conducted by the US Census Bureau.	Survey data	Annually
Adolescent Assessment of Preparation for Transition (ADAPT)	A validated survey, developed by the Center of Excellence for Pediatric Quality Measurement, consisting of youth-reported measures of the quality of health care transition preparation. The survey is designed to be completed by 16- and 17-year-old patients receiving care from a pediatric-focused provider.	Survey data	N/A
Individuals with Disabilities Education Act (IDEA) Child Count, Part C	A measure set of state reported data related to children who are receiving services through the Part C Early Intervention program. States are required to submit this data to the US Department of Education annually.	Hybrid of medical and educational records (paper or electronic) and administrative claims	Annually
CMS Annual Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Participation report	A set of data measures used by CMS to collect basic information about state Medicaid programs to assess the effectiveness of EPSDT services. States are required to submit this data to CMS annually.	Hybrid of medical and educational records (paper or electronic) and administrative claims	Annually
NewSTEPS: Newborn screening quality indicators	A set of quality indicators on key aspects of state newborn screening systems, developed by the NewSTEPS organization. States that have a memorandum of understanding with NewSTEPS submit the data voluntarily on an annual basis.	Newborn screening data	Annually
Promoting Healthy Development Survey (PHDS-PLUS)	The PHDS-PLUS survey measures whether young children are receiving nationally recommended preventive and developmental services, as well as certain other factors related to children’s health. The survey is designed for use by Medicaid and other programs, and was developed under the Child and Adolescent Health Measurement Initiative.	Survey data	N/A

Foundational Standards	Applicable Measures					
<p>Foundational Standard 1: Children and families of CYSHCN are active, core partners in decision making in all levels of care.</p>	<p>National Survey of Children’s Health</p> <ul style="list-style-type: none"> • Children whose families are partners in shared decision-making for their optimal health (composite) • Children who received family-centered care (composite) • Doctor or health care providers worked with youth to gain skills to manage health/health care or understand health care changes at age 18, age 12-17 years (composite) • Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) • Doctors discussed range of health care/treatment options • Doctors helped parents feel like partners in child's care • Doctors worked with parents to decide together health care/treatment options • Doctors listened carefully • Doctors made it easy for parents to raise concerns or disagree with recommendations • Doctors provided information specific to parents' concerns • Doctors showed sensitivity to family's values and customs • Doctors spent enough time with children • Doctor or health care provider actively worked with the child to make positive choices about his/her health, age 12-17 years • Doctor or health care provider actively worked with the child to think about and plan his/her future, age 12-17 years • Doctor or health care provider actively worked with the child to gain skills to manage his/her health and health care, age 12-17 years 	<p>PHDS-PLUS</p> <ul style="list-style-type: none"> • Family-centered care that respects, listens to, and partners with parents (composite) • Helpfulness of care provided to parents (composite) • Assessment of parent concerns about child learning, development, and behavior and provision of specific information for parents with concerns (composite) <p>In the last 12 months, how