EPSDT at 40: Modernizing a Pediatric Health Policy to Reflect a Changing Health Care System

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Introduction

This report presents the results of a two-year project that was conducted to consider the continuing role of Medicaid’s Early and Periodic Screening Diagnostic and Treatment (EPSDT) benefit in a changing health care system. This two-part project, coordinated by the Center for Health Care Strategies (CHCS), was made possible through the commitment and funding of the Annie E. Casey Foundation, The Commonwealth Fund, the Robert Wood Johnson Foundation, and the David and Lucile Packard Foundation. During the time period in which this project was undertaken, Congress enacted significant federal Medicaid reforms as part of the Deficit Reduction Act (DRA) of 2006. EPSDT benefits remain guaranteed for Medicaid-enrolled children. At the same time, however, states have new flexibility to make important structural changes that could influence the effectiveness of EPSDT coverage, as well as the ways in which children gain access to these benefits. Many of the issues crystallized by the DRA amendments are the same issues that states have grappled with for years as they have moved to develop managed care systems for children and families, and there is a good deal to be learned from previous experience.

Part I of this report begins with an overview of EPSDT along with an explanation of the DRA as it relates to EPSDT benefits, particularly its formal establishment of “benchmark coverage” as well as a new statutory concept known as EPSDT “wraparound” coverage. The paper first explores current state practices in implementing EPSDT in managed care, since building effective managed care systems, which can involve the creation of interconnected primary and specialty coverage arrangements, in many ways parallels the DRA amendments. In these states, the EPSDT benefit often functions as a series of coverage “tiers” with most coverage offered as a basic (or primary) managed care service and others offered either by specialty plans or furnished directly by state programs. This current approach to “benefit tiering” offers important insights with respect to the concept of “wrapping around” plans offered by “benchmark issuers” as contemplated under the DRA.

Part II of the report synthesizes the work of a wide range of experts and practitioners who formed several task groups organized by CHCS. CHCS and its funders were committed to obtaining input from a broad range of experts, ranging from Medicaid officials to day care and Head Start providers, to pediatricians, and managed care organizations. They identified promising approaches to EPSDT modernization that take into account Medicaid’s evolution as a purchaser of health benefit and service products. Based on the analysis, the report outlines a series of recommendations both for EPSDT administration generally, as well as for ensuring proper coordination between EPSDT and early childhood development and child care programs. Many of these recommendations reflect experiences with EPSDT administration in a managed care context.

The report concludes with a discussion of the opportunities and challenges that lie ahead in modernizing EPSDT, both in states that use managed care purchasing arrangements and in states that move toward greater use of DRA flexibility to create benchmarks and
tiers. For 40 years, EPSDT benefits have provided a critical set of services for Medicaid-enrolled children. With an impending change in administration in the coming year coupled with the current recessionary fiscal pressures on states, the opportunities to enhance EPSDT coverage are significant. We hope that the information herein supports Medicaid stakeholders in rethinking the delivery, financing, and evaluation of EPSDT benefits to improve health care services for Medicaid-eligible children across the nation.
Part I: The EPSDT and the DRA

Historical Basis and Continuing Importance

Enacted in 1967, EPSDT amendments were part of a broader effort to improve pediatric health care quality and the capacity of the health care system to identify, assess, and treat children with early signs of physical and mental health conditions that could affect growth and development.¹ Health services research findings from both early Head Start demonstration² and the health exams of young Vietnam War draftees³ served as the basis for coverage reform, which represents the single most important public policy effort ever undertaken to define an appropriate health services coverage standard embedded in developmental pediatric practice.⁴ Over the years, a series of bipartisan Congressional reforms have expanded EPSDT benefits still further. As a result of Medicaid eligibility expansion reforms, EPSDT benefits now reach more than 25 million low-income children,⁵ and states have new options to extend this special coverage to children with serious disabilities in moderate-income families.⁶

EPSDT has remained a central component of Medicaid, because of the operational and financial capacity it gives states to create appropriate pediatric health care systems. EPSDT’s strength as a pediatric health care funder is the result of not only its broad benefits but also its use of a developmental standard of medical necessity, which remains as relevant today as it was 40 years ago. Indeed, in enacting EPSDT following Medicaid’s original enactment, Congress sought to elevate Medicaid coverage standards for children above what otherwise might have been a more traditional insurance-like norm. Although its long term care coverage surpasses anything found in private health insurance, Medicaid, like most insurers, generally emphasizes medical interventions to cure acute symptoms, rather than preventive health interventions to achieve growth and development. Whereas preventive coverage is an option for adults, EPSDT makes preventive services a requirement for eligible children.

⁴ “Crossing the Medicaid-Private Health Insurance Divide,” op. cit.
A substantial, robust body of epidemiological and clinical evidence regarding pediatric health risk and treatment standards underscores EPSDT’s continuing importance. Taken together, this evidence supports several key conclusions:

- First, as acute health conditions in children have declined, the relative importance of serious and chronic health conditions, and risks for such conditions, has grown. Additionally, research into chronic illness in adults has shed new light on approaches to managing child health in order to avert long-term consequences. Today, a significant proportion of children live with chronic illnesses such as asthma, autism, sickle cell disease, or cystic fibrosis. Other conditions such as obesity and its attendant physical and mental health consequences, or the effects of conditions of birth that might have claimed children’s lives a generation ago, are also a reality in modern pediatrics. Taken together, these chronic conditions account for the majority of pediatric hospitalizations and health care spending.

