Measuring Preventive Health Performance

A Primer for Child Advocates on the Medicaid EPSDT Reporting Form

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Introduction

Since 1990, state Medicaid programs have been required to use a uniform reporting form to report on their Early and Periodic Screening, Diagnosis and Treatment programs (EPSDT), Medicaid's mandatory benefit for children and youth under age 21, using a uniform reporting form. The Form is commonly called the "Form 416," and it can play an important role in policy-based advocacy to improve children's health.

In 1999, the form was significantly revised. Advocates should become acquainted with the Form and their state's reporting under it.

This primer provides background on the requirements for EPSDT and EPSDT reporting, explains the revisions to the 416 Form, and suggests ways that the Form can aid in advocacy efforts.

Important Terms Used in this Primer

EPSDT Early and Periodic Screening, Diagnostic and Treatment, a mandatory Medicaid service which consists of informing, screening, diagnosis and treatment of physical and mental conditions. EPSDT is mandatory for beneficiaries under age 21.

CMS The Centers for Medicare & Medicaid Services, formerly known as the Health Care Financing Administration (HCFA). The agency within the Department of Health and Human Services which administers the Medicaid program.

Form 416 The uniform reporting form that CMS requires states to use when reporting their rates of screening of Medicaid beneficiaries under 21.

Medicaid Waivers Optional state programs which allow states to "waive" specific federal Medicaid requirements.

Section 1115 Waivers A waiver that allows states to establish demonstration programs to provide services or cover individuals not covered by Medicaid or the State Children's Health Insurance Program.

Medically Needy A category of Medicaid eligibility covering those who have characteristics similar to other beneficiaries, but whose income or resources are too high to qualify. These individuals are allowed to incur medical expenses in order to qualify for Medicaid. This is an optional Medicaid eligibility group.

CPT Codes "Current Procedural Terminology" codes, used by providers for billing purposes.

Background

Medicaid is the single most important source of health insurance for children:

Medicaid and Children: Facts and Figures

- ➤ More than 21 million children in the United States one in five were enrolled in Medicaid in 2000 and more than half of Medicaid enrollees are children.
- ➤ Children account for only 17 percent of Medicaid spending
- Per capita costs for children are the lowest among eligible groups (\$1,225 in 1998, compared to \$11,235 per elderly enrollee).
- ➤ Medicaid primarily covers children in working families, not children in families receiving cash assistance.
- ➤ Medicaid covers 78 percent of poor children under age 5 with disabilities and 70 percent of poor children aged 5 to 17 with disabilities. Medicaid covers 40 percent of near-poor children under age 5 with disabilities and 25 percent of near poor children aged 5 to 17 with disabilities.
- ➤ Medicaid pays for 30 percent of all pediatrician visits, 38 percent of child hospitalizations and 40 percent of all childbirths.
- ➤ More than 80 percent of the low-income uninsured children are eligible for coverage under Medicaid (60 percent) or the State Children's Health Insurance Program (24 percent).

Sources: Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Resource Book*, (July 2002) and *Children's Health: Why Health Insurance Matters* (May 2002) *at* http://www.kff.org. The David and Lucille Packard Foundation, *Health Insurance for Children: Analysis and Recommendations*, 13 THE FUTURE OF CHILDREN (Spring 2003).

All Medicaid-eligible children need EPSDT services

Poverty is dangerous. Low socio-economic status carries with it numerous by products – poor nutrition, fewer educational opportunities, greater exposure to environmental hazards and inadequate housing, to name just a few. All of these disadvantages increase the likelihood that a poor child will be in poor health. Indeed, children living in poverty, particularly children of color, are more likely than other children to suffer from ill health, including vision, hearing and speech problems, dental health problems, skin lesions, elevated blood levels, sickle cell disease, behavioral health problems, anemia, asthma and pneumonia.

Early detection and treatment can avoid or minimize the effects of many of these childhood conditions. For this to occur, however, policy makers designing health insurance options offered to families with children must recognize that the health care needs of children and youth differ from those of adults and that more efforts must be made to provide poor children with health care services. Indeed, children pass numerous health and developmental milestones that must be assessed on time; if problems are not diagnosed promptly, the benefits of treatment may be lost forever. Moreover, children increasingly may experience health problems that cut across physical, mental, developmental and psychosocial domains, for example, family and neighborhood violence or drug and alcohol problems. Thus they may require a range of services: comprehensive assessment, case management, mental health care or rehabilitative therapies.

