Monitoring the Health Status of Hard-to-Serve Children: Lessons for SCHIP Implementation

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Summary

The implementation of the State Children's Health Insurance Program (SCHIP) provides states with an unprecedented opportunity to address the health care needs of some uninsured, "hard-to-serve" children, including migrant children, homeless children, and children with special health care needs. State policymakers need to understand how to measure the quality of care for all children, as required under SCHIP. Further, states with a significant number of hard-to-serve children also need to know how to measure the quality of care for these populations.

More hard-to-serve children will be enrolled in public insurance programs because of the targeted outreach efforts and eligibility expansions. States can learn from the experiences of innovative programs that serve and monitor the quality of services to migrant, homeless, and special needs children. This information can assist state policymakers who are trying to serve these populations under SCHIP.

This *Issue Brief* describes the unique characteristics and conditions of migrant, homeless, and special needs children. It discusses some appropriate quality assurance measures for monitoring the quality of care they receive and highlights projects using these measures.

Quality Monitoring Issues Related to Hard-to-Serve Children

The health care needs of hard-to-serve children frequently differ from those of typical children. For example, children living in certain conditions or having special needs may require more case management or access to specialists. For this reason, different measures may be needed to determine whether hard-to-serve children are receiving appropriate care. For example, the Foundation for Accountability (FACCT) has determined that children with special health care needs (CSHCN) may require disease management indicators, such as indicators for providing appropriate asthma medications for children diagnosed with asthma. Although the health care needs of CSHCN are different from those of migrant and homeless children, it may be important to apply the same consideration to these populations when developing quality assurance measures under SCHIP.

There are many ways to define "quality" in health care. Consumers, providers, and purchasers have different needs and expectations from a health system. The Institute of Medicine defines health care quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and is consistent with current professional knowledge."[1] This broad definition encompasses the elements the health care community deems essential for providing quality care.

States know that providing quality health care is an important investment. Medicaid and SCHIP cover preventive services for children because these services avert more costly treatments for acute and

serious illnesses. Providing appropriate and timely care to CSHCN and migrant and homeless children also helps reduce hospitalizations and emergency room visits, thereby reducing costs to the state.

SCHIP provides states with the opportunity to provide and pay for a comprehensive and consistent package of health services for which the quality of care must be ensured. SCHIP plans submitted to the Health Care Financing Administration (HCFA) contain a variety of quality assurance techniques. HCFA requires states to collect information on certain performance measures, such as the extent to which health coverage has been extended to low-income children, but states may collect information on other measures they deem important. For example, several performance measures, including rates of immunizations, lead screenings, and hospitalizations, are critical for assessing the quality of care for all children. However, the increased incidence and intensity of health problems among migrant, homeless, and special needs children make these measures especially important for assessing the quality of care for hard-to-serve children.

Migrant Children

Children of migrant farmworkers experience unique environmental and cultural influences that can negatively affect their access to health care and the quality of care they receive. [2] As states begin to serve these children under SCHIP, it is important that they understand the characteristics and conditions of this population and the programs measuring and monitoring their health care quality.

Population Characteristics and Conditions

Migrant farmworkers often have limited access to consistent health care systems. Typically, care is provided by local community and migrant health centers, rural health clinics, or migrant clinician networks. Migrant farmworkers move from region to region seasonally, depending on the growing cycles of agricultural products. This geographic mobility raises unique continuity of care issues. Often, there is no medical record that moves with the farmworker family to provide information to the health care providers in the new community.

In addition, some migrant housing is substandard with no or unsanitary indoor plumbing. Migrant workers and their families can be exposed to harmful pesticides in the fields, and sometimes they have no access to toilet facilities or clean water to drink or wash their hands.[3] As a result of their living and working conditions, migrant children can have higher incidences of certain diseases and conditions than their nonmigrant counterparts. Lead poisoning, tuberculosis, baby bottle tooth decay, pesticide exposure, diarrhea, and inappropriate vaccinations are common among children of migrant farmworkers.