- Second, the health care system has improved its capacity to detect, treat, manage, and reduce the impact of (if not eliminate) chronic physical and mental conditions that affect development and to do so in ways that mitigate their developmental effects.7

These advances in pediatric research also have served to focus attention on the importance of both high-performing primary health care as well as regionalized specialty health care systems capable of providing seamless support. These advances in pediatric health research also have important implications for funding pediatric health care, given the link between health care financing and the receipt of appropriate preventive services.8 Furthermore, the implications of this research are particularly important for low-income children, who face the most significant health risks.

Key Components of EPSDT

EPSDT can best be thought of as the pediatric component of Medicaid. The EPSDT service is essentially a bundled benefit governed by a pediatric coverage standard and supported by a series of administrative services. The EPSDT benefit definition contains both classes of items and services, as well as a preventive standard of medical necessity that is directly embedded in the definition. The benefit classes span the entire spectrum of health care for children, from primary pediatric to advanced, while the medical necessity definition, which applies to all aspects of coverage, specifies the provision of “early” services that “correct or ameliorate” both physical and mental health conditions found as a result of “comprehensive” assessments.9

Its breadth and depth make EPSDT benefits particularly important because they finance not only preventive and acute care but also early intervention into potentially long term and serious physical, mental, and developmental conditions, even before they become acute and symptomatic. EPSDT standards also ensure that coverage limits in the case of children are tied to evidence of necessity rather than being fixed and limited as is often the case for private health insurance or Medicaid coverage for adults. States can — and indeed must — assure that health care for children is medically necessary, but EPSDT coverage limits are capable of expanding to meet the needs of children who need extensive care to ameliorate the effects of serious and chronic health conditions. It is because of this breadth and flexibility that Congress included in the DRA a state option to extend Medicaid to moderate-income children with disabilities whose private health insurance coverage is inadequate to meet their needs.

EPSDT coverage begins at birth with periodic and interperiodic (i.e., as needed) assessments that are geared to measure growth and development and are detailed in their content. EPSDT also covers all classes of diagnostic and treatment services that fall within the federal definition of “medical assistance”, as well as comprehensive vision, dental and hearing services that are also structured to ensure early identification, correction, and amelioration. Figure 1 (on the following page) shows the core elements of the EPSDT benefit and special medical necessity standard, as well as state administration obligations.

9 42 U.S.C. §1396d(r).
Figure 1. Core EPSDT Elements

Health Care Benefits

- Periodic assessments of children’s growth and development in accordance with accepted pediatric assessment standards, including:
  - Unclothed physical exam including a nutritional assessment;
  - An assessment to determine a child’s overall physical, mental, and developmental health (the developmental assessment);
  - Health history;
  - Laboratory services as needed, including assessment of blood lead levels;
  - Immunizations in accordance with the recommendations of the Advisory Committee on Immunization Practices; and
  - Anticipatory guidance.
- Interperiodic (as needed) assessments.
- Comprehensive vision, dental and hearing services in accordance with reasonable professional standards.
- All medically necessary diagnostic and treatment items and services that fall within the definition of medical assistance.
- A preventive standard of medical necessity that specifies “early” coverage to “correct or ameliorate” physical and mental conditions in children.
- Coordination with related programs.

State Administrative Support Services

- Information about EPSDT and the value of preventive health care.
- Provision of scheduling and transportation to families who request services in order to ensure the timely provision of care.
- Provision of reports to the United States Department of Health and Human Services regarding the number of children receiving screening and dental services, the number of children referred for corrective treatment, and the state’s results in attaining federally set participation goals.

Although the Medicaid statute itself describes EPSDT benefits with particularity, federal agency interpretive guidance regarding its meaning and uses is limited. The United States Department of Health and Human Services has not revised the federal EPSDT regulations since 1984, despite important benefit expansions enacted in 1989 and far-reaching changes in Medicaid program requirements and practice, particularly the advent of health care purchasing as a Medicaid operational norm. (Although the DRA may somewhat alter the manner in which coverage may be achieved in the case of children, the DRA does not alter the reach of the 1989 reforms.) Nor has the federal government issued comprehensive interpretive guidance taking into account not only

10 42 C.F.R. §441.56 et seq.
changes in the structure of EPSDT benefits but also the changing context of their delivery.11

The evolution of EPSDT has also coincided with equally important changes in other systems that are responsible for child development, particularly early childhood education, child care, and early intervention programs for children with developmental delays and disabilities. When EPSDT was enacted in 1967, the Head Start program was three-years-old, and young children at all income levels overwhelmingly remained at home with their families until entering public school. Today a substantial proportion of low-income children under the age of five spend a portion of each week in some form of out-of-home child care arrangement or early childhood development program. Thus, as pediatric health care has evolved, so has the broader child development landscape in which health care is furnished.

Yet despite these changes, there exists no Centers for Medicare and Medicaid Services (CMS) guidance that explains how Medicaid’s EPSDT benefits can help support effective developmental health care services for children in child care settings. Examples of effective services that involve “mutual reinforcement” between child care services and the health care system include health, developmental, vision, dental, and hearing examinations offered in child care settings, anticipatory health guidance counseling for individual families, and referral arrangements between child care providers and children’s health care providers in the case of children who are exhibiting signs and symptoms that may suggest early physical, mental, or developmental delay.