often did (child’s) doctors or other health care providers:</p> <ul style="list-style-type: none"> • Take time to understand the specific needs of (child)? • Respect you as an expert about (child)? • Build your confidence as a parent (if grandparent: grandparent)? • Help you feel like a partner in your child’s care? • Explain things in a way you can understand? • Show respect for your family’s values, customs, and how you prefer to raise your child? <p>In the last 12 months, did (child’s) doctors or other health care providers:</p> <ul style="list-style-type: none"> • Ask you if you ever feel depressed, sad, or have crying spells? • Ask if you have concerns about (child’s) learning, development, or behavior? • Give you specific information to address these concerns [about (child’s) learning, development or behavior]? <p>In thinking about all of the care provided from (child’s) doctors or health providers in the last 12 months, how helpful has it been in the following areas:</p> <ul style="list-style-type: none"> • Understanding (child's) behavior? • Learning how to protect (child) from injuries? • Giving you the information you needed when you needed it? • Learning how to meet your own needs while caring for (child)? 	<p>CAHPS Health Plan Survey 5.0</p> <ul style="list-style-type: none"> • Doctor listened carefully to respondent • Doctor showed respect for what respondent had to say • Doctor spent enough time with child 	<p>CAHPS Chronic Condition Supplement</p> <ul style="list-style-type: none"> • Parents' experiences with getting needed information about their child's care (composite) • Family-centered care (composite) • Parents' experiences with shared decision-making (composite) • Does your child’s personal doctor understand how these medical, behavioral, or other health conditions affect your child’s day-to-day life? • Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your family’s day-to-day life? <p>In the last 6 months:</p> <ul style="list-style-type: none"> • Did your child’s doctor or other health provider talk with you about the pros and cons of each choice for your child’s treatment or health care? • When there was more than one choice for your child’s treatment or health care, did your child’s doctor or other health provider ask you which choice was best for your child? 	<p>Pediatric Integrated Care Survey</p> <ul style="list-style-type: none"> • Family impact (composite) • Care team members (CTMs) treated family as a full partner • CTMs took the whole family into account 	<p>Title V NOM (Data from NSCH)</p> <ul style="list-style-type: none"> • Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite)
<p>Foundational Standard 2: All services and supports for CYSHCN are implemented and delivered in a culturally</p>	Applicable Measures					
<p>The National Survey of Children’s Health</p> <ul style="list-style-type: none"> • Children who received family-centered care (composite) • Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) 	<p>PHDS-PLUS</p> <ul style="list-style-type: none"> • Family-centered care that respects, listens to, and partners with parents (composite) • Provision of written or other types of health information to parents on caring for their child, 	<p>CAHPS Health Plan Survey 5.0</p> <ul style="list-style-type: none"> • Enrollees’ rating of their health care • Doctor explained things in a way that 	<p>FECC, PQMP</p> <ul style="list-style-type: none"> • Caregiver has access to medical interpreter when needed 	<p>Title V NOM (Data from NSCH)</p> <ul style="list-style-type: none"> • Percent of children with special health care needs (CSHCN), ages 0 through 17, 	<p>Title V NPM (Data from NSCH)</p> <ul style="list-style-type: none"> • Percent of children with and without special health 	

