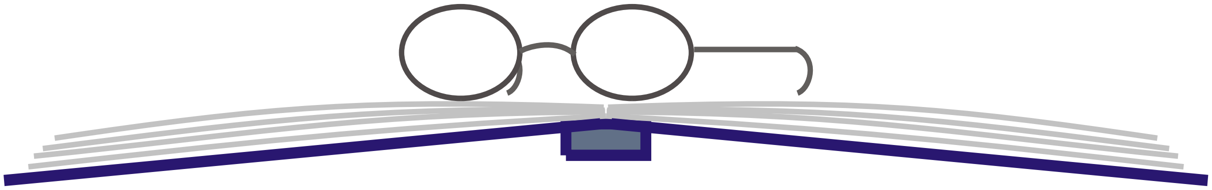

UNDERSTANDING MEDICAID

- Scope of Medicaid Services Available
- Avoiding Cruel Choices: A Guide for Policymakers and Family Organizations on Medicaid's Role in Preventing Custody Relinquishment
- Mix and Match: Using Federal Programs

EPSDT - A Guide for States:

Coverage in the Medicaid Benefit for Children and Adolescents

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Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

JUNE 2014

Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html

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Produced in collaboration with the National Health Law Program under subcontract to
NORC at the University of Chicago
www.NORC.org

I. INTRODUCTION

The Medicaid program's benefit for children and adolescents is known as Early and Periodic Screening, Diagnostic and Treatment services, or EPSDT. EPSDT provides a comprehensive array of prevention, diagnostic, and treatment services for low-income infants, children and adolescents under age 21, as specified in Section 1905(r) of the Social Security Act (the Act). The EPSDT benefit is more robust than the Medicaid benefit for adults and is designed to assure that children receive early detection and care, so that health problems are averted or diagnosed and treated as early as possible. The goal of EPSDT is to assure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting.

> ***EPSDT's goal is to assure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting.***

States share responsibility for implementing the benefit, along with the Centers for Medicare & Medicaid Services (CMS). States have an affirmative obligation to make sure that Medicaid-eligible children and their families are aware of EPSDT and have access to required screenings and necessary treatment services.[1] States also have broad flexibility to determine how to best ensure such services are provided. In general, they either administer the benefit outright (through fee for service arrangements) or provide oversight to private entities with whom they have contracted to administer the benefit (e.g., managed care entities). States must arrange (directly or through delegations or contracts) for children to receive the physical, mental, vision, hearing, and dental services they need to treat health problems and conditions. Through the EPSDT benefit, children's health problems should be addressed before they become advanced and treatment is more difficult and costly.

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[1] CMS, State Medicaid Manual §§ 5010, 5121, 5310 (requiring states to "[a]ssure that health problems found are diagnosed and treated early, before they become more complex and their treatment more costly,. . . that informing methods are effective, . . . [and] that services covered under Medicaid are available.")

EPSDT entitles enrolled infants, children and adolescents to any treatment or procedure that fits within any of the categories of Medicaid-covered services listed in Section 1905(a) of the Act if that treatment or service is necessary to "correct or ameliorate" defects and physical and mental illnesses or conditions.[2] This includes physician, nurse practitioner and hospital services; physical, speech/language, and occupational therapies; home health services, including medical equipment, supplies, and appliances; treatment for mental health and substance use disorders; treatment for vision, hearing and dental diseases and disorders, and much more. This broad coverage requirement results in a comprehensive, high-quality health benefit for children under age 21 enrolled in Medicaid.

Children's health problems should be addressed before they become advanced and treatment is more difficult and costly.

States report annually to CMS certain data about their delivery of services under the EPSDT benefit.[3] The reporting is made on the CMS Form 416. CMS and states use this data to monitor EPSDT performance.

This guide is intended to help states, health care providers and others to understand the scope of services that are covered under EPSDT so that they may realize EPSDT's goals and provide the best possible child and adolescent health benefit through their Medicaid programs. While it does not establish new EPSDT policy, this guide serves the important purpose of compiling into a single document various EPSDT policy guidances that CMS has issued over the years.

This guide outlines:

✓ EPSDT's screening requirements, including when interperiodic screening should be provided;
✓ Scope of services covered under EPSDT;
✓ EPSDT's requirements governing dental, vision, and hearing services;
✓ Permissible limitations on service coverage under EPSDT;

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[2] Section 1905(r)(5) of the Social Security Act.

[3] Sections 1902(a)(43)(D) and 2108(e) of the Social Security Act; CMS, State Medicaid Manual § 2700.4.

- ✓ States' responsibilities to assure access to EPSDT services and providers;
- ✓ Assistance to states as they work with managed care plans to provide the best child health benefit possible; and
- ✓ Notice and appeal procedures required when services are denied, reduced or terminated.

II. PERIODIC AND INTERPERIODIC SCREENINGS

EPSDT covers regular screening services (check-ups) for infants, children and adolescents. These screenings are designed to identify health and developmental issues as early as possible. States have the responsibility to ensure that all eligible children (and their families) are informed of both the availability of screening services, and that a formal request for an EPSDT screening service is not required. States must provide or arrange for screening services both at established times and on an as-needed basis. Covered screening services are medical, mental health, vision, hearing and dental. Medical screenings has five components:

- ✓ Comprehensive health and developmental history that assesses for both physical and mental health, as well as for substance use disorders;4
- ✓ Comprehensive, unclothed physical examination;
- ✓ Appropriate immunizations, in accordance with the schedule for pediatric vaccines established by the Advisory Committee on Immunization Practices;
- ✓ Laboratory testing (including blood lead screening appropriate for age and risk factors);5 and
- ✓ Health education and anticipatory guidance for both the child and caregiver.6

Under the Act, states must establish a periodicity schedule for each type of screening service: medical, vision, hearing, and dental. The periodicity schedules set the frequency by which certain services should be provided and will be covered.[7] The schedules are not prescribed by federal law, but should be based on current standards of pediatric medical and dental practice, and states are required to consult with recognized medical and dental organizations involved in child health care to assist in developing their periodicity schedules. One commonly used source is Bright Futures (developed by the American Academy of Pediatrics), which, for example, suggests that developmental screenings be conducted when children are ages 9 months, 18 months, and 30 months. The American Academy of Pediatric Dentistry (AAPD) has published a recommended periodicity schedule for dental services for children and adolescents. States should review their EPSDT periodicity schedules regularly to keep them up to date.

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[4] CMS issued an Informational Bulletin on March 27, 2013, discussing Prevention and Early Identification of Mental Health and Substance Use Conditions in Children and informing states about resources available to help them meet the needs of children under EPSDT.

[5] CMS issued guidance on June 22, 2012 to align blood lead screening for Medicaid children with recommendations of the Centers for Disease Control and Prevention (CDC). After providing data that demonstrates that universal screening is not the most effective approach to identifying childhood exposure to lead, a state may request to implement a targeted lead screening plan rather than continue universal screening of all Medicaid-eligible children ages 1 and 2.

[6] Section 1905(r)(1)(B) of the Social Security Act.

[7] 42 C.F.R. § 441.58; CMS, State Medicaid Manual §§ 5110, 5140.

States should review their EPSDT periodicity schedules regularly to keep them up to date.

EPSDT also requires coverage of medically necessary “interperiodic” screening outside of the state’s periodicity schedule. Coverage for such screenings is required based on an indication of a medical need to diagnose an illness or condition that was not present at the regularly scheduled screening or to determine if there has been a change in a previously diagnosed illness or condition that requires additional services. The determination of whether a screening service outside of the periodicity schedule is necessary may be made by the child’s physician or dentist, or by a health, developmental, or educational professional who comes into contact with a child outside of the formal health care system. This includes, for example, personnel working for state early intervention or special education programs, Head Start, and the Special Supplemental Nutrition Program for Women, Infants, and Children. A state may not limit the number of medically necessary screenings a child receives and may not require prior authorization for either periodic or “interperiodic” screenings.

Example of Screenings Beyond Those Required by the Periodicity Schedule
A child receives a regularly scheduled periodic vision screening at age 5 at which no problem is detected. According to the state’s periodicity schedule, his next vision screening is due at age 7. At age 6, the school nurse recommends to the child’s parent that the child see an optometrist because a teacher suspects a vision problem. Even though the next scheduled vision screening is not due until the age of 7, the child would be entitled to receive a timely “interperiodic” screening to determine if there is a vision problem for which treatment is needed. The screening should not be delayed if there is a concern the child may have a vision problem. Source: NPRM, 58 Fed. Reg. 51288, 51290, 51291 (Oct. 1, 1993)

Screening services provide the crucial link to necessary covered treatment, as EPSDT requires states to “arrang[e] for . . . corrective treatment,” either directly or through referral to appropriate providers or licensed practitioners, for any illness or condition detected by a screening.[8] The affirmative obligation to connect children with necessary treatment makes EPSDT different from Medicaid for adults.[9] It is a crucial component of a quality child health benefit.

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[8] Section 1902(a)(43)(C) of the Social Security Act.

[9] CMS, State Medicaid Manual § 5124.B.

The affirmative obligation to connect children with necessary treatment makes EPSDT different from Medicaid for adults.

Any qualified provider operating within the scope of his or her practice, as defined by state law, can provide a screening service. The screening *need not be* conducted by a Medicaid provider in order to trigger EPSDT coverage for follow up diagnostic services and medically necessary treatment by a qualified Medicaid provider. A screening service provided before a child enrolls in Medicaid is sufficient to trigger EPSDT coverage, after enrollment, for follow-up diagnostic services and necessary treatment. The family or beneficiary need not formally request an EPSDT screening in order to receive the benefits of EPSDT. Rather, any visit or contact with a qualified medical professional is sufficient to satisfy EPSDT's screening requirement, and states should consider a beneficiary who is receiving services to be participating in EPSDT, whether the beneficiary requested screening services directly from the state or the health care provider.[10]

Any qualified provider operating within the scope of his or her practice, as defined by state law, can provide a screening service.

States establish their own fee schedules for screening services and should be using Health Insurance Portability and Accountability Act (HIPAA) compliant billing codes. States may develop a bundled payment rate to pay for the physical health screening components under one billing code. States may also recognize each component of the EPSDT screening separately. For example, one state pays for the visit itself with one code and pays separately for each individual screening service delivered during the visit. This payment methodology not only encourages providers to perform every component of an EPSDT well-child visit, it also provides the state, through claims, information as to whether the physician actually met the elements of the EPSDT guidelines set out in the periodicity

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[10] CMS, State Medicaid Manual § 5310; HCFA, Title XIX State Agency Letter No. 91-33 (April 3, 1991).

schedules. States may encourage providers to perform all five components of the EPSDT screening but may not exclude providers who perform only partial screenings from being reimbursed for the parts they do provide.