The absence of federal agency guidance has added to the challenges of EPSDT administration over the years. These challenges can be categorized as follows:

- Developing appropriate coverage limits and utilization management techniques. Because of its preventive purpose and emphasis on “early” health care interventions that “ameliorate” the full range of “physical and mental conditions” that may affect children, EPSDT sets the broadest coverage standard within Medicaid of any source of child health financing. At the same time, by law Medicaid pays only for care that is medically necessary. Thus, the challenge is to develop evidence-based coverage standards that are appropriate to pediatric developmental needs and applying those standards in a thoughtful manner, and on the basis of individualized factual information, when the need for care arises in a particular case. Because of the limited attention paid to the development of a robust evidentiary basis for pediatric health care (presumably because children are so inexpensive overall), state efforts to limit coverage – either across the board or in individual cases – tend to fail when challenged. A sizable body of federal caselaw, nearly all of it decided in favor of children, underscores the problems that can arise when states attempt to apply across-the-board treatment limitations, exclusions based on an allegation of the “experimental” status of a proposed treatment, or other form of flat exclusion of certain types of health interventions that fall within the range of professional standards of care.

- Access to primary and specialty care. The broadest coverage standards under law obviously cannot compensate for the shortage of primary health care professionals in medically underserved communities, nor can broad coverage overcome the critical shortage of pediatric health care specialists. Finding pediatric specialists presents major problems across the full spectrum of child health care financing; that is, specialists with the training and skills needed to address complex physical, mental, and developmental conditions in children are frequently in short supply even for affluent families whose children have comprehensive private health insurance. For children who depend on Medicaid, the specialty shortage is far more severe, particularly in the case of children with severe mental illness and developmental delays.

- Weak performance standards. The federal EPSDT statute uses the same performance measures in 2008 that were used nearly 40 years ago: the proportion of eligible and enrolled children who are due for a periodic examination and who in fact receive an exam (with respect to all components including dental care) and are referred for treatment. Superficially this measure makes sense. But there are several problems. First, close inspection of state billing and payment systems shows that states routinely pay health professionals for preventive health care for children, even when treatment is not submitted on an official EPSDT claim form. In other words, much preventive care for children is not captured. This means that the proportion of children receiving at least some preventive care is understated, and states are under-recognized for their efforts to encourage care (indeed, the failure to recognize preventive care outside of the official EPSDT screen means that the very states with the most generous coverage and payment policies may score low when only EPSDT is considered). Most importantly
perhaps, low EPSDT screening numbers create the impression that low income families are poor preventive users of health care, when in fact national probability data from the MEPS and HIS statistical systems show a high use of preventive care among children regardless of family income.

The EPSDT reporting problem also masks serious under-use of certain services. Because not all preventive health care use is considered, it is not possible to ascertain with any certainty whether certain types of procedures – for example lead tests in very young high-risk children or developmental assessments – are under-utilized. In the absence of an electronic health record and the ability to examine the actual provision of care at the record level, special claims analyses would be needed for this type of careful scrutiny of service problem areas.

Finally, of course, screening and referral information does not provide the type of more modern outcome-based measures of health care quality, including measures of quality that have become the focus of performance measurement and reporting. Attachment A, which presents a list of HEDIS and CAHPS child health performance measures available for, and in use by states, shows that states have made extensive efforts to utilize such standards. At the same time, the available measures are small in number in comparison to children’s overall health care needs, and there is no national approach to the stratification of information by race/ethnicity or their comparison to similar measures in the case of privately insured children.

Despite these challenges, EPSDT offers a singular legal standard of coverage and access for low-income children. Even as states struggle to fulfill its mission, EPSDT’s ability to finance early, preventive, and ongoing health care for children at heightened medical and social risk remains unparalleled in public or private health insurance.

**EPSDT and the Deficit Reduction Act of 2006: “Benchmark” and “Wraparound”**

The DRA makes far-reaching changes in federal standards related to eligibility and enrollment, benefit and coverage standards, patient cost-sharing, and the availability of federal funding for state case management activities. One particular aspect of the new law directly relates to EPSDT services because it revises the coverage standards and principles that have guided Medicaid since its earliest days. The DRA gives states the flexibility to provide “alternative” coverage, known as benchmark coverage. The

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12 42 U.S.C. §1396w, added by §6044 of the DRA.
concept of benchmark coverage departs from traditional Medicaid requirements by permitting states, in the case of recognized eligibility groups, to substitute actuarially-determined “benchmark coverage” sold by “benchmark issuers” for Medicaid’s traditional defined benefit style approach to coverage. Actuarial principles are the health spending assumptions and principles that guide commercial health insurance coverage. Low-income Medicaid-enrolled children are included in the eligibility groups for which this benchmark option can be used, thereby aligning Medicaid coverage rules with those used for SCHIP.\(^\text{13}\)

EPSDT coverage principles of course are quite different from commercial insurance and its underlying actuarial assumptions. For example, EPSDT, unlike commercial insurance, contains no exclusions for pre-existing conditions. Furthermore, EPSDT coverage principles do not distinguish between acute conditions (covered by commercial insurance) and serious and long-term conditions linked to developmental problems (typically are excluded from the scope of commercial insurance). Commercial health insurance coverage may extend to certain preventive services, but commercial coverage may also exclude extensive developmental assessment services as well as covered interventions prior to the development of acute symptoms. EPSDT, on the other hand, emphasizes early intervention.\(^\text{14}\) Finally, EPSDT permits no arbitrary limits on the amount, duration, and scope of coverage and requires a preventive standard of medical necessity (“early” treatment to “ameliorate” conditions) in order to achieve early and comprehensive intervention.