<p>competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.</p>	<ul style="list-style-type: none"> • Effective care coordination among those who needed care coordination • Doctors helped parents feel like partners in child's care • Doctors listened carefully • Doctors provided information specific to parents' concerns • Doctors showed sensitivity to family's values and customs • Doctors spent enough time with children 	<p>preventing injuries, and ensuring optimal development (composite)</p> <p>In the last 12 months, how often did (child's) doctors or other health care providers:</p> <ul style="list-style-type: none"> • Take time to understand the specific needs of (child)? • Explain things in a way you can understand? • Show respect for your family's values, customs, and how you prefer to raise your child? 	<ul style="list-style-type: none"> • was easy to understand • Doctor explained things in a way that was easy for child to understand • Doctor spent enough time with child • How often were the forms from your child's health plan easy to fill out? 	<ul style="list-style-type: none"> • Written visit summary was useful and easy to understand • Invited to join hospital rounds • Written hospitalization summary was easy to understand 	<ul style="list-style-type: none"> • who receive care in a well-functioning system (composite) • Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling 	<ul style="list-style-type: none"> • care needs having a medical home (composite)
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<p>Foundational Standard 3: Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.</p>	Applicable Measures						
	<p>The National Survey of Children's Health</p>	<p>PHDS-PLUS</p>	<p>CAHPS Health Plan Survey 5.0</p>	<p>CAHPS Chronic Condition Supplement</p>	<p>Pediatric Quality Measures Program</p>	<p>Title V NOM (Data from NSCH)</p>	<p>Title V NPM (Data from NSCH)</p>
	<ul style="list-style-type: none"> • Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) • Adequacy of current insurance coverage (composite) • Consistent and adequate insurance coverage (composite) • Type of health insurance at time of the survey • Health insurance status at time of survey • Children who had consistent health insurance coverage during the past 12 months • Children who were not covered by health insurance due to change in parent's employment status • Dropped health insurance coverage because it was unaffordable • Dropped health insurance coverage because benefits were inadequate • Dropped health insurance coverage because choice of health care provider was inadequate • Child was not covered by insurance due to problems with application or renewal process • Child was not covered by insurance due to other reasons • Children whose family member(s) avoided changing jobs because of concerns about maintaining health insurance • Family had problems paying for child's medical or health care bills • Current insurance out-of-pocket expenses are reasonable • Unmet need for health care due to cost • Out-of-pocket payment for child's health care including medical, dental and vision care during the past 12 months • Current insurance benefits meet children's needs • Current insurance coverage allows children to see needed providers • Insurance coverage for mental or behavioral health care • Family frustrated in efforts to get services for their children during the past 12 months • Doctors have discussed future insurance needs, age 12-17 years 	<p>Why didn't (child) receive care for [type of care]? Was it because...</p> <ul style="list-style-type: none"> • You could not afford it or had no health insurance? • You had no doctor to go to for (child)? • (Child's) doctor had no one to refer (child) to? • Insurance did not cover the visit? <p>[Did you get care later than you would have liked because...]</p> <ul style="list-style-type: none"> • You could not afford it or had no health insurance? • You had no doctor to go to for (child)? • (Child's) doctor had no one to refer (child) to? • Insurance did not cover the visit? 	<ul style="list-style-type: none"> • Health plan customer service (composite) • Rating of health plan 	<ul style="list-style-type: none"> • Access to prescription medicines 	<ul style="list-style-type: none"> • Duration of first observed enrollment • Duration of newborn's first enrollment 	<ul style="list-style-type: none"> • Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite) • Percent of children without health insurance 	<ul style="list-style-type: none"> • Percent of children ages 0 through 17 who are adequately insured (composite)