Early detection and treatment underlie the entire EPSDT program. Moreover, the EPSDT treatment package is comprehensive and broad precisely because, unlike private insurance, it is designed to cover poor children and children with special health care needs.

The EPSDT benefit is comprehensive and targeted to the eligible population

EPSDT is a comprehensive medical, vision, hearing, and dental screening and treatment program for Medicaid-eligible children and youth under age 21. Medical screenings must include

five elements: (1) health and developmental history, (2) unclothed physical exam, (3) lab tests, (4) immunizations, and (5) health education. These screening services must be offered at pre-set, periodic intervals (periodic screens) and when a problem is suspected (interperiodic screens). The federal government does not set these periodicity schedules. Rather, states are directed to use standards of the American Academy of Pediatrics.

The treatment component of EPSDT must include any health care, diagnostic services, treatment and other measures described in the Medicaid Act needed to "to correct or ameliorate" physical and mental illnesses and conditions, regardless of whether such services are covered for adults in the state's Medicaid program. EPSDT also includes outreach and informing to notify children and their families of EPSDT and the importance of preventive care, and to offer appointment scheduling and transportation assistance, if needed.

Serving children through EPSDT is a primary objective of the Medicaid Act.

How are we doing?

States are required to report on EPSDT

Since 1989, the Medicaid Act has required states to report annually, by age group and basis of eligibility for Medicaid:

- > the number of children receiving screening services;
- the number of children referred for corrective treatment:
- > the number of children receiving dental services;
- the state's results in obtaining participation goals set by the Secretary of the Department of Health and Human Services.

The Medicaid Act also requires the HHS Secretary to develop and set annual participation goals for each state for rates

of participation of children in EPSDT. In 1990, the HHS Secretary established that, by fiscal year 1995, each state should be providing at least 80 percent of EPSDT recipients with timely medical screens.

According to CMS, states are to report EPSDT compliance on the Form 416 and to submit the completed Form to CMS by **April 1** of each year. The information on the Form serves to:

- demonstrate the state's attainment of participant and screening goals; and
- show trend patterns and projections from which decisions and recommendations can be made to ensure that eligible children receive the best possible health care.

The 1999 Revisions

In 1999, CMS revised the Form 416 significantly. A copy of the Form is included as Attachment A.

On the positive side, the revised form:

- > adds age groupings;
- > expands reporting on dental services; and
- > requires reporting on lead blood tests.

On the more negative side, the form:

- allows states to use their own periodicity schedules for purposes of reporting;
- does not distinguish managed care enrollees from fee-for-service enrollees;
- > no longer collects separate information on vision and hearing screens; and
- does not include reporting cells for mental health screens or referrals.

The remainder of this Primer reviews the changes in detail and discusses the pros and cons associated with them.

Advocacy Tip

Obtain copies of the past year's Form 416 from your state. You should also be able to obtain county-by-county information for even more in-depth review. If needed, for assistance, contact the National Health Law Program.

An in-depth look at the Form

Age groupings

Prior to 1999, the Form 416 had required states to use four age groupings when reporting EPSDT information. <1 year, 1-5 years, 6-14 years, and 15-20 years. The new Form requires states to use seven age groupings:

<1 1-2 3-5 6-9 10-14 15-18 19-20

These changes could be of great benefit. For example, such reporting can assist states to better target age-appropriate outreach activities to improve screening rates.

Determining a child's age group

Under the old form, the child's age grouping was determined as of March 31st of the federal fiscal year being reported. The new Form instructs states to report the child's age as of September 30th of the fiscal year.

This change has potentially important consequences. With the exception of children born on October 1st, all children and youth are two different ages during any one federal fiscal year

(Oct. 1st-Sept. 30th). The reporting form, however, only reports the child in one age category. If the child's advance in age causes the child to change age groups (e.g., from ages 15-18 to ages 19-20), then the state must assign the child to one of the two potential age groupings. Under the old form, the method was to split the difference and to look at how old the child was on March 31st, the halfway point in the fiscal year. This meant that if a child were eligible for the full fiscal year, she would be placed in the age grouping in which she spent the majority of the year. The new form, however, looks at how old the child is on September 30th, the last day of the fiscal year. As a result, all children will be placed in the higher age group, even if they spent the majority of the year in the younger age grouping. This change is also notable because it will affect comparison of data collected before and after fiscal year 1999. Advocates should take these limitations into account when evaluating the data.