The use of benchmarks in lieu of traditional benefits in the DRA thus potentially eliminates the EPSDT benefit with its comprehensive coverage classes, its coverage of chronic as well as acute conditions, and its emphasis on achieving optimal growth and development in children, as well as early intervention to ameliorate physical, mental and developmental conditions. In order to guard against this outcome, the DRA also includes a provision with the intent to clarify the continued EPSDT benefit standard for children, whether as part of the benchmark coverage itself, or otherwise. This clause provides that:

\[A \text{ state at its option may provide for...enrollment in coverage that provides...benchmark coverage...or benchmark equivalent coverage... and...for any child under 19 years of age...wrap-around benefits to the benchmark coverage or benchmark equivalent coverage consisting of early and periodic screening, diagnostic, and treatment services defined in section 1905(r)}\]

\(^{13}\) 42 U.S.C. §1397cc.
\(^{14}\) “Crossing the Divide,” op. cit.
Thus, EPSDT benefits may be offered as part of the benchmark or in the form of a “wraparound” to the benchmark. While there is no implementation guidance, the importance of the retention of the EPSDT coverage standard is underscored by Figure 1A. This figure shows that the vast majority of children with functional limitations who receive Medicaid enroll in the program simply as low-income children. In other words, the vast majority of children at risk for disability and delay and for whom EPSDT’s broad reach was intended, are covered not as disabled children, but simply as low-income children. Their need for early and preventive services is particularly great as a means of ameliorating conditions before they become severe.

Operationalizing the EPSDT standard in a benchmark/wraparound context raises the following important issues:

- Which EPSDT benefits are most compatible with a standard commercial offering that is based on an actuarial benchmark, and which might best be offered as a wraparound, either as direct state-financed coverage or through one or more specialty plans? This is a particularly vexing question, since children with special needs may not require distinct benefit classes of care but instead, more of the recognized benefit classes. Is the proper approach to tiering (or layering) benefits thus to place entire benefit classes outside a standard benefit plan for children? Or is it to design the plan so that standard coverage assumes a more limited use of covered health care classes with a special needs assessment used simply to lift limitations and exclusions that otherwise might apply? This basic question – whether the issue is discrete benefit classes or simply more of a
comprehensive list of benefit classes – can be seen in specific EPSDT benefit examples. Some EPSDT benefits — i.e., coverage of comprehensive health exams, vision, dental and hearing care, full immunizations, anticipatory guidance as part of an office visit, treatment for acute health problems, and at least limited coverage for certain chronic conditions — would appear to be entirely compatible with benchmark coverage. Other treatments — although not the coverage class into which they fall, necessarily — go well beyond the benchmark level. For example, virtually all states treat the EPSDT assessment as a “first tier” level of coverage that would be offered in any benchmark plan. A standard assessment includes a rapid developmental assessment. In this way, EPSDT assessment, along with all Advisory Community on Immunization Practices (ACIP)-required immunizations, become the state’s working definition of a pediatric health exam. This approach ensures that the developmental assessment, comprehensive physical examination, and anticipatory guidance that are the hallmark of the primary and preventive aspect of EPSDT are available as a first-tier matter. This approach to well-child exams assures that these exams also satisfy the EPSDT assessment requirements under federal law. But how about a more extensive diagnostic assessment for a child whose exam suggests the presence of developmental delays and a mental health condition? Is this diagnostic assessment to be considered an entirely separate benefit class and thus covered at a benefit tier that exists outside the benchmark? Or is it simply a more extended and intensive version of a diagnostic professional encounter? In the end, tiering may be best conceptualized as tiered treatments and procedures rather than tiered benefit classes. But however it is conceptualized, a tiering strategy must be developed by health and plan administration professionals who are expert in the operationalization of coverage design.

Thus, deciding which special care benefits appear in or out of which tiers presents the largest challenge. Some states that use managed care require full coverage of service classes included in the contract (i.e., the first tier), while supplementing only by entire service class. For example, a state might entirely exclude a benefit class such as nursing facility care or ICF-MR services, leaving these services in the fee-for-service system (the second tier). Other states might include coverage of all service classes up to a limit, supplementing the first-tier coverage with additional coverage for children whose health needs exceed the level of risk assumed by the plan in the first tier. In this example, more advanced care becomes a form of “re-insurance” to first-tier coverage, with the most advanced needs children served through the second tier.

- How does integration happen (at both the benchmark and wraparound levels) with respect to EPSDT’s medical necessity standard? The same question arises here as in the first bullet. That is, does the same medical necessity standard apply across all coverage tiers? The answer would seem to be “yes,” since although children with special needs may require more care, the needs of all
children would appear to be best evaluated by a preventive standard aimed at the earliest possible amelioration of conditions.

- Perhaps the biggest coverage challenge involves the integration (at both the benchmark and wraparound levels) with respect to the EPSDT “override” of the types of fixed amount duration and scope limits and exclusions that are common in commercial plans, along with integration of the special EPSDT medical necessity test. Here states are quite varied. The most common approach may be to use a broad, ameliorative standard in their contracts, but some states do permit contractors to utilize a more standard commercial definition with additional services that can be considered necessary under the expanded EPSDT definitions furnished on a supplemental basis. Thus, for example, a standard plan may exclude or classify as uncovered and unnecessary speech therapy for children with developmental disabilities, because the need does not arise from an acute condition. This type of coverage is completely available through EPSDT of course. One way to address this issue would be through a broader coverage definition in the contract. Another would be to supplement contract services through a second tier of coverage to which providers gain access via request. The only case to date in which this latter model was tested in a sense showed that providers, even when told that additional services were available, virtually never asked.  