- **Lead Poisoning**. Low-income migrant families are at greater risk for lead poisoning because of housing and plumbing that do not adhere to current lead safety standards. In addition, many of these children visit family in other countries where environmental lead levels are not regulated. For example, other sources of lead exposure for migrant children include Mexican candies, dishes, and home remedies made from lead-based ingredients.

- **Tuberculosis**. Tuberculosis (TB) plagues migrant farmworkers and their families for several reasons, including the transient nature of their work, their sometimes overcrowded living conditions, and the TB problems endemic to their countries of origin. Some studies suggest that migrant farmworkers are approximately six times more likely to develop TB than the general population.[4] TB treatment must occur for a long period, and it is difficult to monitor patient compliance with medication therapy and preventive measures given the frequency of farmworker relocation.

- **Baby Bottle Tooth Decay**. Baby bottle tooth decay, a condition indicated by the severe decay of infants' and toddlers' primary teeth, is a significant problem among migrant farmworker families. Cultural practices, such as putting babies to bed with a bottle of juice, and language barriers, such as providers not being able to communicate with parents in their native language to warn them of

the dangers of these practices, are factors contributing to the prevalence of this condition. In addition, migrant farmworkers often live in areas without fluoridated water, which exacerbates the problem.

- **Pesticide Exposure.** Migrant children often are exposed to pesticides. They come in contact with these dangerous chemicals by touching pesticide residue as well as through breathing air, drinking water, and eating food that has been contaminated. Pesticide exposure can cause respiratory problems, skin and eye irritations, systemic poisoning, and even death. It also can cause birth defects, neurological problems, and cancer.
- **Diarrhea and Parasitic Infections.** Children of migrant farmworkers often experience severe diarrhea and parasitic infections as a result of their living and working conditions. Clinicians who treat migrant children report increased incidences of tapeworms and lice.
- **Uneven Rates of Immunizations.** Immunization levels for migrant children are extremely uneven. Clinicians report that because of inconsistent care, these children often are overimmunized or underimmunized.

Providers who regularly treat migrant children see these conditions consistently. However, mainstream providers may not be as familiar with some of the unique health problems of migrant families. Therefore, it is important to examine the health care quality assurance methods used by those providers most closely associated with this population.

Interventions and Performance Indicators

Given the cultural and lifestyle differences between migrant children and typical children, helping migrant children meet even standard quality measures requires much work and coordination among providers. More case management, parent education, tracking efforts, and language services are needed to help migrant children achieve positive health outcomes.

The programs that serve migrant children measure quality using a combination of standard indicators for child health and specific measures for this population. Although most children receive lead screenings, it is especially important to track this measure for migrant children given the high incidence of lead poisoning in the population. TB testing is common in these programs, as is tracking for baby bottle tooth decay.

Quality Measurement Initiatives

The following initiatives serve the children of migrant farmworkers and have quality assurance measures to assess the quality of care they receive. State policymakers could examine these programs' approaches when planning to serve and assess health care quality for migrant children under SCHIP.

- **CHAMPS Quality Assurance Measures.** The Mountain/Plains Clinical Network, in association with the Community Health Association of Mountain/Plains States (CHAMPS) and the federal Bureau of Primary Health Care, developed pilot measures to assess the quality of care provided by community and migrant health centers. The measures include indicators for immunizations, TB, and oral health. The Montana Migrant Council, an organization serving migrant families in Montana, uses these measures to assess quality.

  The CHAMPS measures are used to determine which patient charts will be selected for quality assurance checks. This system applies a stricter standard for migrant children's charts. It requires that quality indicators be checked for migrant children who have had only one visit to the clinic. Given the transient nature of the migrant farmworker population, this check seeks to ensure that clinicians are providing as many essential services as possible during a single visit. Quality indicators are checked for nonmigrant children who have had three or more visits to the clinic.

  Another major difference between the measures for migrant and nonmigrant children is the use of TB testing as an additional measure for the migrant population. The CHAMPS measures cite the rising incidence of TB in this population as the reason clinicians should document administering

the pure protein derivative test for children ages six and older who have had at least one well-child visit to the migrant health center.