Professional guidelines (e.g., Bright Futures) recommend that physicians include an oral health screening as part of the well-child visit at specified ages. In addition, states are permitted to include dental or oral health screening as a separately covered EPSDT service. These screening services, which may be performed by dental professionals or by medical professionals according to state scope of practice rules, can take place in community or group settings as well as in clinics or medical and dental offices. Such screenings can be helpful in identifying children with unmet dental care needs so they can be referred to a dental professional for treatment. Two new procedure codes were added to the Code on Dental Procedures and Nomenclature (CDT) in 2012 to facilitate payment for oral health screenings and assessments: CDT 0190 and CDT 0191.

In 2012, two new procedure codes were added to facilitate payment for oral health screenings and assessments: CDT 0190 and 0191.

Vision and hearing screening services must also be provided. States should consult with ophthalmologists and optometrists to determine what procedures should be used during a vision screening and to establish the criteria for referral for a diagnostic examination. For hearing screenings, appropriate procedures for screening and methods of administering them can be obtained from audiologists or from state health or education departments.[11]

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[11] CMS, State Medicaid Manual § 5123.2.F.

III. DIAGNOSTIC SERVICES

EPSDT covers medically necessary diagnostic services. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for diagnosis without delay.

A child's diagnosis may be performed by a physician, dentist or other practitioner qualified to evaluate and diagnose health problems at locations, including practitioners' offices, maternal and child health (MCH) facilities, community health centers, rehabilitation centers, and hospital outpatient departments. Diagnosis can generally be made on an outpatient basis. However, inpatient services are covered when necessary to complete a diagnosis.

> ***When a screening examination indicates the need for further evaluation of a child's health, the child should be referred for diagnosis without delay.***

IV. THE SCOPE OF EPSDT TREATMENT SERVICES

A. Scope of Services

The Act provides for coverage of all medically necessary services that are included within the categories of mandatory and optional services listed in section 1905(a), regardless of whether such services are covered under the State Plan. These include physician and hospital services, private duty nursing, personal care services, home health and medical equipment and supplies, rehabilitative services, and vision, hearing, and dental services. Covered EPSDT services also include "any other medical care, and any other type of remedial care recognized under State law, specified by the Secretary."[12] The role of states is to make sure the full range of EPSDT services is available as well as to assure that families of enrolled children are aware of and have access to those services so as to meet the individual child's needs. The broad scope of services enables states to design a child health benefit to meet the individual needs of the children served by its Medicaid program—a benefit design that has the potential to result in better care and healthier children at a lower overall cost. As discussed in the next section: while children enrolled in Medicaid are entitled to a broad scope of treatment services, no such service is covered under Medicaid unless medically necessary for that particular child.

The Act provides for coverage of all medically necessary services that are included within the categories of mandatory and optional services listed in section 1905(a), regardless of whether such services are covered under the State Plan.

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[12] Section 1905(a)(29) of the Social Security Act.

If a service, supply or equipment that has been determined to be medically necessary for a child is not listed as covered (for adults) in a State Medicaid Plan, the state will nonetheless need to provide it to the child as long as the service or supply could be covered under the State Plan, that is, as long as it is included within the categories of mandatory and optional services listed in section 1905(a). In such circumstances, the state would need to develop a payment methodology for the service, supply or equipment, including the possibility that payment may need to be made using a single-service agreement with an in-state provider or an out-of-state provider who will accept Medicaid payment.

A service need not cure a condition in order to be covered under EPSDT. Services that maintain or improve the child's current health condition are also covered in EPSDT because they "ameliorate" a condition. Maintenance services are defined as services that sustain or support rather than those that cure or improve health problems. Services are covered when they prevent a condition from worsening or prevent development of additional health problems. The common definition of "ameliorate" is to "make more tolerable." Thus, services such as physical and occupational therapy are covered when they have an ameliorative, maintenance purpose. This is particularly important for children with disabilities, because such services can prevent conditions from worsening, reduce pain, and avert the development of more costly illnesses and conditions. Other, less common examples include items of durable medical equipment, such as decubitus cushions, bed rails and augmentative communication devices. Such services are a crucial component of a good, comprehensive child-focused health benefit.

B. Covering a Range of Treatment Services to Meet a Child's Needs

As noted above, EPSDT covers physical and mental health and substance use disorder services, regardless of whether these services are provided under the State Plan and regardless of any restrictions that states may impose on coverage for adult services, as long as those services *could* be covered under the State Plan. This section provides some examples of EPSDT's broad scope of services, focusing on mental health and substance use services, personal care services, oral health and dental services, and vision and hearing services.

a. Mental Health and Substance Use Services

Treatment for mental health and substance use issues and conditions is available under a number of Medicaid service categories, including hospital and clinic services, physician services, and services provided by a licensed professional such as a psychologist. States should also make use of rehabilitative services. While rehabilitative services can meet a range of children's treatment needs, they can be particularly critical for children with mental health and substance use issues. Rehabilitative services are defined to include:

> *any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.*[13]

Like other services covered under EPSDT, rehabilitative services need not actually cure a disability or completely restore an individual to a previous functional level. Rather, such services are covered when they ameliorate a physical or mental disability, as discussed above. Moreover, determinations of whether a service is rehabilitative must take into consideration that a child may not have attained the ability to perform certain functions. That is, a child's rehabilitative services plan of care should reflect goals appropriate for the child's developmental stage.

Rehabilitative services are particularly critical for children with mental health and substance use issues.

Depending on the interventions that the individual child needs, services that can be covered as rehabilitative services include:

- ✓ Community-based crisis services, such as mobile crisis teams, and intensive outpatient services;
- ✓ Individualized mental health and substance use treatment services, including in non-traditional settings such as a school, a workplace or at home;
- ✓ Medication management;
- ✓ Counseling and therapy, including to eliminate psychological barriers that would impede development of community living skills; and
- ✓ Rehabilitative equipment, for instance daily living aids.

With respect to the provision of rehabilitative services, including those noted above, CMS requires more specificity of providers and services due to the wide spectrum of rehabilitative services coverable under the broad definition. CMS

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[13] Section 1905(a)(13) of the Social Security Act; 42 C.F.R. § 440.130(d).

would expect a state to include in their State Plan the services, and providers with their qualifications, as well as a reimbursement methodology for each service it provides. CMS is available to provide technical assistance to states that are covering a service for children that has not otherwise been identified in their State Plan.

A number of home and community-based services, including those that can be provided through EPSDT, have proven to significantly enhance positive outcomes for children and youth. These include intensive care coordination ("wraparound"), intensive in-home services, and mobile crisis response and stabilization.

CMS has issued detailed guidance encouraging states to include screening, assessments, and treatments focusing on children who have been victims of complex trauma. EPSDT can be a crucial tool in addressing the profound needs of this population, including children who are involved in the child welfare system.

b. Personal Care Services

EPSDT requires coverage of medically necessary personal care services, which:

> *are furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility . . . or institution for mental disease, that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State), otherwise authorized for the individual in accordance with a service plan approved by the State; (B) provided by an individual who is qualified to provide such services and is not a member of the individual's family; and (C) furnished in a home or . . . in other location.*[14]

Personal care services provide a range of assistance with performing activities of daily living, such as dressing, eating, bathing, transferring, and toileting; and instrumental activities of daily living, such as preparing meals and managing medications.[15] While it is optional for states to provide personal care services for adults in locations other than the home, this is not the case for a child. Under EPSDT, personal care services are to be provided, for example, in a school or group home if necessary to "correct or ameliorate" a condition.

The determination of whether a child needs personal care services must be based upon the child's individual needs and provided in accordance with a plan of treatment or service plan. Under regular State Plan Medicaid, no Medicaid payments are available for personal care services provided by the child's legally

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[14] Section 1905(a)(24) of the Social Security Act; 42 C.F.R. § 440.167.
[15] CMS, State Medicaid Manual § 4480.

responsible relatives.[16] In addition, the determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that are actually—not hypothetically—available.

c. *Oral Health and Dental Services*

Dental services required in the EPSDT benefit include:[17]

- ✓ Dental care needed for relief of pain, infection, restoration of teeth, and maintenance of dental health (provided at as early an age as necessary); and
- ✓ Emergency, preventive, and therapeutic services for dental disease that, if left untreated, may become acute dental problems or cause irreversible damage to the teeth or supporting structures.18

In addition, medically necessary oral health and dental services,[19] including those identified during an oral screening or a dental exam, are covered for children. States must provide orthodontic services to EPSDT-eligible children to the extent necessary to prevent disease and promote oral health, and restore oral structures to health and function.[20] Orthodontic services for cosmetic purposes are not covered.

Once a child reaches the age specified by the state in its pediatric dental periodicity schedule, typically age one, a direct dental referral is required.[21] The referral must be for an encounter with a dentist or with another dental professional, such as a dental hygienist, working under the supervision of a dentist.[22] Dental supervision includes the entire range, for example, direct, indirect, general, public health and collaborative practice arrangements.

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[16] 42 C.F.R. § 440.167.

[17] Information on CMS efforts working with states to improve access to oral health services for children enrolled in Medicaid and CHIP can be found in CMS, *Improving Access to and Utilization of Oral Health Services for Children in Medicaid and CHIP Programs: CMS Oral Health Strategy* (April 11, 2011). Approaches states can use to improve the delivery of dental and oral health services to children in Medicaid and CHIP can be found in *Keep Kids Smiling: Promoting Oral Health Through the Medicaid Benefit for Children and Adolescents* and in *Improving Oral Health Care Delivery in Medicaid and CHIP: A Toolkit for States*. All of these documents are available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Dental-Care.html.

[18] CMS, State Medicaid Manual § 5124.B.2.b.

[19] CMS, State Medicaid Manual § 2700.4 (Form 416 Instructions, Note for Line 12 Data). Dental services are those performed by or under the supervision of a dentist. Oral health services are those performed by other licensed providers not working under the supervision of a dentist, for example, a physician or nurse, or by a dental professional operating without a supervisory relationship to a dentist (e.g., an independent practice dental hygienist).

[20] CMS, State Medicaid Manual § 5124.B.2.b

[21] 42 C.F.R. § 441.56(b)(vi).

[22] CMS, State Medicaid Manual § 5123.2.G.

Current clinical guidelines recommend that a child have a first dental visit when the first tooth erupts or by age one.

Dental care must be provided at intervals indicated in the pediatric dental periodicity schedule adopted by the state after consultation with a recognized dental organization involved in child health care.[23] Current clinical guidelines recommend that a child have a first dental visit when the first tooth erupts or by age one, whichever occurs first. Dental care that is deemed medically necessary for an individual child is covered even when the frequency is greater than specified in the periodicity schedule.[24] For example, a child determined by a qualified provider to be at moderate or high risk for developing early childhood caries could be covered to receive dental exams and preventive treatments more frequently than the twice-yearly periodicity schedule recommended by the AAPD.