Domain 1:
Identification,
Screening,
Assessment,
and Referral

Applicable Measures					
National Survey of Children's Health	CAHPS Health Plan Survey 5.0	Pediatric Quality Measures Program	Title V NOM (Data from NSCH)	CMS Annual Medicaid EPSDT Participation Report	NewSTEPS
<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) Doctor asked about parental concerns about the child's learning, development, or behavior, age 0-5 years 	<ul style="list-style-type: none"> Doctor talked about how child feeling, growing, or behaving 	<ul style="list-style-type: none"> Pediatric Medical Complexity Algorithm Children with Disabilities Algorithm 	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite) 	<ul style="list-style-type: none"> Screening ratio Total eligibles referred for corrective treatment Total eligibles receiving any dental services Total eligibles receiving preventive dental services Total eligibles receiving dental treatment services Total eligibles receiving a sealant on a permanent molar tooth Total eligibles receiving diagnostic dental services Total number of screening blood lead tests 	<ul style="list-style-type: none"> Percent of disorders detected by newborn screening with a confirmed diagnosis by an appropriate medical professional Percent of missed [newborn screening] cases, reported by disorder

Screening

Applicable Measures								
PHDS-PLUS	CMS Child Core Set	HEDIS	HEDIS, CMS Child Core Set	FECC, PQMP	Title V NPM (Data from NSCH)	CMS Annual Medicaid EPSDT Participation Report	NewSTEPS	
<ul style="list-style-type: none"> Anticipatory guidance and parental education provided by doctors or other health care providers (composite) Assessment of parent concerns about child learning, development, and behavior and provision of specific information for parents with concerns (composite) Provision of written or other types of health information to parents on caring for their child, preventing injuries, and ensuring optimal development (composite) <p>In the last 12 months did (child's) doctors or health providers:</p> <ul style="list-style-type: none"> Have you fill out a survey or checklist about concerns you may have had about (child's) learning, development, or behavior? Have you fill out a survey or checklist about activities that (child) may be able to do such as certain physical tasks, whether (child) can draw certain objects, or ways (child) can communicate with you? Ask you if you or someone in your household smokes? Ask you if you or someone in your household drinks alcohol or uses other substances? Ask you if you have any firearms in your home? Talk with you about the kinds of behaviors you can expect to see in (child) as he/she gets older? Tell you that they were doing an assessment or test of your child's development? Talk with you about things you can do to help (child) grow and learn? Ask you if you ever feel depressed, sad, or have crying spells? 	<ul style="list-style-type: none"> Dental sealants for 6–9 year-old children at elevated caries risk Developmental screening in the first three years of life Percentage of eligibles who received preventive dental services Audiological diagnosis no later than 3 months of age 	<ul style="list-style-type: none"> Annual dental visit Lead screening in children 	<ul style="list-style-type: none"> Childhood immunization status (composite) Immunizations for adolescents (composite) Weight assessment and counseling for nutrition and physical activity for children/adolescents Well-child visits in the first 15 months of life Well-child visits in the third, fourth, fifth, and sixth years of life Adolescent well-care visits 	<ul style="list-style-type: none"> Electronic health record has immunization and medication information 	<ul style="list-style-type: none"> Percent of children, ages 9 through 35 months, receiving a developmental screening using a parent-completed screening tool 	<ul style="list-style-type: none"> Total eligibles receiving at least one initial or periodic screen 	<ul style="list-style-type: none"> Timeliness of newborn screening activities (composite) Percent of eligible newborns not receiving a newborn screen, reported by dried blood spot or point of care screen(s) Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional) with the newborn screening program 	

Referral	<ul style="list-style-type: none"> • Ask if you have concerns about (child's) learning, development, or behavior? • Give you specific information to address these [behavior] concerns? • Test (child's) learning and behavior? 							
	Applicable Measures							

	National Survey of Children's Health	PHDS-PLUS	Pediatric Quality Measures Program	FECC, PQMP	IDEA Child Count
	<ul style="list-style-type: none"> • Problems getting needed referrals, all children 	<ul style="list-style-type: none"> • Follow-up for children at risk for developmental, behavioral, or social delays (composite) <p>In the last 12 months did (child's) doctors or health providers do any of the following...</p> <ul style="list-style-type: none"> • Refer (child) to another doctor or other health provider? • Refer (child) for speech-language or hearing testing? 	<ul style="list-style-type: none"> • Follow-up referral after positive developmental screen • Follow-up referral tracking • Follow-up with patient's family after developmental screening 	<ul style="list-style-type: none"> • Care coordinator assisted with specialist service referrals 	<ul style="list-style-type: none"> • Number and percent of infants and toddlers receiving early intervention services under IDEA, Part C, by age and state. • Number and percent of at-risk infants and toddlers birth through 2 receiving early intervention services under IDEA, Part C, by race/ethnicity and state.

	Applicable Measures	
Domain 2: Eligibility and Enrollment in Health Coverage	National Survey of Children's Health	CAHPS Health Plan Survey 5.0
	<ul style="list-style-type: none"> • Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) • Unmet need for health care because child was not eligible • Family frustrated in efforts to get services for their children during the past 12 months • Child was not covered by insurance due to problems with application or renewal process • Insurance coverage for mental or behavioral health care 	<ul style="list-style-type: none"> • Health plan customer service (composite) • Rating of health plan • Customer service gave necessary information/help • Customer service was courteous and respectful • In the last 6 months, how often were the forms from your child's health plan easy to fill out?