- How are the special coverage rules best explained to parents and caregivers, treating health care professionals and providers, and referring social service and educational providers? The question of family and provider health communication is consistently recognized as critical, yet little has been done to test effective means of communication about coverage tiers for children.

- How can EPSDT’s broad treatment provisions be meshed with the numerous limitations and exclusions found in most forms of private group health coverage that form the actuarial basis for the benchmark system? For example, private dental insurance offered through a benchmark plan may be more limited than EPSDT coverage. Similarly, private insurance often limits or excludes therapy for certain types of mental disorders such as autism, imposes “hard” amount duration and scope limits on physical and speech therapy or prescribed drugs, and excludes coverage for health care needs connected to developmental delays resulting from conditions at birth such as cerebral palsy.

- How can EPSDT’s emphasis on expanded service settings (e.g., schools, child care centers, home services) be integrated into the standard practices of

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benchmark issuers, which typically may emphasize coverage of a relatively narrow range of medical care service providers in medical care settings?

- How should wraparound coverage be implemented? Through a separate application for additional coverage or through automatic enrollment and coverage based on medical need?

- What types of referral systems work best between health care and social service providers, health professionals, and benchmark and supplemental coverage plans (or the state agency) offering wraparound services?

- What types of provider networks best address the needs of children in relation to the effectiveness of care and coverage? All states require managed care contractors to maintain networks capable of furnishing all covered services, although no state requires plans to furnish uncovered services. Presumably in states that supplement plan coverage with second-tier EPSDT coverage, access to these second-tier services would take place either through the network or through out-of-network, Medicaid-participating providers.

- How should coordination between Medicaid-covered and related services take place? Modern Medicaid managed care practice makes use of “memoranda of understanding” that require plans to coordinate their activities with one or more programs and services. Some states identify child care, child development, and early childhood education providers as entities with which plans must coordinate, although states define differently what is meant by coordination.

- What types of quality and performance measures are necessary in order to measure performance and outcomes linked to “benchmark” coverage? Attachment A lists current child health performance measures now in use. Many of these existing measures would permit assessment of the effectiveness of primary preventive services for different categories of children. But special measures would be needed both for EPSDT’s extended wraparound treatments as well as for the extent to which children are linked into and between coverage tiers, as well as the degree to which referral systems are working. Special measures are also needed for children with serious and chronic physical, mental, and developmental conditions that necessitate special treatment interventions over a sustained time period.

It would be possible of course to contract with a health services benefit entity to furnish coverage that fully meets all EPSDT coverage rules and states vary in their approaches to defining EPSDT’s coverage standards into tiers. These issues have never been systematically evaluated, even though answering these questions is critical to preserving effective coverage.
Previous research by George Washington University through its managed care contract studies suggests that some states using managed care arrangements (which raise many of these benefit tiering, performance measurement, and service linkage issues) do, in fact, maintain special contractual standards that require their contractors to ensure children’s access to the full – or nearly full – array of services and treatments contemplated by EPSDT as well as referral for related services. These contracts may utilize varying risk-sharing arrangements that take into account health care costs associated with children and conditions that are considered actuarially unpredictable. Special risk-sharing arrangements may consist of special “stop loss” corridors for certain treatments; alternatively they may entail use of the managed care entity as an administrative services organization for certain treatments, with the costs associated with actual coverage borne by the state.

The challenge, therefore, becomes testing and evaluating approaches to EPSDT benefit tiering that makes use of modern health care purchasing and performance measurement techniques while still preserving full access to effective coverage for all Medicaid eligible children.
Part II: Results of the CHCS EPSDT Modernization Project

In 2005, with funding from the Annie E. Casey Foundation, The Commonwealth Fund, the Robert Wood Johnson Foundation, and the David and Lucile Packard Foundation, CHCS convened a task force of child health and development experts to discuss approaches to EPSDT modernization (see Appendix B). Much of the impetus for these discussions arose out of lessons learned from the state Medicaid managed care experience as well as from state efforts to improve and strengthen child developmental services generally. Following a general meeting, the larger group formed three working sub-groups, each charged with a specific aspect of “modernization:” 1) making coverage work effectively; 2) measuring performance; and 3) integrating Medicaid-covered health services with services essential to child development that are educational or social in nature and that are financed through other non-medical programs.

Although the developmental work carried out by these subgroups preceded the enactment of the DRA, the parallels between EPSDT tiering in Medicaid managed care and the DRA alternative option/EPSDT wraparound are sufficiently strong. In our view, the recommendations developed by the subgroups and outlined herein are pertinent to state decision-making, regardless of the approach taken to Medicaid administration.

Making Coverage Work

If a coverage arrangement utilizes benefit tiering, the most important issues become:

- Identifying, as early as possible, children who are likely to need “upper-tier” services;
- Maintaining an upper tier that is relatively discrete and limited, so that the first tier remains strong, comprehensive, and accessible; and
- Adopting a process that assures a smooth and seamless transition to upper-tier coverage.

In keeping with these principles, the subgroup recommended the adoption of an approach to “first tier” coverage that incorporates a comprehensive assessment of child health, growth and development into the first tier, using relevant and reliable assessment instruments aimed at identification of children with special health care needs (CSHCN), as the term currently is used in the Title V Maternal and Child Health Services Block Grant program:

[...hose [children] who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally; or...
Children who are eligible for services any of the following programs:

a. SSI based on disability, or
b. State Title V programs for Children with Special Health Care Needs, or
c. Children’s Mental Health Services Block Grant, or
d. Parts B or H of IDEA if an Individual Education Plan or Individual Family Service Plan has been put in place, or
e. Developmental Disability Assistance,
f. Section 504 of the Rehabilitation Act or
g. Child Welfare Programs, or
h. Current Medicaid enrollment for categorically or medically needy children, or
i. Current Medicaid enrollment for special needs programs.  