Illustration

An infant is born on August 1st and remains Medicaid-eligible for ten months. Using the September 30th reporting date, the infant will be counted in the age 1-2 group, even though he will be less than one during all or the vast majority of his period of eligibility. This change could inflate screening results. Under the federal periodicity schedule, a child under age one is expected to receive a screen six times during the first year. After age one, the expected number of screens goes down. By placing the child in an older age grouping, the state can provide substantially fewer screens while still increasing its screening rates.

States are allowed to exclude certain groups of children from reporting. To understand the implications of this exclusion, it is necessary for advocates to know some basic facts about Medicaid eligibility and Medicaid services.

Recipients of Medicaid can be divided into three groups: (a) mandatory categorically needy; (b) optional categorically needy and (c) medically needy. Federal law requires states to provide Medicaid to the mandatory categorically needy, while coverage of the optional categorically and medically needy is optional.

The mandatory categorically needy qualify automatically because they fit into a specified group of low-income families and children or low-income aged, blind or disabled individuals. For many years, most of the mandatory categories were linked to receipt of cash assistance. Increasingly, and particularly in the wake of the welfare "reforms" of the mid-1990's, the program has become delinked from cash assistance. Eligibility now often depends on income level, however, vestiges of the historical linkage to Aid to Families with Dependent Children (AFDC) program persist. For example, individuals who would have qualified for AFDC before it was abolished are mandatory categorically needy, as are children between ages 6 and 19 with family incomes below 100 percent of the poverty level. Also, in most states, individuals who receive Supplemental Security Income (SSI) are mandatory categorically needy.

The optional categorically needy may also have low incomes but, for one reason or another, may not qualify for a federal cash benefit. Others may have higher incomes than the categorically needy. States may choose to cover some of these individuals. For example, states may choose to cover aged, blind or disabled individual who do not receive SSI, but have incomes below 100% of the poverty level. Also, states can choose to cover pregnant women and infants with incomes up to 185 percent of the poverty level.

The medically needy are individuals who fit into a federal benefit program category, such as the aged blind or disabled, or pregnant women, but have higher incomes the categorically needy. These individuals may deduct medical bills until their income reaches a certain low level. States must offer EPSDT to the categorically needy, but do not have to offer it to the medically needy.

States may also offer experimental, pilot or demonstration projects which may assist in promoting the objectives of Medicaid. Known as Section 1115 Waivers, after the section of the Social Security Act which authorizes them, these programs provide increased access to health services for uninsured individuals. These individuals are known as "expansion populations."

The old Form instructed states to exclude medically needy children from their reporting if the state did not offer EPSDT to the medically needy. The revised Form tells states to exclude the following additional groups:

- children eligible only under an 1115 demonstration waiver as part of an expanded group for which the full complement of EPSDT services is not available:
- undocumented aliens eligible only for emergency services; and
- other groups "eligible for only limited services as part of their Medicaid eligibility (i.e., pregnancyrelated services)."

Advocacy Tip

Advocates should obtain clarification of how states are counting child Medicaid beneficiaries and be monitoring implementation of this change.

State periodicity schedules

The previous Form 416 required states to use the screening periodicity schedule recommended by the American Academy of Pediatrics to complete the form. On the revised Form, states can report according to their own state-developed periodicity schedules.

This change raises a number of issues. First, the Form does not indicate that, for immunizations, the state must use the schedule established by the Advisory Committee on Immunization Practices. More importantly, the change frustrates the very purpose of the Form: uniformly tracking patterns and projections for the nation, individual states, and geographic regions. Because each state can use a different periodicity schedule, comparison among states can be more difficult. In addition, if the state chooses not to use the same periodicity schedule during and after fiscal year 1999 as in previous years, it will be difficult to determine the extent to which performance has improved or deteriorated.