As determined by dental practice acts in individual states, there is a wide range of dental professionals who can work under the supervision of a dentist, for example, dental hygienists, dental therapists, dental health aide therapists, dental hygienists in advanced practice, advanced practice dental therapists, dental assistants, and community dental health coordinators. Some state practice acts permit specified dental professionals to work without dentist supervision in certain circumstances. Such provisions can help ensure access to dental care as well as promote an integrated health care delivery system. As with medical care, any qualified provider operating within the scope of his or her practice, as defined by state law, can provide a dental or oral health service to a Medicaid enrollee. To qualify for federal matching funds, State Plans must list all provider types that will be permitted to bill for dental or oral health services. However, rendering providers (providers who actually serve the patient) need not be separately enumerated in the State Plan.

Better integration of primary medical care with dental care can help identify children at risk for tooth decay at the youngest age possible, offer evidence-based preventive care, such as fluoride varnish and oral health education, and refer children to a dental professional for a complete check-up and any needed treatment. Three oral health risk assessment CDT billing codes can support this

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[23] Section 1905(r)(3) of the Social Security Act; CMS, State Medicaid Manual § 5110.

[24] CMS, State Medicaid Manual § 5110.

approach, potentially preventing the need for costly treatment, such as that provided in an operating room.

State Medicaid and CHIP programs can use risk assessment codes to help children access services based on their individual levels of risk, instead of assuming that all children need the same level of intervention. AAPD guidelines encourage providers to customize care plans based on an assessment of each child's individual risk for developing dental disease. Risk assessment resources are available for providers, including an assessment tool from AAPD that includes a caries-risk assessment form, clinical guidelines and treatment protocols.

In addition to dental providers, states may reimburse primary care medical providers for conducting oral health risk assessments, providing oral health education to parents and children, applying preventive measures such as fluoride varnish, and making referrals to dental professionals. The CMCS oral health strategy guide, *Keep Kids Smiling: Promoting Oral Health Through the Medicaid Benefit for Children & Adolescents*, provides additional information on oral health and EPSDT.

d. Vision and Hearing Services

Vision and hearing services are an essential component of the EPSDT benefit. Hearing impairments can lead to other problems, including interference with normal language development in young children. They can also delay a child's social, emotional, and academic development. Vision problems can be evidence of serious, degenerative conditions, and can also lead to delays in learning and social development.

EPSDT requires that vision and hearing services be provided at intervals that meet reasonable standards as determined in consultation with medical experts, and at other intervals, as medically necessary, to determine the existence of a suspected illness or condition. At a minimum, vision services must include diagnosis and treatment for defects in vision, including eyeglasses. Glasses to replace those that are lost, broken, or stolen also must be covered. Hearing services must include, at a minimum, diagnosis and treatment for defects in hearing, including hearing aids.[25]

In addition, if hearing and vision problems are detected through screening, medically necessary services that are coverable under section 1905(a) must be covered. This includes not only physician and clinic services, but services from licensed professionals such as ophthalmologists, and equipment such as augmentative communication devices and cochlear implants.

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[25] Sections 1905(r)(2) and (4) of the Social Security Act.

e. *Other Services*

Examples of other services covered for children under Medicaid when medically necessary (and for which a federal match is available) include, but are not limited to, case management services (including targeted case management);[26] incontinence supplies; organ transplants and any related services; a specially adapted car seat that is needed by a child because of a medical problem or condition; and nutritional supplements.

Physicians and other providers use medical terminology, not Medicaid terms or legal terms, when recommending or prescribing medical services and treatments. If a requested service or treatment is not listed by name in Medicaid's list of services, it should nonetheless be provided if the service or item is determined to be medically necessary and coverable under the list of services at section 1905(a). In general, states are encouraged to include in their State Plans a range of provider types and settings likely to be sufficient to meet the needs of enrollees. Nonetheless, there may be cases in which the type of provider that is needed is not already participating in Medicaid. In such an instance, the state could meet the EPSDT requirement by, for example, entering into a single-service agreement with the needed provider.

When providers use medical terminology instead of Medicaid or legal terms to recommend medically necessary services, the recommended services should be covered if coverable under section 1905(a).

C. Enabling Services

a. *Transportation Services*

In order to promote access to needed preventive, diagnostic and treatment services, states must offer appointment scheduling assistance and are required to assure necessary transportation, to and from medical appointments, for children

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[26] Section 1905(a)(19) of the Social Security Act; 42 C.F.R. §§ 440.169, 441.18.

enrolled in Medicaid.[27] This includes covering the costs of an ambulance, taxi, bus, or other carrier. It can also include reimbursing for mileage. As with other services covered through EPSDT, states may cover the least expensive means of transportation if it is actually available, accessible, and appropriate. For example, public transportation can be covered instead of a taxi if the public transportation is physically accessible for a particular beneficiary and takes a reasonable amount of time. In addition, “related travel expenses” are covered if medically necessary, including meals and lodging for a child and necessary attendant.[28]

Some states have addressed the transportation requirement by offering non-emergency transportation through brokers who coordinate transportation services, or through administrative managers who act as gatekeepers for transportation services. Transportation may also be included in managed care contracts. If a state chooses not to include transportation services in their managed care contracts, or otherwise to contract out administration of the service, the state must administer the service itself. No matter the type of arrangement, it is important to remember that the state has ultimate responsibility for ensuring the provision of transportation services.

b. Language Access and Culturally Appropriate Services

Many Medicaid-enrolled children live in families where English is not spoken at home. State Medicaid agencies and their contractors should inform eligible individuals about the EPSDT benefit with a combination of written and oral methods “using clear and nontechnical language” and “effectively informing those individuals who . . . cannot read or understand the English language.”[29] State Medicaid agencies and Medicaid managed care plans, as recipients of federal funds, also have responsibilities to assure that covered services are delivered to children without a language barrier. They are required take “reasonable steps” to assure that individuals who are limited English proficient have meaningful access to Medicaid services.[30] This may include providing interpreter services, including at medical appointments, depending on factors such as the number of limited English proficient individuals served by the program.[31]

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[27] Section 1905(a)(29) of the Social Security Act; 42 C.F.R. §§ 440.170, 441.62.

[28] 42 C.F.R. § 440.170(a).

[29] 42 C.F.R. § 441.56(a); CMS, State Medicaid Manual §§ 5121.A, 5121.C.

[30] 42 U.S.C. § 2000d (Title VI of the Civil Rights Act); Affordable Care Act § 1557; CMS Dear State Medicaid Director (Aug. 31, 2000).

[31] Department of Health & Human Services, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 68 Fed. Reg. 47311 (August 8, 2003).

Though interpreter services are not classified as mandatory 1905(a) services, all providers who receive federal funds from HHS for the provision of Medicaid services are obligated, under Title VI of the Civil Rights Act, to make language services available to those with limited English proficiency.

Though interpreters are not Medicaid qualified providers, their services may be reimbursed when billed by a qualified provider rendering a Medicaid covered service.

States are not required to (but may) reimburse providers for the cost of language services. States may consider the cost of language services to be included in the regular rate of reimbursement for the underlying direct service. In those cases, Medicaid providers are obligated to provide language services to those with limited English proficiency and to bear the costs for doing so. Alternatively, states may allow providers to bill specifically for interpreter services. States have the option to claim for the cost of interpretation services, either as medical-assistance related expenditures or as administration.[32]

Claiming Federal Matching Funds for Interpreter Services. Interpreters are not Medicaid qualified providers. However, their services may be reimbursed when billed by a qualified provider rendering a Medicaid covered service. Interpreters may not be paid separately. As of February 2009, oral interpreter services can be claimed using billing code T-1013 along with the CPT code used for the medical encounter. States can also raise reimbursement rates to recognize additional service costs, including interpreter costs, but must do so for services rendered by all providers in the class. With the enactment of the Children's Health Insurance Program Reauthorization Act in 2009, states were given the option to claim a higher federal matching rate (75% under Medicaid) for translation and interpretation services that are claimed as administration and are related to the enrollment, retention and use of services under Medicaid and CHIP by children of families for whom English is not their primary language.[33] Otherwise, longstanding CMS policy permits reimbursement at the standard 50% federal

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[32] CMS, Dear State Medicaid Director (July 1, 2010); CMS, CMCS Informational Bulletin: *Recent Developments in Medicaid* (April 26, 2011).

[33] Section 1903(a)(2)(E) of the Social Security Act.

matching rate for translation and interpretation activities that are claimed as an administrative expense, so long as they are not included and paid for as part of the reimbursement rate for direct services.[34]

> ***State Medicaid programs, managed care entities, and Medicaid-participating health care providers should all be culturally competent.***

The HHS Office for Civil Rights and the Department of Justice have provided guidance for recipients of federal funds on expectations of how to provide language services.[35]

State Medicaid programs, managed care entities, and Medicaid-participating health care providers should all be culturally competent. This means they need to recognize and understand the cultural beliefs and health practices of the families and children they serve, and use that knowledge to implement policies and inform practices that support quality interventions and good health outcomes for children. Given changing demographics, this process is ongoing. The DHHS Office of Minority Health offers numerous resources, including:

✓ Center for Linguistic and Cultural Competence in Health Care;
✓ Think Cultural Health;
✓ A Physician's Practical Guide to Culturally Competent Care;
✓ The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards); and
✓ The National CLAS Standards' implementation guide, A Blueprint for Advancing and Sustaining CLAS Policy and Practice.

D. Settings and Locations for Services

a. Services Provided Out of State

States may need to rely upon out-of-state services if necessary covered services are not available locally, or if a Medicaid beneficiary is out of state at the time a need for medical services arises. States are required to pay for services provided

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[34] CMS, Dear State Medicaid Director (August 31, 2000).
[35] *Id*; U.S. Department of Justice, Executive Order 13166.

in another state to the same extent services furnished in-state would be paid for if:

- ✓ The out-of-state services are required because of an emergency;
- ✓ The child's health would be endangered if she or he were required to travel to their home state;
- ✓ The state determines that the needed services are more readily available in the other state; or
- ✓ It is a general practice of the locality to use the services of an out-of-state provider, for example, in areas that border another state.[36]

Including out-of-state providers gives states the opportunity to expand the range and accessibility of Medicaid services that are available to their enrollees.[37]

b. Services Provided in Schools

Services provided in schools can play an important role in the health care of adolescents and children. Whether implemented for children with special needs under the Individuals with Disabilities Education Act (IDEA) or through school-based or linked health clinics, school-centered programs may be able to provide medical and dental care efficiently and effectively while avoiding extended absences from school.

In order for Medicaid to reimburse for health services provided in the schools, the services must be included among those listed in section 1905(a) of the Act and included in the State Plan, or be available under the EPSDT benefit. There is no benefit category in the Medicaid statute titled "school health services" or "early intervention services." Therefore a state must describe its school health services in terms of the specific section 1905(a) services which will be provided. In addition, there must be a provider agreement in place between the state Medicaid agency and the provider billing for the service; and the school must agree to comply with Medicaid-specific requirements regarding service documentation and claims submission.[38] States are encouraged to promote relationships between school-based providers and managed care plans.