The CHAMPS measures also address oral health care needs, requiring clinicians to document efforts to verify the fluoridation status of the migrant water supply. The measures also require clinicians to document efforts to educate parents about oral health in patient charts.

Contact: Montana Migrant Council, 3318 Third Avenue North, Suite 100, Billings, Montana 59101, 406/248-3149 (phone), 406/245-5636 (fax).

- **Keystone Health Center Quality Assurance Measures.** The Keystone Farmworker Health Program in Chambersburg, Pennsylvania, uses standard pediatric quality indicators and some population-specific measures to assess the quality of care. At the beginning of the agricultural season, these quality measures are recorded in the charts of the migrant farmworker patients. Providers are instructed to review the charts at each visit and check the quality indicators.

  Like the CHAMPS measures, the Keystone Health Center measures require clinicians to document not only standard child health indicators, such as immunizations, but also to document efforts to educate parents about health concerns, such as baby bottle tooth decay. These measures also require clinicians to document that a fluoride assessment was completed and that a fluoride supplementation was prescribed, if necessary. Similar to the CHAMPS measures, the Keystone Health Center measures require a TB test for migrant children.

  Contact: Keystone Health Center, 151 Cedar Street, Chambersburg, Pennsylvania 17201, 717/263-4013 (phone), 717/263-4056 (fax).

- **East Coast Migrant Head Start Project Measures.** Based in Arlington, Virginia, the East Coast Migrant Head Start Project (ECMHSP) targets children of migrant farmworkers who travel and work on the east coast. The project serves approximately 8,620 migrant children from birth through age five in Alabama, Delaware, Florida, Georgia, Maine, Maryland, New Jersey, New York, North Carolina, Pennsylvania, South Carolina, and Virginia.

  Similar to other programs that serve migrant children, ECMHSP tracks standard children's health quality measures, such as immunizations, vision, and hearing. Health screenings are completed for all children in accordance with Head Start performance standards, including anemia screening, TB screening for children older than twelve months, lead screening, dental screening, and developmental screenings. Based on its experience with the health problems of migrant children, ECMHSP specifically follows the indicators for lead poisoning, TB, dental screenings to identify baby bottle tooth decay, and speech and hearing screenings to diagnose ear infections.

  To address the needs of this mobile population, ECMHSP completes a continuity record for each child enrolled in the project as soon as the staff become aware that his or her family will be leaving the community. The portable record contains the child's immunizations, health screening results, and developmental screening results. The family can give the record to health care providers or school personnel in the new community.

  Contact: East Coast Migrant Head Start Project, 4200 Wilson Boulevard, Suite 740, Arlington, Virginia 22203, 703/243-7522 (phone), 703/243-1259 (fax).

Homeless Children

Homeless children face dangers in everyday life that can negatively affect their health status. Most homeless children live in extreme poverty in an unstable environment. Their mobile lifestyle means that they often obtain health care from a variety of sources, sometimes with little continuity. Specific characteristics of homeless children dictate certain protocols and quality assurance indicators for their treatment.

Population Characteristics and Conditions

Homeless children experience more illnesses than housed children, including ear and skin infections, upper-respiratory infections, and gastrointestinal problems because of unsanitary food and water. Asthma and anemia are especially prevalent among homeless children because of their living conditions and sporadic food supply. The effects of living on the street or in temporary shelters contribute to the higher levels of behavioral problems, developmental delays, depression, anxiety disorders, and psychosis seen in this population. Many homeless children live in fragmented family units and experience abuse and neglect. Similar to migrant children, homeless children often are overimmunized or underimmunized. Providers who treat homeless children also report many cases of sexual abuse among homeless children. Among homeless adolescents, clinicians see increased cases of substance abuse, pregnancy, and sexually transmitted diseases (STDs).

Interventions and Performance Indicators

Providers often must provide additional services to ensure that homeless children achieve the same health outcomes as housed children. These services include extensive outreach, case management, transportation and translation services, immunization followup, and care coordination. Frequently, the services must be provided through mobile units.