This definition was preferred because it focuses on developmental risk rather than specific underlying diagnoses, thereby aligning with current concepts of pediatric practice and ensuring that coverage limitations that might exist in first-tier coverage will be lifted when child development is at risk, regardless of the nature of the underlying diagnosis.

The identification – at any stage of enrollment – of a child with special health care needs also could serve to automatically trigger the availability of upper-tier coverage, without separate application. That is, no separate application for upper-tier coverage would be needed; instead, the assessment tool would operate as a way of identifying as soon as possible those children who might require greater-than-normal levels of medical and patient support resources. The identification of a child’s special needs status would form the basis for all subsequent coverage decision-making, regardless of whether benefits are first or second tier.

Because the EPSDT benefit reaches children from birth to adulthood, the subgroup placed special emphasis on the use of age appropriate assessment instruments, the application of EPSDT’s existing preventive, developmental, and ameliorative concept of medical necessity to all services regardless of tier, and the consideration of developmental stage when making medical necessity determinations. The subgroup also recommended efforts to operationalize the EPSDT standard into more modern language for use in purchasing agreements. Drawing on published definitions, the subgroup endorsed standards that would ensure that regardless of tier or class of coverage benefit, any coverage determination would take into account the following factors:

a. Whether the proposed covered intervention is intended to promote normal
growth and development and prevent, diagnose, detect, treat, ameliorate, or
palliate the effects of a physical, mental, behavioral, genetic, or congenital
condition, injury, or disability; and

b. Whether the evidence taken as a whole, including clinical experience and
reasonable inferences, the professional opinion of treating and consulting health
professionals, and the patient’s and family’s own experience, values and
preferences, indicates that the proposed intervention can be reasonably expected
to produce the intended results for children and to have expected benefits that
outweigh potential harmful effects.

The consensus of the group was that current concepts of cost-effectiveness bore no
relevance to pediatric coverage decision-making.

With respect to tiering, the consensus was that the proportion of children with special
needs — an estimated 13 percent of all children living in poverty — is sufficiently
small and the need for comprehensive primary preventive and acute coverage is so
important for the vast majority of children that primary emphasis should be given to the
quality of the primary tier. The distinction between the standard and prime coverage
should be based on providing services for children with special health care needs. That
is, the needs of most children in EPSDT will be met through the standard benefit
package. However, a small percentage with special health care needs should receive the
prime benefit as needed. Children may move back and forth between standard and
prime coverage as their situation dictates.

Although the subgroup favored a strong first-tier benefit, they were able to achieve
consensus regarding certain EPSDT treatment benefits that could be reserved for a
second tier. In some cases the distinction was drawn based on duration and tendency:
that is, certain benefits would exist to some extent in the first coverage tier and on a
supplemental basis in the second tier. In other cases, however, services could be reserved
in their entirety for upper-tier coverage because of their intensity, their low prevalence,
and their cost. In other words, while cost effectiveness should not be the deciding factor
in coverage design or decision making for children, the group recognized the importance
of a careful approach to managing higher-cost services. Such services include:

and Services Administration, 2004.

20 Note that we have chosen not to try to change the current federal law and regulation (and lack thereof)
as it relates to medical necessity.
a. Extensive case coordination integrated with a child’s primary care provider and family as required by those with special health care needs;
b. Family support services;
c. Respite care;
d. Extended visits paid with risk-adjusted rates;
e. Transportation not already covered by the standard Medicaid benefit;
f. Enhanced home care services: home health aides, personal care attendant and private duty nursing, skilled nursing visits, etc. intended for maintenance of function or to lessen loss of function or for rehabilitation. Behavioral health in-home services may be accessed in the standard package;
g. Durable medical equipment. Items that assist in activities of daily living, including ambulatory aids or equipment necessary for medical treatment and home management; and
h. Nutritional and enteral products and services.

Measuring Performance

The performance measurement subgroup recommended that the following considerations guide the development and use of performance measures that would focus on preventive and primary health care as well as the treatment of serious conditions that affect children’s growth and development. Overall, the subgroup recommended that the approach and measures should be applicable both to children with typical health care needs and those with special health care needs, with recognition that children with special needs have unique health, social, mental and developmental issues.

- **Clinical Guidance.** The approach should be based on currently accepted clinical and scientific evidence/guidance. The approach should be revisited and revised over time as relevant new clinical and scientific evidence becomes available.

- **Accountability.** The roles and responsibilities for reporting targeted measures should be clearly defined. The system should specify benchmarks for performance on targeted measures, and assure communication of the results of measurement to consumers and purchasers. The approach should be based upon widely accepted measures of good well-child care both for children with typical and special health care needs. The sources of data should be valid and reliable.

- **Health Disparities.** Sampling and data collection for measures should be conducted to make possible robust analysis for subsets of children and youth who traditionally suffer from health disparities and to identify other factors associated with significant disparities to enable monitoring of those disparities and identification of root causes amenable to intervention.

- **Maximize Value to Providers.** The approach should seek to limit any increased administrative or financial burden on providers.
• **Leverage.** The approach should support the use of existing systems of quality and performance measurement.