> ***Services provided in schools can play an important role in the health care of adolescents and children.***

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[36] Section 1902(a)(16) of the Social Security Act; 42 C.F.R. § 431.52.
[37] HCFA, Dear State Medicaid Director (July 25, 2000).
[38] 42 C.F.R. § 431.107.

Schools are particularly appropriate places to provide medical, vision, and hearing screenings; vaccinations; some dental care; and behavioral health services. The Individuals with Disabilities Education Act (IDEA) requires that every child with a disability have available a free appropriate public education that includes special education and related services. Part B of IDEA requires the development and implementation of an individualized education program (IEP) that addresses the unique needs of each child with a disability ages 3 through 21.[39] A child's IEP identifies the special education and related services needed by that child. Medicaid covered services included in the IEP may be provided in, and reimbursed to, schools. Part C of IDEA covers early intervention services, which are developmental services designed to meet a child's developmental needs in physical, cognitive, communication, adaptive, and social and emotional development, for children from birth to age 3. These services are provided pursuant to an Individualized Family Service Plan (IFSP).

Examples of IDEA services that can be covered by Medicaid for a Medicaid eligible child include physical therapy, occupational therapy, personal care, and services for children with speech, hearing and language disorders.[40]

c. Most Integrated Setting Appropriate

Title II of the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in public programs, including Medicaid. In *Olmstead v. L.C.*, the Supreme Court held that unjustified institutionalization of Medicaid beneficiaries violates the ADA. Accordingly, states must cover services in the community, rather than in an institution, when the need for community services can be reasonably accommodated and providing services in the community will not fundamentally alter the state's Medicaid program.

Community-based care is a best practice for supporting children with disabilities and chronic conditions.

CMS has long encouraged states to provide services in home and community settings, particularly for children, not only because of *Olmstead,* but because community-based care is considered a best practice for supporting children with

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[39] While EPSDT covers children only through age 20 (up to the 21st birthday), the IDEA covers children through age 21 (up to the 22nd birthday).

[40] Additional information about Medicaid-covered services provided in schools can be found in the CMS, *Medicaid School Based Administrative Claiming Guide* (2003).

disabilities and chronic conditions. In addition, it is generally more cost-effective.[41]

EPSDT provides states with many options for covering physical and mental health services in the community. The EPSDT benefit requires coverage of medically necessary personal care, private duty nursing, physical, occupational and speech-language therapy. And, as discussed below, optional services provided through home and community based services waivers can further advance the state's efforts to provide services in the community.

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[41] HCFA, Dear State Medicaid Director, Olmstead Update Nos. 2 and 3 (July 25, 2000), No. 5 (January 10, 2001); CMS, Dear State Medicaid Director (May 20, 2010); CMS, Joint CMCS and SAMHSA Informational Bulletin: *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013).

V. PERMISSIBLE LIMITATIONS ON COVERAGE OF EPSDT SERVICES

A. Individual Medical Necessity

Services that fit within the scope of coverage under EPSDT must be provided to a child only if necessary to correct or ameliorate the individual child's physical or mental condition, i.e., only if "medically necessary." The determination of whether a service is medically necessary for an individual child must be made on a case-by-case basis, taking into account the particular needs of the child. The state (or the managed care entity as delegated by the state) should consider the child's long-term needs, not just what is required to address the immediate situation. The state should also consider all aspects of a child's needs, including nutritional, social development, and mental health and substance use disorders. States are permitted (but not required) to set parameters that apply to the determination of medical necessity in individual cases, but those parameters may not contradict or be more restrictive than the federal statutory requirement. As discussed above, services such as physical and occupational therapy are covered when they have an ameliorative, maintenance purpose.

> ***Determination of whether a service is medically necessary must be made on a case-by-case basis, taking into account a particular child's needs.***

Because medical necessity decisions are individualized, flat limits or hard limits based on a monetary cap or budgetary constraints are not consistent with EPSDT requirements.[42] States may adopt a definition of medical necessity that places tentative limits on services pending an individualized determination by the state, or that limits a treating provider's discretion, as a utilization control, but additional services must be provided if determined to be medically necessary for

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[42] HCFA, *Regional Transmittal Notice* (Region IV) (Sept. 18, 1990); Memorandum from Rozann Abato, Acting Director, HCFA, to Associate Regional Administrator, Atlanta (Sept. 5, 1990); Memorandum from Christine Nye, HCFA Medicaid Director, to Regional Administrator Region VIII (FME-42) (1991).

an individual child.[43] For example, while a state may place in its State Plan a limit of a certain number of physical therapy visits per year for individuals age 21 and older, such a "hard" limit could not be applied to children. A state could impose a "soft" limit of a certain number of physical therapy visits annually for children, but if it were to be determined in an individual child's case, upon review, that additional physical therapy services were medically necessary to correct or ameliorate a diagnosed condition, those services would have to be covered.

While the treating health care provider has a responsibility for determining or recommending that a particular covered service is needed to correct or ameliorate the child's condition,[44] both the state and a child's treating provider play a role in determining whether a service is medically necessary. If there is a disagreement between the treating provider and the state's expert as to whether a service is medically necessary for a particular child, the state is responsible for making a decision, for the individual child, based on the evidence. That decision may be appealed by the child (or the child's family) under the state's Medicaid fair hearing procedures, as described in Section VIII below.

B. Prior Authorization

States may impose utilization controls to safeguard against unnecessary use of care and services. For example, a state may establish tentative limits on the amount of a treatment service a child can receive and require prior authorization for coverage of medically necessary services above those limits.[45] Prior authorization must be conducted on a case-by-case basis, evaluating each child's needs individually. Importantly, prior authorization procedures may not delay delivery of needed treatment services and must be consistent with the "preventive thrust" of EPSDT.[46] As such, prior authorization may not be required for any EPSDT screening services. In addition, medical management techniques used for mental health and substance use disorders should comply with the Mental Health Parity and Addiction Equity Act.

C. Experimental Treatments

EPSDT does not require coverage of treatments, services, or items that are experimental or investigational. Such services and items may, however, be covered at the state's discretion if it is determined that the treatment or item would be effective to address the child's condition.[47] Neither the Federal Medicaid statute nor the regulations define what constitutes an experimental

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[43] 42 C.F.R. §§ 440.230(c), (d); HCFA Dear State Medicaid Director (May 26, 1993).
[44] Sections 1905(a) and (r) of the Social Security Act.
[45] *Id*.
[46] H.R. Rep. No. 101-247 at 399, *reprinted in* U.S.C.C.A.N. 1906, 2125.
[47] CMS, State Medicaid Manual §§ 4385.C.1, 5122.F.

treatment. The state's determination of whether a service is experimental must be reasonable and should be based on the latest scientific information available.[48]

Medicare guidance on whether a service is experimental or investigational is not determinative of the issue and may not be relevant to the pediatric population.[49]

D. Cost-Effective Alternatives

A state may not deny medically necessary treatment to a child based on cost alone, but may consider the relative cost effectiveness of alternatives as part of the prior authorization process. Also, a state need not make services available in every possible setting as long as the services are reasonably available through the settings where the service is actually offered. States may cover services in the most cost effective mode as long as the less expensive service is equally effective and actually available.[50] The child's quality of life must also be considered.[51] In addition, the ADA and the *Olmstead* decision require states to provide services in the most integrated setting appropriate to a child's needs, as long as doing so does not fundamentally alter the state's program. See above, Section IV.D. Thus, if an institutional setting is less costly than providing services in a home or community, the ADA's integration mandate may nevertheless require that the services be provided in the community.[52]

A state may not deny medically necessary treatment based on cost alone, but may consider the relative cost effectiveness of alternatives as part of the prior authorization process.

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[48] Memorandum from S. Richardson to State Medicaid Directors (April 17, 1995).
[49] Memorandum from S. Richardson to State Medicaid Directors (April 17, 1995).
[50] CMS, Dear State Medicaid Director, Olmstead Update No. 4 (January 10, 2001); Letter from Rozann Abato, Acting Director, Medicaid Bureau, to State Medicaid Directors (May 26, 1993).
[51] *Id*.
[52] 28 C.F.R. § 35.130(d); CMS, Dear State Medicaid Director, Olmstead Update No. 4 (January 10, 2001); DOJ, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the ADA and *Olmstead v. L.C.* (June 22, 2011).

VI. SERVICES AVAILABLE UNDER OTHER FEDERAL AUTHORITIES

A. Home and Community Based Services Waivers

A state Medicaid program may offer services through home and community based services (HCBS) waiver programs. Such programs allow states to provide HCBS to individuals who would otherwise need long-term care in a nursing facility, intermediate care facility, or hospital. Waiver programs provide for coverage of services that are not otherwise available through the Medicaid program (including EPSDT) because they do not fit into one of the categories listed in section 1905(a). This includes habilitative services, respite services, or other services approved by CMS that can help prevent institutionalization. These programs are sometimes called 1915(c) waivers after the section of the Social Security Act that authorizes them.[53]

Children under age 21 who are enrolled in an HCBS waiver program are also entitled to all EPSDT screening, diagnostic, and treatment services. Because HCBS waivers can provide services not otherwise covered under Medicaid, waivers and EPSDT can be used together to provide a comprehensive benefit for children with disabilities who would otherwise need the level of care provided in an institutional setting. This enables those children to remain in their homes and communities while receiving medically necessary services and supports. The HCBS waiver services essentially “wrap-around” the EPSDT benefit. If a child enrolled in Medicaid is on a waiting list for HCBS waiver services, EPSDT requirements apply and necessary services that fit into the categories listed in 1905(a) must be covered.[54]

Children who are enrolled in an HCBS waiver program are also entitled to all EPSDT services.

States may also choose to offer services to children under section 1915(j) (self-directed personal assistance services), section 1915(k) (home and community-based attendant services and support) and section 1945 (coordinated care in

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[53] Section 1915(c) of the Social Security Act.

[54] CMS, Dear State Medicaid Director, Olmstead Update No. 4, Att. 4-B (Jan. 10, 2001).

health homes for individuals with chronic conditions). Like services provided pursuant to a 1915(c) waiver, these services are not subject to EPSDT coverage provisions, but are instead available to supplement EPSDT services.

B. Alternative Benefit Plans

States must assure access to services available under the EPSDT benefit for all EPSDT-eligible children under age 21 enrolled in Alternative Benefit Plans (formerly known as benchmark plans and benchmark-equivalent plans).[55]

C. Role of Maternal and Child Health Services

Federal rules require state Medicaid agencies and Title V Maternal and Child Health (MCH) agencies and grantees to collaborate to assure better access to and receipt of the full range of screening, diagnostic, and treatment services covered under EPSDT.[56] Title V is administered by the Health Resources and Services Administration. Many state Medicaid agencies have entered into written agreements with their sister MCH programs and collaborate on improving access to EPSDT services in order to improve child health status. Among other things, cooperating MCH agencies can provide outreach, screening, diagnostic or treatment services, health education and counseling, case management and other assistance in achieving a comprehensive and effective child health benefit. MCH programs can also help Medicaid programs to enlist providers who can help deliver a broad array of services. In addition, they can inform potential and actual Medicaid recipients about EPSDT and refer them to necessary services.[57] CMS encourages such collaborations as MCH programs are crucial partners in the creation and delivery of a high quality, well-integrated child health benefit.