Domain 3: Access to Care	Applicable Measures						
	National Survey of Children's Health	PHDS-PLUS	HEDIS, CMS Child Core Set	CAHPS Health Plan Survey 5.0	CAHPS Chronic Condition Supplement	PICS	Title V NOM (Data from NSCH)
	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) Current insurance benefits meet children's needs Children who were not able to receive needed health care in the past year Children who were not able to receive needed mental health services during the past 12 months Children who were not able to receive needed medical care during the past 12 months Unmet need for health care because the service this child needed was not available in their area Unmet need for health care because there were problems getting an appointment Unmet need for health care because there were problems with getting transportation or child care Unmet need for health care because child was not eligible Unmet need for health care because the office was not open when the child needed care Unmet need for health care due to cost Family frustrated in efforts to get services for their children during the past 12 months Family had problems paying for child's medical or health care bills Children who received any type of medical care during the past 12 months Children who had one or more preventive medical care visits during past 12 months Time with doctor during last preventive check-up 	<ul style="list-style-type: none"> When (child) needed care right away for an illness or injury, how often did (child) get this care as soon as you wanted? In the last 12 months (For children younger than 12 months, since child's birth) was there any time that (child) needed health care but did not get it? <p>Why did (child) need health care? Was it for a...</p> <ul style="list-style-type: none"> Regular or routine visit? A medical problem or concern? A behavioral problem or concern? A speech and/or language problem or concern? For another reason? <p>Why didn't (child) receive care for [type of care]? Was it because...</p> <ul style="list-style-type: none"> You could not afford it or had no health insurance? You had no doctor to go to for (child)? (Child's) doctor did not consider it a problem? (Child's) doctor had no one to refer (child) to? You had transportation/childcare problems? Problems related to work? Insurance did not cover the visit? Doctor's schedule was full/no free appointments? <p>Did the lack of health care for (child's) medical problem ...</p> <ul style="list-style-type: none"> Create concerns about (child's) future development? Create problems for (child) attending day care? Create problems for you and/or your spouse/partner meeting work responsibilities? <ul style="list-style-type: none"> In the last 12 months (For children younger than 12 months, since child's birth) was there any time that (child) received care, but got the care later than you would have liked? <p>Why did (child) need health care? Was it for a...</p> <ul style="list-style-type: none"> Regular or routine visit? A medical problem or concern? A behavioral problem or concern? A speech and/or language problem or concern? For another reason? <p>Why was (child's) care for [type of care] delayed?</p> <ul style="list-style-type: none"> You could not afford it or had no health insurance? You had no doctor to go to for (child)? (Child's) doctor did not consider it a problem? (Child's) doctor had no one to refer (child) to? You had transportation/childcare problems? Problems related to work? Insurance did not cover the visit? Doctor's schedule was full/no appointments? <p>Did the delay in health care for (child's) medical problem ...</p> <ul style="list-style-type: none"> Create concerns about (child's) future development? Create problems for (child) attending day care? Create problems for you and/or your spouse/partner meeting work responsibilities? 	<ul style="list-style-type: none"> Children and adolescent's access to primary care practitioners (composite) 	<ul style="list-style-type: none"> Getting needed care (composite) Getting care quickly (composite) Child got non-urgent appointment as soon as needed Child got care for illness/injury as soon as needed Easy for child to get necessary care, tests, or treatment Have a personal doctor 	<ul style="list-style-type: none"> Access to prescription medicines Did anyone from your child's health plan, doctor's office, or clinic help you get your child's prescription medicines? In the last 6 months, how often was it easy to get special medical equipment or devices for your child? Did anyone from your child's health plan, doctor's office, or clinic help you get special medical equipment or devices for your child? 	<ul style="list-style-type: none"> Delays: lack of sufficient services 	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite)

Access to specialist providers

Applicable Measures

National Survey of Children's Health	CAHPS Health Plan Survey 5.0	CAHPS Chronic Condition Supplement	FECC, PQMP	Title V NOM (Data from NSCH)
<ul style="list-style-type: none"> Received care from a specialist doctor other than a mental health professional during the past 12 months Problem obtaining specialist care among those who received or needed a specialist care during the past 12 months Children who received treatment or counseling from a mental health professional during the past 12 months, age 3-17 years Problems obtaining mental health care among those who received or needed care, age 3-17 years Children who were not able to receive needed vision care during the past 12 months Children who were not able to receive needed dental care during the past 12 months Children who were not able to receive needed hearing care during the past 12 months Children who were not able to receive needed other health services during the past 12 months 	<ul style="list-style-type: none"> Respondent got child an appointment with specialists as soon as needed 	<ul style="list-style-type: none"> Access to specialized services (composite) In the last 6 months, how often was it easy to get this therapy for your child? Did anyone from your child's health plan, doctor's office, or clinic help you get this therapy for your child? In the last 6 months, how often was it easy to get this treatment or counseling for your child? 	<ul style="list-style-type: none"> Care coordinator assisted with specialist service referrals 	<ul style="list-style-type: none"> Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling

Domain 4: Medical Home

Applicable Measures

National Survey of Children's Health	PHDS-PLUS	CAHPS Health Plan Survey 5.0	CAHPS Chronic Condition Supplement	PQMP	Title V NOM (Data from NSCH)	Title V NPM (Data from NSCH)
<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN) receiving care in a well-functioning system (composite) Children who receive coordinated, ongoing, comprehensive care within a medical home (composite) Children whose families are partners in shared decision-making for their optimal health (composite) Children who received family-centered care (composite) Doctors discussed range of health care/treatment options Doctors helped parents feel like partners in child's care Doctors listened carefully Doctors made it easy for parents to raise concerns or disagree with recommendations Doctors provided information specific to parents' concerns Doctors showed sensitivity to family's values and customs Doctors spent enough time with children Doctors worked with parents to decide together health care/treatment options Time with doctor during last preventive check-up Family frustrated in efforts to get services for their children during the past 12 months Children who were not able to receive needed health care in the past year Children who were not able to receive needed other health services during the past 12 months Unmet need for health care because child was not eligible 	<ul style="list-style-type: none"> Family-centered care that respects, listens to, and partners with parents (composite) Provision of written or other types of health information to parents on caring for their child, preventing injuries, and ensuring optimal development (composite) Anticipatory guidance and parental education provided by doctors or other health care providers (composite) Helpfulness of care provided to parents (composite) Do you have one person you think of as your child's personal doctor or nurse? <p>In the last 12 months:</p> <ul style="list-style-type: none"> How often did (child's) doctors or other health providers take time to understand the specific needs of (child)? How often did (child's) doctors or other health providers respect you as an expert about (child)? How often did (child's) doctors or other health providers build your confidence as a parent (if grandparent: grandparent)? How often did (child's) doctors or other health providers help you feel like a partner in your child's care? How often did (child's) doctors or other health providers explain things in a way you can understand? How often did (child's) doctors or other health providers show respect for your family's values, customs, and how you prefer to raise your child? <p>In thinking about all of the care provided from (child's) doctors or other health providers in the last 12 months, how helpful has it been in the following areas:</p> <ul style="list-style-type: none"> Understanding (child's) behavior? Learning how to protect (child) from injuries? Giving you the information you needed when you needed it? 	<p>Doctor explained things in a way that was easy to understand</p>	<p>Family-centered care (composite)</p>	<ul style="list-style-type: none"> Follow-up referral after positive developmental screen Follow-up with patient's family after developmental screening Developmental screening follow-up: follow-up referral tracking 	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite) 	<ul style="list-style-type: none"> Percent of children with and without special health care needs having a medical home (composite)

	<ul style="list-style-type: none"> Unmet need for health care because the office was not open when the child needed care Unmet need for health care because the service this child needed was not available in their area Unmet need for health care because there were problems getting an appointment Unmet need for health care because there were problems with getting transportation or child care Number of hospital emergency room visits for any health reason in the past 12 months 	<ul style="list-style-type: none"> Learning how to meet your own needs while caring for (child)? <p>In the last 12 months did you see or hear any information about the following:</p> <ul style="list-style-type: none"> Safety information, such as how to make your house and car safe for (child) Health care information, such as when and how often (child) should see the doctor or reminders about immunizations Developmental information, such as things you can do with (child) to help (him/her) grow and learn 					
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Medical Home Management

Applicable Measures

CAHPS Health Plan Survey 5.0	PICS	FECC, PQMP
<ul style="list-style-type: none"> How well the child's doctors communicate (composite) 	<ul style="list-style-type: none"> Care team members (CTMs) had access to same medical record 	<ul style="list-style-type: none"> Caregiver has access to medical interpreter when needed Electronic health record has immunization and medication information Caregiver has access to electronic health record Appropriate written visit summary content Appropriate written hospitalization summary content Written visit summary was useful and easy to understand Child has shared care plan Child has emergency care plan