Immunizations, lead screenings, and TB screenings are especially important for homeless children, as they are for migrant children. Measures that track asthma, anemia, and hepatitis B virus (HBV) status also are useful in monitoring health care quality for homeless children.

Quality Measurement Initiatives

The following initiatives serve homeless children and have quality assurance measures to assess the quality of care they receive. State policymakers could include some of these measures in their SCHIP performance goals for homeless children.

- **Dallas Children's Health Project.** The Dallas Children's Health Project in Texas uses two forty-foot-long mobile medical units to provide basic health care and services crucial to the homeless population. Because it is often difficult for homeless families to fill prescriptions at conventional pharmacies, the mobile medical units also distribute medications to increase the likelihood that prescribed treatments will be followed.

  The project uses a quality assurance protocol for children and adolescents that was developed by Parkland Health and Hospital Systems' quality assurance department. For children from birth to age four, the measures tracked are immunizations; HBV status; well-child examinations; hearing screenings; anemia screenings, including anemia education and nutrition; and asthma education. For the adolescent population, the quality assurance measures include asthma; injury prevention; STD assessment, including intervention and education; assessment and counseling for nicotine, alcohol, and drugs; first-trimester prenatal care; and pap smears.

  Contact: Dallas Children's Health Project, 6269 Harry Hines Boulevard, Suite 405, Dallas, Texas 75235, 214/590-0153 (phone), 214/630-6489 (fax).

- **Center for the Vulnerable Child Immunization Project.** The Center for the Vulnerable Child (CVC) in California provides coordinated care to homeless children and those at risk of becoming homeless. One significant difference between this project and mainstream providers is that CVC provides case management to participating children and their families to help them achieve standard health outcomes.

  CVC conducted a pilot study to examine the appropriateness of certain outcome measures, such as immunization rates for homeless and at-risk children. The study found that immunization rates are important quality of care indicators for homeless children. However, significant interventions, including case management, are needed to achieve appropriate immunization rates. For this reason, indicators that measure interventions also are important for this population.

Contact: Center for the Vulnerable Child, Children's Hospital Oakland, 747 Fifty-second Street, Oakland, California 94609-1809, 510/428-3783 (phone), 510/601-3913 (fax).

Children with Special Health Care Needs

Children with special health care needs are those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who require more health and related services than are typically required by other children. CSHCN also often require more and unique services from the health care system.

Population Characteristics and Conditions

Given their complex conditions and the amount of contact most CSHCN have with the health care system, it is very important that they have access to appropriate and adequate care and that system interactions are satisfactory. FACCT has identified a need for specific quality of care measures for children who live with chronic illness. Disease-specific measures (e.g., peak flow rates for asthma patients) may be difficult to develop for less common chronic ailments (e.g., spina bifida). However, some measures, such as access to specialists, would apply across illnesses for CSHCN.

CSHCN have frequent contacts with the health care system. Providers must help families learn to manage illness and use services, such as emergency rooms, appropriately. Relationships between parents and providers must be open, and parents must feel comfortable with their providers' responses to their questions and concerns.

Interventions and Performance Indicators

More research has focused on quality assurance for CSHCN than on quality assurance for migrant or homeless children. This research suggests that both standard quality measures and population-specific measures are appropriate. However, the health care needs of CSHCN are significantly different from those of migrant and homeless children. For example, CSHCN have frequent contacts with the health care system, so locating these children is not a problem. Children with special health care needs may need special equipment or tests to help them manage their illnesses. Because of these differences, population-specific quality assurance measures do not necessarily apply across populations. Measures such as access to specialists, appropriate management of chronic illness, unplanned hospitalizations, and family satisfaction with care could be included in SCHIP performance objectives.

State Title V programs can be very important in monitoring the quality of care for CSHCN.[5] Congress requires these programs to report on key maternal and child health indicators. They have data and analytical expertise that can be used for performance measurement and other information required for federal reports and evaluations. The federal Maternal and Child Health Bureau (MCHB) has developed eighteen performance measures, many of which address the needs of CSHCN and quantify the degree to which CSHCN have access to needed services. The measures address insurance levels for primary and specialty care, access to specialty and subspecialty services, and the percent of CSHCN who have a "medical/health home."[6] States could use these measures for assessing quality under SCHIP. They also could use their Title V agencies, which currently have responsibility for evaluating and coordinating care for CSHCN, to coordinate SCHIP performance measures for CSCHN.