Many state Medicaid agencies have written agreements with their states' MCH programs and collaborate to improve access to EPSDT services.

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[55] 42 C.F.R. § 440.345.
[56] 42 U.S.C. §§ 705(a)(5)(F), 709(a)(2); 42 C.F.R. § 441.61(c).
[57] CMS, State Medicaid Manual § 5230.

VII. ACCESS TO SERVICES

A. Access to Providers

Access to covered services is of course a critical component of delivering an appropriate health benefit to children. Accordingly, a number of Medicaid and EPSDT provisions are intended to assure that children have access to an adequate number and range of pediatric providers. For example, states are required to "make available a variety of individual and group providers qualified and willing to provide" services to children.[58] States must also "take advantage of all resources available" to provide a "broad base" of providers who treat children."[59] Some states may find it necessary to recruit new providers to meet children's needs.[60] In the event a child needs a treatment that is not coverable under the categories listed in section 1905(a), states are to provide referral assistance that includes giving the family or beneficiary the names, addresses, and telephone numbers of providers who have expressed a willingness to furnish uncovered services at little or no expense to the family.[61]

States are required to make available a variety of providers who are qualified and willing to treat EPSDT children.

A child is entitled to receive Medicaid services from any provider qualified to provide the service and willing to furnish it, unless CMS has decided that this "freedom of choice" requirement will not apply.[62] Most states have received permission from CMS to provide some services to some children through managed care arrangements that restrict the free choice of provider.

An appropriate level of reimbursement can be critical to ensuring adequate access to providers.[63] While the statute provides states with broad authority to set provider payment rates, it requires that payments to providers must be consistent with efficiency, economy, and quality care and be sufficient to enlist enough

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[58] 42 C.F.R. § 441.61.
[59] CMS, State Medicaid Manual § 5220.
[60] *Id.*
[61] 42 C.F.R. § 441.61(a).
[62] Sections 1902(a)(23) and 1932(a) of the Social Security Act; 42 C.F.R. § 431.51(b).
[63] HCFA, Dear State Medicaid Director (Jan 18, 2001).

providers that care and services are available to Medicaid beneficiaries at least to the extent that they are available to the general population in the geographic area.[64]

Federal regulations provide that a Medicaid provider must agree to accept, as payment in full, the Medicaid payment for a covered service or item.[65] This means that a provider *may not* bill a Medicaid beneficiary for the difference between the provider's charge and the Medicaid payment (called "balance billing"). The payment in full requirement also prohibits Medicaid providers from billing beneficiaries for missed appointments. States may need to monitor compliance with this requirement.

Section 1905(a) lists coverable Medicaid services and some provider types. There are at least two means by which a state may cover a service by a provider type that is not specified in section 1905(a). Section 1905(a)(6) permits states to cover "medical care, or any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State law." Thus, a state may cover services performed by a class of providers (such as licensed dieticians) when the service they provide is not specified in section 1905(a) as long as the service is determined medically necessary for a child. Alternatively, a provider's services can be covered as a component of a section 1905(a) service. For example, in the case of a licensed social worker, the services could be provided through a federally qualified health center or a clinic, both of which are recognized providers under section 1905(a). The process for covering a provider for a service not specified in section 1905(a) varies depending on how the state intends to provide the service.

B. Managed Care

EPSDT benefits must be available to all children covered by Medicaid. As such, children enrolled in managed care plans, prepaid inpatient health plans, prepaid ambulatory health plans, primary care case management systems (collectively referred to as managed care entities) are entitled to the same EPSDT benefits they would have in a fee for service Medicaid delivery system. Properly implemented, managed care can enhance and promote EPSDT's goals of ensuring that care is provided in a coordinated way and with an emphasis on prevention.

States are responsible for assuring that the full EPSDT benefit is available to all Medicaid children in the state, even if the state contracts with a managed care entity to deliver some or all of the services available under EPSDT. The state's

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[64] Section 1902(a)(30)(A) of the Social Security Act; Medicaid Program: Methods for Assuring Access to Covered Medicaid Services, 76 Fed. Reg. 26,342 (May 11, 2011) (proposed regulations).
[65] 42 C.F.R. § 447.15.

contracts with managed care entities should be drafted with sufficient precision so that the entity's responsibilities with respect to children are clearly delineated. A contract can provide that the managed care entities will be responsible for providing services under the EPSDT benefit to the same degree that the services are covered by the state. Or, if certain responsibilities are carved out of the managed care contract, those carve-outs must be explicit, and the state will retain the responsibility for ensuring that those carved-out services are provided to enrolled children. For example, the state may 'carve out' dental services from the managed care contract; nonetheless, the state must assure that children receive those services (through either fee for service or a specialized dental plan).

Managed care entities may not use a definition of medical necessity for children that is more restrictive than the state's definition.

Managed care entities may not use a definition of medical necessity for children that is more restrictive than the state's definition. One way to ensure this is for the state to include its definition of medical necessity in the entity's contract. States should review managed care entities' medical necessity definitions and criteria to ascertain whether they meet this requirement. As a further step to provide for consistency across the delivery system and proper implementation of the children's benefit package, it is the state's responsibility to educate its contracted managed care entities about EPSDT requirements, as well as to verify that managed care providers are informed about EPSDT requirements through trainings and provider manuals. Further, states are responsible for ensuring that managed care entities fulfill their contractual responsibilities to inform all families of the services available under EPSDT and how to access them.[66] Information made available to enrollees, usually included in a member handbook, should clearly explain which EPSDT services the managed care entity will provide and how any EPSDT services not within the scope of the contract can be accessed by enrollees. Managed care entities must make available to all enrolled children the entire scope of services included in the EPSDT benefit that is within their contract with the state.[67]

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[66] Sections 1902(a)(5) and (a)(43) of the Social Security Act.

[67] 42 C.F.R. § 438.210(a)(4).

Managed care entities must demonstrate to the state that they have adequate provider capacity in the plan to serve enrolled children, including an appropriate range of pediatric and specialty services; access to primary and preventive care; and a sufficient number, mix and geographic distribution of providers.[68]

Monitoring managed care entities' compliance with EPSDT requirements is essential; a strong oversight framework ensures that states are meeting their responsibilities to children as well as Federal monitoring requirements.[69] There are several methods of exercising effective oversight in managed care systems.

First, states contracting with managed care organizations (MCOs) or prepaid inpatient health plans (PIHPs) are statutorily required to draft, implement, and maintain a managed care quality strategy.[70] The quality strategy is intended to provide a blueprint for states in assessing and improving the quality of care provided to managed care enrollees.[71] By means of this strategy, states can monitor and evaluate managed care entities' compliance with quality initiatives, track their performance on specified performance measures, and require them to design, implement and report the results of performance improvement projects.

Second, states are also required to ensure that external quality review of MCOs and PHIPs are performed by unbiased, external entities.[72] In this way, states can determine whether managed care entities are reporting accurate performance outcomes data and whether they are in compliance with state contract provisions.

Third, states can engage in an ongoing review of grievances and appeals related to children's services, as well as monitoring complaints filed with the state's enrollee and provider hotlines (if the state operates such hotlines). States could also require reports and perform data analysis of managed care entities' encounter data to detect underutilization of services by children.

In addition, all states are required to complete and file the Form 416 each year.[73] This reports the number of children receiving health screening services, dental and oral health services, and referrals for corrective treatment, as well as the state's rates of meeting EPSDT participation goals.

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[68] 42 C.F.R. § 438.206.

[69] 42 C.F.R. § 438.240.

[70] Section 1932(c)(1) of the Social Security Act; 42 C.F.R. §§ 438.202, 438.204.

[71] 42 C.F.R. § 438.202.

[72] Section 1932(c)(2) of the Social Security Act; 42 C.F.R. § 438.350.

[73] Section 1902(a)(43)(D) of the Social Security Act.

C. Timeliness

Services under the EPSDT benefit, like all Medicaid services, must be provided with “reasonable promptness.”[74] The state must set standards to ensure that EPSDT services are provided consistent with reasonable standards of medical and dental practice. The state must also ensure that services are initiated within a reasonable period of time. What is reasonable depends on the nature of the service and the needs of the individual child. Because states have the obligation to “arrang[e] for . . . corrective treatment” either directly or through referral to appropriate providers, a lack of providers does not automatically relieve a state of its obligation to ensure that services are provided in a timely manner. For example, as noted above, it may be necessary to cover services provided out of state.

Services under the EPSDT benefit, like all Medicaid services, must be provided with reasonable promptness.

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[74] Section 1902(a)(8) of the Social Security Act.

VIII. NOTICE AND HEARING REQUIREMENTS

Children under age 21, like all other people enrolled in Medicaid, have the right to notice and an opportunity for a hearing. If a state or managed care entity takes an "action" – to deny, terminate, suspend, or reduce a requested treatment or service, it must give the beneficiary written notice of the action and of their right to a hearing (a pre-termination hearing, in instances where services are reduced or terminated), including instructions on how to request a hearing.[75] When services are being terminated or reduced, the notice must be sent at least ten days before the effective date of the action.[76] Under exceptional circumstances, the notice must be mailed no later than the day of the action, such as when the beneficiary's physician prescribes a change in treatment or the beneficiary has been admitted to an institution and is no longer eligible.[77] The notice must contain a statement of the intended action, the specific reasons and legal support for the action, and an explanation of the individual's hearing rights, rights to representation and to continued benefits.[78]

If a state or managed care entity takes an action to deny, terminate, suspend, or reduce a requested treatment or service, it must give the beneficiary written notice of the action and of their right to a hearing.

The beneficiary is entitled to a hearing before the state Medicaid agency, or, if a state's hearing process provides for it, an evidentiary hearing at the local level (for example at a county department of social services) with a right of appeal to the state agency.[79] The hearing must be conducted at a reasonable time, date, and place by an impartial hearing official. A beneficiary must be allowed to present his or her case to an impartial decision maker and present evidence and

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[75] Section 1902(a)(3) of the Social Security Act; *Goldberg v. Kelly*, 397 U.S. 254 (1970).
[76] 42 C.F.R. § 431.211.
[77] 42 C.F.R. § 431.213.
[78] 42 C.F.R. §§ 431.206, 431.210.
[79] 42 C.F.R. § 431.205(b).

witnesses.[80] The beneficiary is also entitled to have representation, including legal counsel, a relative, or a friend.[81] Before the hearing, beneficiaries must have the right to examine the case file and all documents that will be used at the hearing.[82]

When a service is terminated or reduced, if the beneficiary requests a hearing within ten days of receiving notice of the termination or reduction, the beneficiary has the right to continued coverage of services pending a hearing decision.[83] This is sometimes called "aid paid pending." Once the agency issues a final decision, the beneficiary generally has the right to appeal that decision to state court.