In order to ensure the provision of quality care, the subgroup also developed recommendations related to the process of health care delivery:

• **Evidence Based Practice.** American Academy of Pediatrics (AAP) Policy on Recommendation for Preventative Pediatric Care should serve as the clinical guidance for the content and periodicity of well-child visits, particularly as many states have already adopted the previous edition (Bright Futures) for their EPSDT programs. These guidelines are already in use in many state EPSDT programs.21

• **Federal Reporting.** Existing EPSDT reporting requirements (currently the HCFA-416) should be revised to increase the availability of qualitative measures that supplement quantitative data (e.g., numbers of services expected to be and actually delivered). Revised measurements should reflect the pediatric health care domains outlined on the following page, ranging from high to low prevalence care. At a minimum, consideration should be given to identifying critical measures that reflect quality child well-visits, and the associated service billing codes to move toward consistency in reporting across states.

• **Comprehensiveness of Measures.** A minimum data set for use in all states should be established, supplemented by a small group of measures that periodically rotate, with selection of this supplemental measurement group to be determined by state health priorities. The periodic rotation should be in accordance with a schedule that permits rotation of measures in order to permit measurement within a specified time period but consistent with the need for state flexibility. In the interest of reducing the administrative burden of data collection, health service entities should (1) link administrative-based measures with broader survey-based measures (e.g., Promoting Healthy Development Survey) and (2) leverage the chart reviews that are required for HEDIS accreditation for the collection of the proposed domains of measures. The primary data sources for these areas of measures are parent report, laboratory data, and administrative claims data.

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21 Bright Futures is a philosophy and approach that is dedicated to the principle that every child deserves to be healthy, and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community. As part of this initiative, *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* was developed to provide comprehensive health supervision guidelines, including recommendations on immunizations, routine health screenings, and anticipatory guidance. The American Academy of Pediatrics and the Maternal and Child Health Bureau are committed to the multidisciplinary and multicultural nature of the Bright Futures initiative.
Proposed Areas of Measurement. Evidence that critical events have taken place at the appropriate intervals (depending on the age of the child) should be documented in the child’s medical record. Thus, for example, EPSDT requires the provision of anticipatory guidance to parents and health education to children. The expected trajectory of a child from access through service delivery would be Screening → (if cause for concern is identified) Referral → and Follow-up contact with the referred entity. Appropriate measures of performance should indicate: (1) whether a screen was conducted; (2) whether a referral was noted in the chart; and (3) whether a visit to the referral entity in which a formal assessment took place.

The subgroup identified areas of high-value well-child care for both children with typical and special health care needs in the form of sentinel events, along with the rationale for their selection.

Anticipatory Guidance. Age-appropriate information about the development of a child should be provided to parents at each well-child visit. Parents spend much more time with their children than any health care professional and are most likely to notice any problems as they emerge, especially if they have information about the developmental and behavioral milestones that can be expected at their child’s age.

Immunization. Age-appropriate immunizations are a well-documented indicator of the provision of appropriate well-child care, and one of the most cost-effective intervention strategies, saving more than $5 for each dollar spent.22 A proposed modification to the HEDIS measure that factors in the mobility of the Medicaid population would be a six-month extension of the timeframe in which to calculate immunization rates.

Preventive Dental Visit. The disparities in access to oral health care for low-income populations are striking. Lack of oral health care manifests in untreated dental caries and increased periodontal disease, which result in pain, and can result in increased school absenteeism. Poor oral health can have harmful effects on speech, nutrition, and self-image, a particular concern for low-income populations who are likely at increased risk for poor outcomes in these areas.

Vision/Hearing Screen. Children should receive regular vision and hearing screening tests to identify problems early. Screening should begin with newborns and continue at periodic intervals consistent with the AAP recommendations for

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preventive pediatric care. Early detection can lead to early intervention with treatment that can reduce the likelihood of further deterioration of vision, damage to speech, or negative effects on learning, including inappropriate placements in special education classes.

- **Lead Screen.** Low-income children and children of color are particularly susceptible to exposure to lead, in the form of paint or other materials. Despite decreased lead poisoning rates for all children, Black children and children in low-income families continue to have higher levels of lead detectable in their blood than other children. Long-term sequelae include learning disabilities, lower IQ scores, mental retardation, and other developmental delays.

- **Mental Health Screen.** Mental disorders can lead to suicide, one of the United States’ leading preventable causes of death among youth. Early detection and appropriate treatment and follow-up can reduce the impact of mental illness and the likelihood of crises.

- **Developmental Screen.** Early identification and intervention for children with developmental disorders is critical and has tremendous implications for long-term outcomes. Along with developmental surveillance – which should occur at every preventive care visit – screening can identify children in need of formal assessment. Earlier identification can help ensure that they receive appropriate services at the earliest possible point to improve their developmental trajectory.

- **Body Mass Index.** Obesity among American children has reached epidemic status. The number of children who are overweight has doubled in the last two to three decades; currently one child in five is overweight. The increase is in both children and adolescents, and in all age, race and gender groups. Overweight children are at increased risk for developing Type 2 diabetes, and becoming overweight adults, which puts them at greater risk for heart disease, high blood pressure, and stroke. Beyond the impact on health, childhood obesity subjects those children to social stigma and being ostracized, both often resulting in low self-esteem and depression.

In the view of the subgroup, these measurement domains in preventive care have implications for long-term physical, emotional, social, educational, and functional outcomes for children.