Quality Measurement Initiatives

The following initiatives serve children with special health care needs and have quality assurance measures to assess the quality of care they receive. State policymakers could examine these programs' approaches when planning to serve and assess health care quality for CSHCN under SCHIP.

- **Quality Community Managed Care for CSHCN—University of Illinois at Chicago.** Using Title V block grant funds from the Maternal and Child Health Bureau, the Quality Community Managed Care (QCMC) project developed a quality assurance model that addresses the needs of CSHCN. The model, which uses two sets of measures, can be used to monitor the well-being of CSHCN in managed care plans or monitor services funded by state CSHCN programs. The first set

of measures was developed by QCMC and incorporates indicators such as the rate of unplanned hospitalizations for children served, the proportion of parents reporting that their child's health status improved in the last year, and the proportion of children referred to services who received those services. The second set of measures is a subset of the Medicaid Health Plan Employer Data and Information Set (HEDIS) measures. It was developed by the National Committee for Quality Assurance and determined relevant for children and youth. Examples of these measures are average total cost of prescriptions per member per month and vaccine-specific and combined immunization rates for two-year-olds.

The QCMC measures are organized by topical area, as are the HEDIS measures. The QCMC guide explains various options for using QCMC measures alone or in combination with the Medicaid HEDIS measures. It also explains how to use only the HEDIS measures to better assess the quality of care for CSHCN.

Contact: Quality Community Managed Care for Children with Special Health Care Needs, The University of Illinois at Chicago, Division of Specialized Care for Children, 1919 West Taylor Street, Eighth Floor (M/C 618), Chicago, Illinois 60612-7255, 312/996-6380 (phone), 312/413-0367 (fax).

- **"Purchaser's Tool"—Children's Hospital, Columbus, and Ohio State University, Department of Pediatrics.** "Evaluating Managed Care Plans for CSHCN: A Purchaser's Tool" is a tool to assist purchasers in selecting health plans that include coverage for children. Although this tool could be used by purchasers of health insurance for all children, it was designed specifically to ensure that the special needs of children with chronic health conditions are addressed. The "Purchaser's Tool" contains specific measures that a purchaser can use to better understand health plans' coverage for children. These measures include the type of pediatric services covered, the cost-sharing requirements of the plan, the capacity of the plan's pediatric provider network, and the plan's approach to quality management. The tool can be used by all types of purchasers, including employers, government agencies, and families. The "Purchaser's Tool" was developed through a grant from the federal Maternal and Child Health Bureau to the Children with Special Health Care Needs Continuing Education Institute at Children's Hospital in Columbus, Ohio, and the Department of Pediatrics of The Ohio State University.

  Contact: Institute for Child Health Policy, 5700 SW Thirty-fourth Street, Suite 323, Gainesville, Florida 32608, 352/392-5904 (phone), 352/392-8822 (fax), info@ichp.edu (e-mail), http://www.ichp.edu (web site).

Policy Implications for SCHIP

Through SCHIP, states will be providing health insurance to a large number of uninsured children. They also must report their progress on quality of care indicators. Because some of the children covered under the program will come from migrant, homeless, and special needs populations, states should be aware of the additional performance measures needed to adequately assess the quality of care for these hard-to-serve populations (see table).

Additional Performance Measures for Hard-to-Serve Children

Performance Measure	Migrant Children	Homeless Children	Children with Special Health Care Needs
Lead Screening	✔	✔	✔
Immunizations	✔	✔	✔
Unplanned Hospitalizations for Ambulatory Sensitive Conditions	✔	✔	✔
Asthma Condition		✔	✔
Tuberculosis Testing	✔	✔	
Hepatitis B Status		✔	
Baby Bottle Tooth Decay Condition	✔		
Anemia Screening		✔	
Access to Specialists			✔
Family Satisfaction with Care			✔

Providers of health care for migrant and homeless children routinely screen for and treat conditions not common among patients of mainstream providers, including TB, lead poisoning, HBV, HIV, asthma, gastroenteritis and dehydration, and pesticide exposure. SCHIP administrators should be aware of these conditions so they can address them in the quality measures applied to hard-to-serve populations.