Preventative, Primary and Specialty Care

Applicable Measures

National Survey of Children's Health	PHDS-PLUS	HEDIS	HEDIS, CMS Child Core Set	CAHPS Health Plan Survey 5.0	CAHPS Chronic Condition Supplement	Title V NPM (Data from NSCH)	Title V NOM (Data from NSCH)
<ul style="list-style-type: none"> Children who received any type of medical care during the past 12 months Children with a personal doctor or nurse Usual source for sick care Usual source for preventive care Children who had one or more preventive medical care visits during past 12 months Children who had time alone with health care provider at last preventive visit, age 12-17 years Received care from a specialist doctor other than a mental health professional during the past 12 months Children who received treatment or counseling from a mental health professional during the past 12 months, age 3-17 years Problems obtaining mental health care among those who received or needed care, age 3-17 years Children who received any type of dental care during the past 12 months, age 1-17 years Children who had one or more preventive dental care visits during the past 12 months, age 1-17 years Children who were not able to receive needed dental care during the past 12 months Children who received vision screening ever (0-5 years)/ during the past 2 years (6-17 years) Children who were not able to receive needed vision care during the past 12 months 	<ul style="list-style-type: none"> Percent of children with a mental/behavioral condition who receive treatment or counseling 	<ul style="list-style-type: none"> Annual dental visit Lead screening in children 	<ul style="list-style-type: none"> Childhood immunization status (composite) Immunizations for adolescents (composite) Follow-up after hospitalization for mental illness 	<ul style="list-style-type: none"> Rating of specialist Have a personal doctor Rating of personal doctor Easy for child to get necessary care, tests, or treatment Child got non-urgent appointment as soon as needed 	<ul style="list-style-type: none"> Composite: access to specialized services Did anyone from your child's health plan, doctor's office, or clinic help you get your child's prescription medicines? 	<p>Percent of children, ages 1 through 17 who had a preventive dental visit in the past year</p>	<ul style="list-style-type: none"> Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling

Care Coordination	<ul style="list-style-type: none"> Children who were not able to receive needed hearing care during the past 12 months 				
	Applicable Measures				
	National Survey of Children's Health	PHDS-PLUS	CAHPS Chronic Condition Supplement	PICS	FECC, PQMP
	<ul style="list-style-type: none"> Effective care coordination, all children (composite) Family needed extra help to coordinate child's health care Family gets help with coordinating child's health care among those who needed Got all needed extra help with care coordination Time spent coordinating health care for child in an average week Effective care coordination among those who needed care coordination Satisfaction with communication among child's doctor and other health care provider Health care provider communicated with child's school, child care provider, or special education program Satisfaction with communication among child's doctors and school, child care provider, or special education program Children who needed a referral to see any doctors or receive any services Problems getting needed referrals, all children 	<ul style="list-style-type: none"> Coordination of care for children requiring multiple types of health care services or seeing more than one health care provider (composite) In the last 12 months, did anyone from your child's doctor's office or clinic help coordinate your child's care among these different providers or services? 	<ul style="list-style-type: none"> Coordination of care and services (composite) In the last 6 months, did you need your child's doctors or other health providers to contact a school or daycare center about your child's health or health care? In the last 6 months, did anyone from your child's health plan, doctor's office, or clinic help coordinate your child's care among these different providers or services? 	<ul style="list-style-type: none"> Communication with care team members (CTMs) (composite) Care goal creation/planning (composite) Team functioning/quality (composite) CTMs explained things in understandable manner Family comfortable voicing concerns with CTMs CTMs listened carefully to what family had to say CTMs treated family as a full partner CTMs discussed things that cause family stress CTMs discussed things that made it hard to care for child CTMs took the whole family into account CTMs considered "big picture" CTMs offered other than in-person communication CTMs offered peer connections CTMs created short-term care goals CTMs created long-term care goals CTMs knew about advice from other CTMs CTMs aware of tests and evaluations CTMs assigned and explained responsibility CTMs followed through on responsibilities 	<ul style="list-style-type: none"> Has care coordinator Access to care coordinator Care coordinator contact in the last 3 months Care coordinator assisted with specialist service referrals Care coordinator helped to obtain community services Care coordinator asked about concerns and health changes Care coordinator asked about progress towards goals Care coordinator was knowledgeable, supportive and advocated for child's needs Health care provider communicated with school staff about child's condition