Managed care enrollees must have access to in-plan grievance and appeal processes, in addition to the state fair hearing system.[84] Managed care plans must provide enrollees written notices that explain the action, the reason for the action, and the procedures for using the in-plan grievance and state fair hearing processes, including rights to continued benefits. Managed care plans must resolve complaints in a timely manner, including within three working days when the enrollee or provider indicates that delay could seriously jeopardize the enrollee's life, health or ability to attain, maintain, or retain maximum function.[85] The state can require enrollees to exhaust the plan's internal grievance process before obtaining a state fair hearing.

The state agency must issue and publicize its hearing decisions.[86] In addition, the public must have access to all fair hearing decisions, subject to regulatory requirements providing for safeguarding of confidential personal and health information.[87]

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[80] 42 C.F.R. §§ 431.240, 431.242.
[81] 42 C.F.R. § 431.206(b)(3).
[82] 42 C.F.R. § 431.242.
[83] 42 C.F.R. § 431.230.
[84] 42 C.F.R. § 438.402.
[85] 42 C.F.R. § 438.408.
[86] 42 C.F.R. § 431.206(a).
[87] 42 C.F.R. § 431.244(g).

IX. CONCLUSION

The goal of EPSDT is to assure that all Medicaid-enrolled children under age 21 receive the health care they need. EPSDT covers not only medically necessary treatment to correct or ameliorate identified conditions, but also preventive, and maintenance services. In addition, EPSDT covers age-appropriate medical, dental, vision and hearing screening services at specified times, and when health problems arise or are suspected.

The broad scope of EPSDT provides states with the tools necessary to offer a comprehensive, high-quality health benefit. To fully realize EPSDT's potential, however, attention is needed on issues affecting access to services, including supply of providers, the presence of managed care, linguistic and disability access, and transportation. CMS is available to help states address these issues to ensure that EPSDT coverage meets the needs of children under age 21 who depend on Medicaid for their health care.

X. WHAT YOU NEED TO KNOW ABOUT EPSDT

EARLY: Assessing and identifying problems early

Children covered by Medicaid are more likely to be born with low birth weights, have poor health, have developmental delays or learning disorders, or have medical conditions (e.g., asthma) requiring ongoing use of prescription drugs. Medicaid helps these children and adolescents receive quality health care.

EPSDT is a key part of Medicaid for children and adolescents. EPSDT emphasizes preventive and comprehensive care. Prevention can help ensure the early identification, diagnosis, and treatment of conditions before they become more complex and costly to treat. It is important that children and adolescents enrolled in Medicaid receive all recommended preventive services and any medical treatment needed to promote healthy growth and development.

PERIODIC: Checking children's health at age-appropriate intervals

As they grow, infants, children and adolescents should see their health care providers regularly. Each state develops its own "periodicity schedule" showing the check-ups recommended at each age. These are often based on the American Academy of Pediatrics' Bright Futures guidelines*:* Recommendations for Preventive Pediatric Health Care. Bright Futures helps doctors and families understand the types of care that infants, children and adolescents should get and when they should get it. The goal of Bright Futures is to help health care providers offer prevention-based, family-focused, and developmentally-oriented care for all children and adolescents. Children and adolescents are also entitled to receive additional check-ups when a condition or problem is suspected.

SCREENING: Providing physical, mental, developmental, dental, hearing, vision and other screening tests to detect potential problems

All infants, children and adolescents should receive regular well-child check-ups of their physical and mental health, growth, development, and nutritional status. A well-child check-up includes:

- A comprehensive health and developmental history, including both physical and mental health development assessments;
- Physical exam;
- Age-appropriate immunizations;
- Vision and hearing tests;
- Dental exam;
- Laboratory tests, including blood lead level assessments at certain ages; and
- Health education, including anticipatory guidance.

DIAGNOSTIC: Performing diagnostic tests to follow up when a health risk is identified

When a well-child check-up or other visit to a health care professional shows that a child or adolescent might have a health problem, follow up diagnostic testing and evaluations must be provided under EPSDT. Diagnosis of mental health, substance use, vision, hearing and dental problems is included. Also included are any necessary referrals so that the child or adolescent receives all needed treatment.

TREATMENT: Correct, reduce or control health problems found

EPSDT covers health care, treatment and other measures necessary to correct or ameliorate the child or adolescent's physical or mental conditions found by a screening or a diagnostic procedure. In general, States must ensure the provision of, and pay for, any treatment that is considered "medically necessary" for the child or adolescent. This includes treatment for any vision and hearing problems, including eyeglasses and hearing aids. For children's oral health, coverage includes regular preventive dental care and treatment to relieve pain and infections, restore teeth, and maintain dental health. Some orthodontia is also covered.

XI. RESOURCES

CMS Resources

- CMS, *State Medicaid Manual §§ 2700.4 and 5010-5360*
- CMS, *Early and Periodic Screening Diagnostic and Treatment Resources*

Adolescent Health

- CMS, *Paving the Road to Good Health: Strategies for Increasing Medicaid Adolescent Well-Care Visits (Feb. 2014)*

Oral Health

- CMS, *Keep Kids Smiling: Promoting Oral Health Through the Medicaid Benefit for Children and Adolescents* (September 2013)
- CMS, *Improving Access to and Utilization of Oral Health Services for Children in Medicaid and CHIP Programs*, CMS Oral Health Strategy (April 11, 2011)
- CMS, *CMCS Informational Bulletin, CMS Oral Health Initiative and Other Dental Related Issues* (April 18, 2013)
- *Improving Oral Health Care Delivery in Medicaid and CHIP: A Toolkit for States* (February 2014)

Mental Health

- CMS, *CMCS Informational Bulletin, Prevention and Early Identification of Mental Health and Substance Use Conditions* (March 27, 2013)
- CMS, *Joint CMCS and SAMHSA Informational Bulletin, Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013)

Screening Services

- CMS, *Guide for States Interested in Transitioning to Targeted Blood Lead Screening for Medicaid-eligible Children* (May 2012)

Accessibility

- CMS, *CMCS Informational Bulletin* (April 26, 2011) (federal funding for interpretation and translation services)
- CMS, *Dear State Medicaid Director* (Aug. 31, 2000) (Limited English Proficiency)
- CMS, *Dear State Medicaid Director, Olmstead Update No. 4*, Att. 4-B EPSDT (Jan. 10, 2001)
- CMS, *Medicaid School-Based Administrative Claiming Guide* (May 2003)

Other Federal Resources

- CDC, Vaccine Recommendations of the ACIP
- HRSA, *EPSDT & Title V Collaboration to Improve Child Health*
- Health Resources and Services Administration EPSDT website
- HHS Office of Minority Health's *Think Cultural Health: Advancing Health Equity at Every Point of Contact*
- HHS Office of Minority Health's *A Physician's Practical Guide to Culturally Competent Care*
- HHS Office of Minority Health's *Culturally Competent Nursing Care: A Cornerstone of Caring*
- HHS Office of Minority Health's *Cultural Competency Curriculum for Disaster Preparedness and Crisis Response*
- HHS Office of Minority Health's *Cultural Competency Program for Oral Health Professionals*
- HHS Office of Minority Health's *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards*)
- HHS Office of Minority Health's *A Blueprint for Advancing and Sustaining CLAS Policy and Practice (The Blueprint)*

Other Resources

- American Academy of Pediatrics, *Bright Futures* (2014)
- American Academy of Pediatrics, *Bright Futures Recommendations for Pediatric Preventive Care* (2014)
- American Academy of Pediatric Dentistry, *Guideline on Periodicity of Examination, Preventive Dental Services, Anticipatory Guidance/Counseling, and Oral Treatment for Infants, Children, and Adolescents* (2013)
- Association of Maternal and Child Health Programs, *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (March 2014)
- George Washington University, Health Information & The Law, *Understanding the Interaction Between EPSDT and Federal Health Information Privacy and Confidentiality Laws* (2013)
- National Academy of State Health Policy, Managing the "T" in EPSDT Services (2010)
- National Academy of State Health Policy, Resources to Improve Medicaid for Children and Adolescents
- National Health Law Program, Toward a Healthy Future: Medicaid EPSDT Services for Poor Children and Youth
- National Health Law Program, Annotated Federal Documents

Medicaid Amount Duration Scope

FACT SHEET

MEDICAID'S AMOUNT, DURATION AND SCOPE REQUIREMENT: CHALLENGING CUTS TO SERVICES FOR ADULTS

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April 2004

I. Introduction

This fact sheet will describe how courts and the federal Department of Health and Human Services have interpreted and applied Medicaid's requirements addressing sufficiency of services provided under state Medicaid programs. In particular, it discusses the requirement that services be provided in a sufficient amount, duration and scope to reasonably achieve their purpose. It will also provide tips for advocates who are dealing with state cuts to Medicaid services.

II. Medicaid Background

The Medicaid Program was established by Title XIX of the Social Security Act in 1965 to enable states to provide medical services to individuals with limited ability to pay for health care.[1] Medicaid is a cooperative federal-state program in which the federal government shares the cost of health care provided by states through the program. The agency charged with administering the Medicaid program is the Centers for Medicare & Medicaid Services (CMS)[2]

While states are not obligated to participate in the Medicaid program, if they do they must operate their programs in compliance with federal statutory and regulatory requirements.[3] States are required to provide coverage of certain categories of individuals and have the option of covering others.[4] Similarly, states must offer certain basic services and have the option of providing others.[5]

Congress did not establish a specific minimum level of each service that states must provide. Instead, states are required to establish reasonable standards, comparable for all eligibility groups, to determine the extent of the medical assistance provided.[6] These standards must be consistent with the objectives of the Medicaid Act.[7] In addition, regulations require that services be Asufficient in amount, duration and scope to reasonably achieve their purpose.[8] Moreover, states cannot Aarbitrarily deny or reduce the amount, duration or scope of services to an otherwise eligible individual solely because of diagnosis, type of illness or condition.[9]

Beneficiaries have challenged the sufficiency of Medicaid services numerous times over the past thirty years, however, no concrete rule has emerged as to what constitutes a sufficient amount of services. The limits of some particular services have been more clearly drawn, however, courts and administrative law judges continue to evaluate the individual service and beneficiary circumstance in each situation. Courts have in large part given states leeway in determining the limits of services but, however, may not hesitate to strike down arbitrary or unreasonable classifications. In the late 1970s and early 1980s, a series of important cases upheld statewide numerical limits on hospital days and doctor visits covered under Medicaid programs.[10] During the mid 1980s, the trend appeared to reverse and a number of challenges to limitations on the amount, duration and scope of services succeeded.[11] In the 1990s, judges and CMS found irrebuttable presumptions that particular services could never be medically necessary to be troublesome. Meanwhile, as managed care has become an integral part of many state Medicaid programs, these issues have taken on even greater importance.