Advocacy Tip

Monitor your state. Compare its periodicity schedules with those of the child health professionals. Here are some helpful web sites:

American Academy of Pediatrics: Recommendations for Preventive Pediatric Health Care, *available at* http://www.aap.org

American Medicaid Association: Guidelines for Preventive Health Screening, *available at* http://www.ama-assn.org

Bright Futures, available at http://www.brightfutures.org

American Academy of Pediatric Dentistry, *available at* http://www.aapd.org

American Dental Association, available at http://www.ada.org

Reporting using CPT codes

The revised Form adds a provision allowing states to use certain listed CPT codes or state-specific EPSDT codes as a proxy for the EPSDT medical screen. The listed codes are CPT-4 codes for preventive medical services; thus, sick visits or episodic visits are not to be reported unless an initial or periodic exam also was performed during the visit.

This change may have been made to accommodate managed care organizations and states who are using the "Form 1500" claim form. This claim form bases reporting on CPT codes and, along with its commercial counterpart, is increasingly being used by insurance companies. Managed care organizations have complained that EPSDT reporting asks them to submit data they do not ordinarily collect.

Unfortunately, nothing in the CPT codes or on the Form 1500 reveals whether all five of the mandatory components of the EPSDT medical screen have been provided (that is, a health and developmental assessment, unclothed physical examination,

immunizations, laboratory tests, and health education). However, CMS has stated that use of these proxy codes is for reporting purposes only and has reiterated that states must continue to ensure that all five age-appropriate elements of an EPSDT screen are provided to EPSDT recipients.

Advocacy Tip

Advocates should contact their states to find out whether the state is allowing CPT reporting and, if so, what steps are taken to assure effective and routine monitoring of the five screening elements.

Screening ratio

The screening ratio indicates the extent to which EPSDT-eligible children receive the number of initial and periodic screening services required by the state's periodicity schedule, adjusted by the proportion of the year for which they are Medicaid eligible. Using the previous reporting form, some states showed screening ratios in excess of 100 percent. CMS has indicated that, if states submit data that exceeds 100 percent, in the final report it will be reflected as 100 percent.

This change will certainly minimize the appearance of faulty data. Capping rates in this manner, however, will not increase the accuracy of the reported data. First, if reported rates of greater than 100 percent are inaccurate, there is no reason to presume that the actual rate is 100 percent. Second, there should be recognition that rates higher than 100 percent are possible. For example, states may attempt to screen all children regardless of their length of eligibility. This type of effort recognizes that many EPSDT-eligible children have undiagnosed conditions and may not have been screened as frequently as they should have been in the past. In addition to aggressive screening, these states may seek to address the on-again, off-again eligibility of many Medicaid children, which allows children to fall through the cracks. These

states have the potential to achieve screening rates of greater than 100 percent.

Illustration

A state's periodicity schedule calls for screening once every two years for adolescents 19-20 years of age. Eight such adolescents are enrolled in a managed care plan. Suppose the average period of eligibility for this age group is three months. Under the screening rate formula, eight adolescents each enrolled for three months is considered the equivalent of one teenager enrolled for 24 months. [8 teenagers × 3 months = 1 teenager × 24 months]. So, the plan would only need to screen one of the eight teenagers to achieve a screening rate of 100 percent. Suppose, however, that the state requires the managed care plan to screen each EPSDT-eligible child within 90 days of enrollment. If the plan is partially successful in following this requirement and manages to screen six of the eight teenagers, the plan would have a legitimate screening rate of 600 percent.

Vision and hearing assessments

The revised Form **eliminates** reporting for vision and hearing assessments. The only mention of these important screening activities is a reminder to states to include vision and hearing referrals when reporting on the total number of eligible children and youth referred for corrective treatment.

It is not clear why these reporting cells were eliminated from the Form. It could be motivated by a desire to keep the Form to a certain length. It could be because managed care plans were complaining about having to report this information because of the CPT coding. At any rate, CMS has written off monitoring the provision of these two mandatory elements of the EPSDT screen and in so doing has made it more difficult for advocates to monitor EPSDT performance and possibly less likely that children will receive these screens.

Advocacy Tip

Contact your state to ask whether it collects information about vision and hearing screens elsewhere and whether you can obtain the information.