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Coordinating Medicaid and Other Child Serving Programs

The coordination subgroup developed broad recommendations aimed at establishing the framework for more detailed agreements between health care entities and other child-serving programs. The rationale for this group of recommendations is that Medicaid eligible children are served in numerous non-medical settings. Taking advantage of the opportunity to engage Medicaid-eligible children and their families in these other settings can into increased access to needed Medicaid services. The following principles should guide the development of coordination efforts:

1. There should be clear roles and responsibilities for each agency or program that participates in a service coordination agreement.

2. Shared information about child health status, health-related needs, services received, and the outcome of services is essential to coordination and delivery of appropriate care. Attention must be paid, however, to the applicable rules regarding privacy that apply to medical information and to protected information in other systems.

3. The home for health care information should be the child’s accountable medical home, which bears primary responsibility for referrals and for integrating into the child’s health record information furnished by referral providers.

4. Financing should be available to support with coordination efforts.

5. Family involvement is a vital part of improving coordination.

Based on these principles, the subgroup identified a series of strategies for achieving greater coordination of Medicaid and other services often provided to Medicaid-eligible children:

1. **Strengthen Linkages among Service Providers.** In light of the ability of early intervention to ameliorate or resolve developmental delays and other health concerns in children and adolescents, the capabilities of the health care system should be augmented by strengthening ties with state and local child-serving agencies with a particular emphasis on the youngest children. Coordination can be improved through greater use of co-location of assessment and primary preventive services, provision of services in non-medical settings, out-stationing health care and public health agency staff in early childhood education and child care settings, and provision of anticipatory guidance in those non-medical settings. Many successful outstationing models exist that support partnerships to better identify and respond to the needs of young and pre-school aged children. Medicaid financing should explicitly support the use of trained, outstationed outreach, service provider, and enrollment staff in Head Start, large child care
centers, child care resource and referral centers, and other early care and learning sites serving low-income children.

2. **Develop Comprehensive Approaches to Coordinate Care.** Coordination of care is critical for populations with serious disorders or disabilities. This is particularly true for the case management activities typically needed by children with special health care needs. Resources should be invested in care coordination for children with special health care needs who are highly likely to benefit from services that facilitate the attention to their physical, behavioral and social service needs. To this end, clear federal guidance is needed regarding the uses of medical case management funding in publicly financed educational and social service settings that are not funded to provide medical case management services.

3. **Establish Medical Home to Oversee Full Range of Service Requirements.** All children must attend school, and those with special physical, developmental, or emotional disabilities have treatment or service plans developed to improve their functioning in those areas. These children often have several independent, uncoordinated plans. In order to improve coordination and ultimately child health outcomes, accountable health care entities involved in the development of those plans should ensure that one entity, preferably the primary care physician, be at a minimum notified and at best have approval authority over the health care elements of those plans.

4. **Adopt Effective Methods to Share Information Across Providers.** Because the coordination of services is essential to achieving positive health care outcomes, information exchange is critical. Comprehensive and definitive guidance on the exchange of pediatric health information that takes into account Medicaid and HIPAA requirements as well as the information requirements of other child-serving systems, including child care and Head Start programs, schools, and child welfare agencies, is urgently needed. To the extent possible, information relevant to treatment planning and information should be available to health care providers, and health care information essential to child development, educational attainment, and the promotion of children’s health should be available to child-serving agencies and programs through secure and interoperable systems.
Conclusion

The overarching goals of EPSDT remain as relevant today as at the time of its enactment 40 years ago. What is also clear however, is that health care systems have changed profoundly since the 1967 amendments, and that there has been insufficient investment in systematically thinking about how to modernize EPSDT operations in order to meet the needs of changing families, changing concepts of child health, and a changing health care system that emphasizes the use of purchased health care arrangements configured to reflect market priorities and realities. Integrating these two visions has never been more important, particularly in light of the broad shift to purchase coverage arrangements over the past decade and a half, as well as the potential for these arrangements to grow still further in the wake of the DRA alternative benefit option.

Much can be learned from current state practices related to aligning EPSDT benefits and coverage rules with managed care performance. Much remains to be examined, in particular, how states approach EPSDT integration when the purchased coverage is employment benefits rather than a state-negotiated coverage agreement. Similarly, there is limited explanation on the precise process by which children move among EPSDT coverage tiers within existing contractual frameworks, and the actual experience with implementing cross-service agreements has never been studied.

Given the enduring nature of EPSDT’s guiding principles, the value of carefully developed approaches to institutionalizing tiered coverage arrangements can hardly be overstated. This is especially true as the federal government faces a change in administration, which may lead to a reexamination of multiple facets of our health care system. At the same time states, faces with new recessionary fiscal pressures are still looking to design and test new coverage strategies, including ones that flow from the DRA. Key elements of such demonstrations might focus on the precise structure of tiers in state-contracted models, approaches to tiering in situations in which employer-sponsored benefits serve as the first tier, testing the effects of tiering on children with special needs, promoting the use of common standards of child health quality, and developing model information sharing arrangements that can traverse multiple child-serving systems.
### Appendix A: Current HEDIS® and CAHPS® Quality Measures

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25 Institute for Clinical Systems Improvement.
Appendix B: EPSDT Modernization Task Force Members

Sincere thanks are extended to each of the members of the three task forces for their thoughtful contributions to the development of these recommendations. The following are the members of the EPSDT Modernization Project Task Forces:

**Benefit Structure**
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James Mumford, AmeriChoice Health Services, Inc.
Patrick Roohan, New York State Department of Health
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