CSHCN generally do not experience the environmental dangers that migrant and homeless children do, so efforts to measure the quality of care for CSHCN should focus on different measures. Parent and patient satisfaction with care and the use of appropriate providers to manage illness are especially important for this population. Title V programs have primary responsibility for CSHCN. SCHIP administrators should coordinate with the Title V program to monitor quality for CSHCN under SCHIP. For example, New Hampshire's SCHIP plan specifies that the state Title V bureau will coordinate care and funding for CSHCN enrolled in SCHIP.

Some states have included specific quality measures in their SCHIP plans that are particularly relevant for migrant, homeless, and special needs children. For example, Illinois' SCHIP plan contains measures for childhood lead poisoning and hospitalizations for gastroenteritis and asthma. These measures could apply to migrant and homeless children as well as children with special health care needs. Georgia's SCHIP plan speaks to decreasing the use of emergency departments for nonemergency services, minimizing preventable hospitalizations, and promoting the appropriate use of health care services by children with asthma. Similarly, Ohio has focused evaluation efforts on the appropriate treatment of asthma under its SCHIP plan.

The Wisconsin Medicaid Eligibility for Migrant Farmworkers program seeks to make it easier for the children of migrant farmworkers to receive Medicaid. The program allows state workers to automatically enroll in the program any children of migrant farmworkers who have Medicaid cards issued by other states. States interested in meeting the needs of migrant children could replicate this program for SCHIP.

Considerations for State Policymakers

Information from earlier efforts to monitor the quality of care for migrant children, homeless children, and CSHCN can guide SCHIP implementation efforts. Programs targeting hard-to-serve populations have used their quality assurance data to identify areas that need improvement as well as focus attention and resources on the sometimes unique health care problems of these populations. Their experiences suggest that most standard quality measures are appropriate for hard-to-serve populations. However, additional population-specific measures are needed to adequately assess the quality of care they receive. Further, extensive outreach, case management, translation services, and mobile clinics are extremely important to help providers meet even the most common outcome measures.

State policymakers can use the experience of programs that monitor health care quality for hard-to-serve populations as they develop their SCHIP quality assurance plans. Many of the measures deemed important for hard-to-serve populations could be easily incorporated into a performance measurement plan for SCHIP. By monitoring the quality of health care for these populations early on, states can identify and address areas that need further attention and resources. Addressing these areas sooner will produce savings from reduced emergency room use for ambulatory services, reduced unplanned hospitalizations for chronic conditions, and reduced hospitalizations for conditions that could have been treated earlier on an outpatient basis.

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[1]Institute of Medicine, ed. by Kathleen N. Lohr, *Medicare: A Strategy for Quality Assurance, Volumes I and II* (Washington, D.C.: National Academy Press, 1990).

[2]See the web sites of the National Center for Farmworker Health, Inc., at http://www.ncfh.org and the Migrant Clinicians Network at http://migrantclinician.org for more information on the characteristics and conditions of migrant farmworker families.

[3]Dianne Itterly, memorandum to author, 5 June 1998; and Gary Huang, *Health Problems Among Migrant Farmworkers' Children in the United States* (Charleston, W. Va.: Clearinghouse on Rural Education and Small Schools, 1993).

[4]M. F. Goldsmith, "As Farmworkers Help Keep America Healthy, Illness May Be Their Harvest," *Journal of the American Medical Association 261* (1989): 3207–13.

[5]The Maternal and Child Health Services Title V Block Grant to States program is a federal-state partnership to improve the health and well-being of mothers and children.

[6] For more information on the Maternal and Child Health Bureau measures, see http://www.hhs.gov/hrsa/mchb/guidance.htm#titlev. See also http://www.hhs.gov/hrsa/mchb/.