Dental screening

The revised Form requires states to report additional information about the number of children who are receiving dental services. States must report the unduplicated number of children:

- receiving any dental services;
- receiving *preventive* dental services, using American Dental Association (ADA) codes; and
- receiving dental treatment services, using ADA codes.

The inclusion of these additional cells on the reporting Form could serve as an important reminder that children's access to preventive dental care and treatment services is a mandatory part of the EPSDT program and that states' performance in this area will increasingly be an area for federal monitoring and public inquiry.

Referrals for corrective treatment

The revised Form requires states to report the unduplicated number of individuals who were referred for further diagnostic or treatment services, *including* vision and hearing screens.

Previously, referrals for vision and hearing screens were not counted under the number of individuals receiving referrals. As a result of this change, it will be impossible to compare the number and percent of children receiving referrals before and after fiscal year 1999. In addition, the new reporting requirements do not explicitly prevent states from including referrals for dental care in this number. Since referrals for dental care should be part of the medical screen, the inclusion of this information could confuse the number of referrals.

In addition, CMS neglected the opportunity to include a specific line item on mental health referrals. This information would be of great use to advocates and researchers. Instead, such referrals are lumped together with all other conditions, making it impossible to use the Form 416 to track how many children are receiving mental health referrals.

Eligible children in managed care

The Form 416 requires states to report all individuals eligible for EPSDT services in the state who are enrolled in managed care at any time during the reporting year. This reporting is included for "informational purposes only." Children in both capitated and primary care case management entities are to be reported.

However, while the state must report the number of individuals enrolled in managed care, the Form does not require screening rates to be reported separately for managed care versus fee-for-service. This would be critical information for determining which health care delivery arrangements are most successful in providing preventive care.

Blood lead testing

The revised Form 416 requires states to enter the total number of screening blood lead tests furnished to eligible individuals under fee-for-service or managed care arrangements. Blood lead tests performed on persons who have been diagnosed with elevated lead levels or being treated for poisoning are not to be counted. While the addition of this cell is important, it collects only the number of children screened without also asking for the number of children who are identified through the screen as having elevated lead blood levels.

Moreover, as a matter of reporting on the states' performance, CMS is only concerned with lead testing of children under age five. Older children who receive these tests are not counted by CMS, even though the state may report the data.

EPSDT Reporting: Points of Contention

Given the demands being placed on states (and their contractors) by the Medicaid EPSDT laws, it is not surprising that reporting on performance is a source of contention. Complaints by states and managed care organizations about having to provide information and complete the form should **not** cause child

advocates to back away from using this Form aggressively. After all, the completed form is the state's own representation to the federal government of the screening that it is performing. Advocates should, however, be aware of the criticisms, which are summarized in the box below.

- Few states report that they meet the 80 percent participation goal, which they were required to have met in 1995.
- ➤ States and managed care organizations say that the Form 416 under-represents the actual number of children receiving EPSDT services because providers render services that are not recorded.
- Child advocates complain that the Form over-represents the number of children receiving EPSDT services because children are counted as having received a complete screen when they did not receive any or all required medical screening services.
- ➤ When studies have occurred to verify the accuracy of the numbers or to enforce accurate reporting, they have confirmed the low compliance rates reflected on most of the states' Form 416s.

How to Use this Information

Advocates should use the information provided on the Form to monitor their state's success in providing EPSDT to Medicaideligible children. There are many ways in which the Form 416 can be used to help improve health care for children, for instance, to:

- ✓ create new alliances with other advocacy groups, for example, mental health advocates;
- ✓ reach out to health care providers (e.g. pediatricians, pediatric dentists) to advocate for Medicaid improvements;
- ✓ request meetings with state, federal or local policy makers;

- ✓ request that state legislative committees hold hearings on child health;
- ✓ provide information to local health departments and work with them to improve or maintain their services and funding;
- ✓ share the information with the press to educate reporters and editors about child health problems and encourage them to cover child health issues;
- ✓ create linkages with local universities and research organizations to find more evidence about problems;
- ✓ apply for foundation grants to further explore problems, or to help provide health care services to remedy lack of care;
- ✓ advocate for new legislation.

Conclusion

The Form 416 is an essential tool for child advocates. Advocates should make themselves familiar with the Form and their state's data, and how this information can be used to advance the cause of effective child health preventive care.