Amount, duration and scope issues can arise in several contexts. First, advocates might challenge state Medicaid program limitations services provided on behalf of a class of beneficiaries in a systemic attempt to invalidate the limitation itself. Second, advocates may challenge such limitations in representing an individual client requesting a services not covered by the state. Third, advocates can challenge refusals to provide services to a particular client without arguing that the state's coverage rules themselves are illegal. For example, a state may decide to make cuts in its personal care services (PCS) and may create a policy restricting coverage of PCS to beneficiaries who cannot ambulate without a wheelchair. Advocates may contemplate a class action on behalf of Medicaid beneficiaries who need PCS but who do not have disabilities affecting their ability to walk. Advocates may also challenge the policy on behalf of an individual client. Another alternative would be to argue that an individual client beneficiary who does not meet the new state criteria needs PCS, without challenging the policy itself.

III. Legal Theories

The following sections discuss frequently-used amount, duration and scope theories. All apply to mandatory medicaid services. It is open to question whether one of the theories applies to optional services, as will be discussed below. As discussed above, states are required to provide Amandatory servicesincluding physician services, inpatient hospital services, outpatient hospital services and home health services for severely disabled individuals.[12] Optional services are those that the state may choose to cover, such as prescription drugs, personal care services, and dental services.[13]

The three most commonly-used theories are: (1) all medically necessary treatment within a covered service area must be covered; (2) a service must be covered in an amount sufficient to achieve its purpose; (3) particular illnesses cannot be singled out for restricted coverage; and (4) states must use reasonable standards in administering their Medicaid programs. In addition, another possible federal and state theories will be discussed.

A. Medical Necessity

Courts have recognized that the Abasic objective of the Medicaid program is to provide individuals with medically necessary care and, moreover, that the Atouchstone for evaluating whether a state plan is reasonable is whether medically necessary procedures are covered.[14] Court have split on the issue of whether, within a covered service area, all Amedically necessary treatment must be provided. Because this requirement is neither stated in the Medicaid statute nor the regulations, different courts have based medical necessity theory upon different legal provisions.[15] Advocates may find it more useful to cite various cases supporting this theory, rather than attempting to tie the requirement to a specific statutory or regulatory source.

Several courts have held that, when the patient's physician and the state agency's decision maker disagree about whether requested treatment is medically necessary, the treating physician's opinion should be given more weight. Courts have so held for two essential reasons. First, the provider is generally Aintimately familiar with the patient's medical history and needs, unlike the Aclerical personnel or government officials reviewing the request for treatment.[16] Second, the provider is frequently more qualified than the reviewer as, for example, when the provider is a physician and the reviewer is not, or when the provider specializes in the condition at issue and the reviewer does not.[17] It can be helpful to advocates to cite one or both of these reasons if applicable. Advocates should also point to the Senate Report on the original Medicaid bill, which confirms that Congress intended that states show deference, stating: AThe Committee's bill provides that the physician is to be the key figure in determining utilization of health services - and provides that it is a physician who is to decide upon admission to a hospital, order tests, drugs and treatments and determine the length of a stay.[18] Further, when challenging policies or rules of state Medicaid agencies, advocates should note a still-valid Ninth Circuit decision holding that general determinations by administrative agencies concerning medical necessity are unpersuasive when compared to the judgment of a treating provider.[19]

The Supreme Court has not spoken directly on this issue in its 1977 opinion, *Beal v. Doe*.[20] Two principles emerged from this case. First, the Court noted that states are given broad discretion in determining the extent of medical services they will offer. However, the Court also noted that Aserious statutory questions might be presented if a state Medicaid plan excluded necessary medical treatment from its coverage.[21] Decisions dealing with medical necessity must grapple with the tension between the Abroad deference given to a state in choosing the services it will cover with the deference accorded a treating physician. To harmonize these apparently competing concepts, it may be useful for advocates to think about the concept of medical necessity as having two levels of judgment. The first is the structural decision of whether a particular service is sufficiently necessary to fall under the coverage of its plan while the second is the patient-specific decision of the physician that the condition of a particular patient warrants treatment which the state plan makes available.[22] While the first decision is not necessarily completely insulated from judicial or agency scrutiny, a state will be afforded more deference in this area. This concept will be discussed more fully below in connection with the requirement that states have Areasonable standards.

B. Coverage Sufficiency

The second theory of amount, duration and scope cases is based on the regulation requiring that A[e]ach service must be sufficient in amount, duration and scope to reasonably achieve its purpose.[23] Restrictions on covered services that prevent the services from achieving their objectives have been held to violate this regulation.[24] The question becomes, how to determine what those objectives are.[25] To ascertain the purpose of a particular service, courts have looked to federal provisions concerning the service, including those defining the service.[26] Others have looked at legislative history.[27] Guidance from CMS, from its*State Medicaid Manual* or from its periodic letters to state Medicaid directors may also be helpful.[28] State statutes and regulations can be helpful as well, unless advocates are asserting that the state definition itself violates the requirement.[29] Courts and administrative law judges have also discerned the purpose of a covered service even without reference to any statutory or regulatory provision.[30]

A state may defend a coverage restriction from challenge under this regulation by arguing that most patient's needs for services are met and, although a particular patient's needs may not be met, the covered services do, generally speaking, Areasonably achieve their purpose. This argument is based upon cases like *Curtis v. Taylor*, in which the Fifth Circuit upheld coverage of only a certain number of hospital days or physician visits per year because the vast majority of patients' needs for services were satisfied despite the challenged limitations.[31] However, these cases deal with numerical limits applicable across the board to medical care of all kinds, rather than with restrictive criteria applied to a particular treatment. In fact, cases invalidating limited coverage of particular services have examined *individuals'* needs for services, expressly finding it irrelevant whether *most* patients' needs could be satisfied.[32]

States have frequently attempted to buttress their arguments in this area with language from the Supreme Court's decision in *Alexander v. Choate*: AMedicaid programs do not guarantee that each recipient will receive that level of health care precisely tailored to his or her needs.[33] Advocates must keep in mind that this case was interpreting Section 504 of the Rehabilitation Act of 1973, however, and that the Court expressly declined to rule on whether the state policy at issue - a 14 day annual limit on hospital care - violated the Medicaid statute.[34] The Court did reason that even though people with disabilities frequently require hospital stays longer than 14 days, the 14 day limit did not deny meaningful benefit to them because the Abenefit provided under Medicaid is Aa particular package of health services rather than Aadequate health care. [35]

C. Discrimination by Condition

The third federal amount, duration and scope theory stems from the regulatory prohibition that Athe Medicaid agency may not arbitrarily deny or reduce the amount, duration or scope of a required service under " 440.210 and 440.220 to an otherwise eligible recipient solely because of the diagnosis, type of illness or condition.[36] In other words, as one court explained, A[T]he regulations permit discrimination in benefits based upon the degree of medical necessity but not upon the medical disorder from which the person suffers.[37] A number of courts have relied upon this regulation in invalidating coverage limitations.[38] And, although on its face the regulation applies only to mandatory services, several courts have applied the regulation to strike down restricted coverage of optional benefits as well.[39] Making such a claim may be a risky strategy in the current judicial climate, however.

D. Reasonable Standards

As discussed above, state plans must set Areasonable standards . . . which are consistent with the objectives of [the Medicaid Act].[40] While courts and CMS do afford states significant deference in this area, there is a reluctance to find standards reasonable that they establish irrebuttable presumptions or that allow for no exceptions. The most important example comes from the coverage of durable medical equipment (DME). Connecticut's Medicaid agency had developed a list of DME items that could be covered and denied requests for any items not on the list. In *Dasario v. Thomas*, the Second Circuit held that Connecticut was not required to cover medically necessary DME items under its plan as long as the health care provided was adequate with respect to the needs of the Medicaid population as a whole.[41] In response to this decision, CMS made it clear that this was an incorrect interpretation of the Medicaid Act. In a letter to state Medicaid directors, CMS indicated that states could develop a list of pre-approved DME items Aas an administrative convenience because such a list eliminates the need to administer an extensive application process for each [DME] request submitted. However, the letter went on to state that a DME policyAthat provides no reasonable and meaningful procedure for requesting items not on the approved list is inconsistent with 42 U.S.C. ' 1396a(a)(17), 42 C.F.R. '440.230(b) and 42 C.F.R. ' 440.230(c).[42] Following issuance of this letter, the United States Supreme Court, in *Slekis v. Thomas*, vacated the lower court's ruling and remanded for consideration in light of CMS' guidance.[43]

The Supreme Court's remand and CMS' guidance have been of great help to advocates challenging DME lists and exclusions.[44] States have generally been reluctant to apply this reasoning outside of the DME context, however, even after *Slekis*. However, in individual cases where clear medical need is demonstrated, courts have shown a reluctance to accept categorical exclusions of certain types of treatment or procedures.[45] AA state law that categorically denies coverage for a specific, medically necessary procedure except in those rare instances when the patient's life is at stake is not a Areasonable standard. . . .[46]

E. Other Federal Theories

Another argument based on federal law involves procedural issues. If the coverage limitation at issue in a particular case resulted from a state's reduction in services, advocates should determine whether a state satisfied federal requirements for making such reductions. According to the regulations, before a state agency takes action to terminate, suspend, or reduce services, it must provide notice to each affected beneficiary.[47] Unless the reduction is the result of a change in law [or policy] beneficiaries must be afforded an opportunity for a hearing.[48] The notice must contain: (1) a statement of the action that the state or facility intends to take; (2) the reasons for the intended action; (3) the specific regulation that supports, or the change in federal or state law that requires the action; (4) an explanation of the individual's right to request a hearing; (5) the circumstances under which a hearing will be granted; and (6) an explanation of the circumstances under which Medicaid is continued if a hearing is requested.[49]

The concept of Aservice reduction subject to these regulations has been broadly construed to include, for example, the imposition of copayments.[50] Service reductions have been invalidated and states ordered to return to prior service levels for failure to furnish advance notice,[51] or adequate notice, or for failure to give notice in a proper manner, and for failure to provide an opportunity for a hearing.

F. State Theories

In addition to these federal approaches, advocates should explore theories available under the laws of their particular states. State statutes and regulations requiring provision of particular benefits, as well as more general language from state Medicaid statutes and regulations, can prove useful in amount, duration and scope cases.[52] Advocates should also investigate whether the Medicaid agency has complied with applicable state Administrative Procedures Acts (APAs). State APAs, like the federal APA,[53] usually requires that general policy changes be preceded by notice to the general public and an opportunity for the public to comment. Particular state statutes may impose other requirements as well.

IV. Practical Considerations

When determining whether a restriction is illegal, advocates should, if possible, request all recent internal memoranda concerning the service restriction at issue under state public records acts.[54] Such memoranda may help identify state officials who disagree with the state's restrictions and who can be subpoenaed for hearing or deposed. Such memoranda may also help to show that the restrictions are based upon financial rather than medical considerations, and are thus unrelated to the purposes of the Medicaid program. The records request should seek all documents concerning the state's compliance with federal and state procedural requirements before implementing the questioned policy.