Domain 5:	Applicable Measures				
Community-Based Services and Supports	The National Survey of Children's Health	CAHPS Chronic Condition Supplement	FECC, PQMP	Title V NOM (Data from NSCH)	IDEA Child Count
	<ul style="list-style-type: none"> Family frustrated in efforts to get services for their children during the past 12 months Children who ever received special education or early intervention plan, age 1-17 years Age started special education or early intervention plan, age 1-17 years Age started receiving special services to meet child's developmental needs such as speech, occupational or behavioral therapy Time spent providing health care at home for child in an average week Family members stopped working/ reduced work hours due to child's health 	<ul style="list-style-type: none"> In the last 6 months, did you get the help you needed from your child's doctors or other health providers in contacting your child's school or daycare? Did anyone from your child's health plan, doctor's office, or clinic help you get special medical equipment or devices for your child? 	<ul style="list-style-type: none"> Care coordinator helped to obtain community services 	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite) Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling 	<ul style="list-style-type: none"> Number and percent of infants and toddlers receiving early intervention services under IDEA, Part C, by age and state Number and percent of at-risk infants and toddlers birth through 2 receiving early intervention services under IDEA, Part C, by race/ethnicity and state

Domain 6: Transitions to Adulthood	Applicable Measures			
	The National Survey of Children's Health	FECC, PQMP	Adolescent Assessment of Preparation for Transition, PQMP	Title V NOM (Data from NSCH)
	<ul style="list-style-type: none"> Children received care in a well-functioning system, age 12-17 years (composite) Youth received necessary services for transition to adulthood, age 12-17 years (composite) Doctor or health care providers worked with youth to gain skills to manage health/health care or understand health care changes at age 18, age 12-17 years (composite) Percent of adolescents, ages 12 through 17, with a preventive medical visit in the past year. Children who had time alone with health care provider at last preventive visit, age 12-17 years Provider discussed shift to adult health care providers if needed, age 12-17 years Doctors have discussed future insurance needs, age 12-17 years Doctor or health care provider actively worked with the child to make positive choices about his/her health, age 12-17 years Doctor or health care provider actively worked with the child to gain skills to manage his/her health and health care, age 12-17 years Doctor or health care provider actively worked with the child to think about and plan his/her future, age 12-17 years Youth currently has an up-to-date written plan to meet specific health goals and needs, age 12-17 years 	<ul style="list-style-type: none"> Child has written transition plan 	<ul style="list-style-type: none"> Counseling on transition self-management (composite) Counseling on prescription medication (composite) Transfer planning (composite) <p>In the last 12 months:</p> <ul style="list-style-type: none"> Did you talk with this [main] provider without your parent or guardian in the room? Did you and this [main] provider talk about you being more in charge of your health? Did you and this provider talk about you scheduling your own appointments with this provider instead of your parent or guardian? How often did you schedule your own appointments with this provider? How often did you and this provider talk about all of your prescription medicines at each visit? Did you and this provider talk about remembering to take your medicines? Did you and this provider talk about you refilling your own prescriptions instead of your parent or guardian? Did you and this provider talk about whether you may need to change to a new provider who treats mostly adults? Did this provider ask if you had any questions or concerns about changing to a new provider who treats mostly adults? Did you and this provider talk about a specific plan for changing to a new provider who treats mostly adults? Did you and this provider talk about how your health insurance might change as you get older? 	<ul style="list-style-type: none"> Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system (composite)

Domain 7: Health Information Technology	Applicable Measures	
	PICS	FECC, PQMP
	<ul style="list-style-type: none"> Care team members (CTMs) had access to same medical record 	<ul style="list-style-type: none"> Electronic health record has immunization and medication information Caregiver has access to electronic health record