Given the uncertainty that currently surrounds the enforceability of Medicaid requirements, advocates should strongly consider challenging restrictions on individual bases at fair hearings.[55] Such a course would avoid any issue of exhaustion of remedies. Moreover, a fair hearing allows for more effective discovery than anything possible after filing a lawsuit.

For example, the states' witnesses will usually not have received the advice of counsel and will be unaware of the arguments that might be made and will frequently make astonishing admissions. It can be helpful to think out theories carefully and determine in advance what kind of admissions might be particularly useful. Moreover, to the extent possible, advocates should attempt to have the treating provider (or another knowledgeable provider) present at the hearing. Failing that, participation by phone can be helpful. The informality of hearings allows such providers to respond immediately to statements by state witnesses. These responses usually should be followed up by cross-examination of state witnesses, which can be quite effective in hearings when opposing counsel is not present.

The key to an amount, duration and scope case is the factual record. If possible, advocates should show that the requesting provider knows the patient very well or possesses expertise concerning the treatment. Pursuing the latter angle may also involve establishing that the state employee rejecting the treatment request possesses little expertise or few qualifications. Accordingly, advocates should find out as much as possible about the state employee rejecting the treatment. The requesting provider should phrase his or her conclusions in terms consistent with applicable legal principles. The provider should state that, based on considered medical judgment and personal knowledge of the patient, the treatment at issue is (1) medically necessary and (2) required in order to achieve a particular purpose - the purpose of the particular benefit category. For example, in challenging a state's refusal to cover a particular prescribed drug, one might argue, based upon the regulation, that the purpose of the state's coverage of prescribed drugs is Athe cure, mitigation or prevention of disease.[56] The treating provider could then state that the drug is necessary to cure, mitigate or prevent a particular disease. The provider should phrase additional conclusions in terms of state law requirements. For example, in challenging a state's refusal to approve a request for speech therapy where the state covers that service and state law requires the approval of treatment whenever Anecessary to prevent significant disability, the treating provider should state that the therapy is indeed necessary to do so. Of course, it is also essential that the provider set forth in full detail the basis for these conclusion, spelling out precisely what it likely to happen to the patient if the request treatment is not provided.

It is also crucial to focus on the inadequacies of alternative treatments that the state may provide. Amount, duration and scope cases have been lost because advocates failed to provide evidence that state-furnished treatments would not meet the patients' medical needs. Further, to the extent possible, provider declarations should also be included to document the consequences of restricted state coverage. Relevant university providers or provider organizations can be helpful in obtaining such expert assistance.

For more information on this issue contact National Health Law Program's Chapel Hill office.

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[1] 42 U.S.C. ' 1396 - 1396v.

[2] Until 2002, CMS was known as the Health Care Finance Administration, or HCFA. Agency guidance and court decisions issued before the change will refer to HCFA.

[3]42 U.S.C. ' 1396a. For an overview of the Medicaid program administration, services and eligibility, *see* National Health Law Program, *An Advocates Guide to the Medicaid Program* (June 2001).

[4]42 U.S.C. ' 1396a(a)(10).

[5]42 U.S.C. ' 1396d(a).

[6]42 U.S.C. ' 1396a(a)(17).

[7]*Id.*

[8]42 C.F.R. ' 440.230(b). *See also* 42 U.S.C. ' 1396a(a)(10)(B).

[9]42 C.F.R. ' 440.230(c).

[10]*See e.g. Charleston Memorial Hospital v. Conrad*, 693 F.2d 324 (4th Cir. 1982); *Curtis v. Taylor*, 625 F.2d 645 (5th Cir. 1980); *Virginia Hosp. Ass'n v. Kenley*, 427 F. Supp. 781 (E.D. Va. 1977).

[11]*See e.g. Meyers v. Reagan*, 776 F.2d 241 (8th Cir. 1985); *Vogel v. Perales*, No. 81 Civ. 7992, 1983 U.S. Dist. LEXIS 15303 (S.D. N.Y. 1983);*Jeneski v. Meyers*, 163 Cal. App. 3d 18 (1984); *cert. denied sub nom Vizer v. Jeneski*, 105 S. Ct. 2677 (1985); *Kirk v. Dunning*, 370 N.W.2d 2677 (Neb. 1985).

[12]42 U.S.C. ' 1396d(a)(1)-(5), (17) and (21). 42 U.S.C. " 1396d(a)(1) (inpatient hospital services); 1396d(a)(2)(A) (outpatient hospital services); 1396d(d)(a)(5)(A) (physician services); 1396d(a)(7).

[13]42 U.S.C. " 1396d(a)(10) (dental services); 1396d(a)(12) (prescription drugs); 1396d(a)(24) (personal care services).

[14]*Hern v. Beye,* 57 F.3d 906, 910-911 (10th Cir. 1995)

[15]*See e.g. Hern,* 57 F.3d 906; *Weaver v. Reagan,* 886 F.2d 194 (8th Cir. 1989); *Pinneke v. Priesser*, 623 F.2d 546, 548 n. 2 (8th Cir. 1980) (apparently relying on 42 U.S.C. " 1396, 1396a(a)(10)(c)); *Vogel v. Perales,* (relying on 42 C.F.R. ' 440.320(b)); *Meyers*, 776 F.2d at 244; *Roe v. Casey*, 464 F. Supp. 487, 499-501 (E.D. Pa. 1978) (relying on 42 U.S.C. ' 1396, 42 C.F.R. ' 440.320(b)).

[16]*Dodson*, 427 F. Supp. at 108; *Pinneke,* 623 F.2d at 550.

[17]*Dodson*, 427 F. Supp. at 107, 108; *Jeneski*, 163 Cal. App. 3d at 32.

[18]S. Rep. No. 404, 89th Cong., 1st Sess., *reprinted in* 1965 U.S. Code Cong. And Ad. News, 1943, 2986. For cases discussing applying this deference, *see Holman v. Ohio Dep't Human Services,* 757 N.E.2d 382, 388 (Ohio Ct. App. 2001); *A.M.L. v. Utah Dep't Health,* 863 P.2d 44, 48 (Utah Ct. App. 1993); *Pinneke*, 623 F.2d at 550; *Dodson v. Parham*, 427 F. Supp. 97, 108 (N.D. Ga. 1977); *Jeneski*, 163 Cal. App. 3d at 32.

[19]*Vista Hill Found., Inc. v. Heckler*, 767 F.2d 556, 560-61 (9th Cir. 1985).

[20]*Beal v. Doe*, 432 U.S. 438, 448 (1977) (holding that the requirement that two physicians concur in attending physician's conclusion that abortion is medically necessary may not have been Acontemplated by Congress, remanded for determination of Aprecise role of two additional physicians.)

[21]*Id.*, at 444.

[22]*See Preterm, Inc. v. Dukakis,* 591 F.2d 121, 125 (1st Cir. 1979); *McCoy v. Idaho Dep't Health & Welf.,* 907 P.2d 110, 113-114 (Idaho 1995) (characterizing these two levels as the Amacro-decision and the Amicro-decision.)

[23]42 C.F.R. ' 440.230(b). The statutory source for this requirement is 42 U.S.C. '1396a(a)(10)(B), although the statute does not contain this regulatory language.

[24]*See e.g. Esteban v. Cook,* 77 F. Supp. 2d 1256, 1261 (S.D. Fla. 1999) (holding that $582 cap on wheelchairs prevented service from fulfilling its purpose of minimizing effects of mobility problems); *Cushion v. Path,* 807 A.2d 425, 478 (Vt. 2002) (holding that restriction on partial dentures prevented service from achieving purpose of providing dental services to those most in need); *Jackson v. O'Bannon* No. 80-500 (E.D. Pa. Feb. 8, 1980) (available from NHeLP);*Kirk v. Dunning*, 370 N.W.2d at 115-6.

[25]*See Sobky v. Smoley*, 855 F. Supp. 1123, 1143 (E.D. Cal. 1994) (nothing that Awhat is considered Areasonable [to achieve the purpose] is not defined and reviewing decisions interpreting this requirement).

[26]*Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990) (federal regulatory definition of private duty nursing); *Cushion*, 807 A.2d at 428; *Dodson,* 427 F. Supp. at 108; *Philadelphia Welfare Rights Org. v. Schapp*, 602 F.2d 1114, 1122-23 (3d Cir. 1979), *cert. denied*, 444 U.S. 106 (1980); *Simpson v. Wilson*, 480 F. Supp. 97, 102 (D. Vt. 1979).

[27]*But see Detsel*, 895 F.2d at 64 (noting that definition of private duty nursing that prevailed when Medicaid was enacted in 1965 would not necessarily remain reasonable when case was decided in 1990).

[28]CMS, *State Medicaid Manual*, *available at* www.cms.gov. *See also Philadelphia Welfare Rights Org.*, 602 F.2d at 1122.

[29]*Esteban,* 77 F. Supp. 2d at 1260-1261; *Morgan v. Idaho Dep't Health & Welf.,* 813 P.2d 345, 349 (Id. 1991) *But see Hines v. Sheehan,* No. 94-326-P-H, 1995 U.S. Dist. LEXIS 11031, *5 (D. Me. July 26, 1995) (holding that Maine's policy of providing liquid diet supplements only to those with end stage renal disease or receiving the supplement through a feeding tube does not violate Medicaid Act).

[30]*Kirk*, 370 N.W.2d at 115-116.

[31]*Curtis v. Taylor*, 625 F.2d 645 (5th Cir. 1980). *See also*, *Charleston Memorial Hospital*, 693 F.2d at 324; *Virginia Hosp. Ass'n*, 427 F. Supp. At 781. *But see Community Service Society v. Cuomo*, 561 N.Y.S.2d 461 (N.Y. 1990) (holding that covering only a certain number of physician visits according to the nature of the specialty involved might not afford access to medically necessary services, upholding entry of preliminary injunction).

[32]*Jeneski*, 163 Cal. App. 3d at 33 (holding that Ajudgments of medical necessity . . . must be made in individual cases.)

[33]*Alexander v. Choate*, 469 U.S. 287 (1985).

[34]*Id.* at 303 n. 23.

[35]*Id.* at 303.

[36]42 C.F.R. ' 440.230(c).

[37]*White v. Beal*, 555 F.2d 1146, 1152 (3d Cir. 1977); *cited with approval in Jeneski v. Meyer,* 163 Cal. App. 3d at 33.

[38]*White*, 555 F.2d at 1151-52; *Pinneke*, 623 F.2d at 549, 550; *Hodgson v. Board of County Comm'rs*, 614 F.2d 601, 608 (8th Cir. 1980);*Simpson v. Wilson*, 480 F. Supp. 97, 101; *Jeneski,* 163 Cal. App. 3d at 33.

[39]*White v. Beal*, 555 F.2d at 1152, n. 6; *Simpson,* 480 F. Supp. at 102*; Jeneski v. Meyer*, 163 Cal. App. 3d at 30, n. 9, *Weaver v. Reagan*, 886 F.2d 194 (8th Cir. 1989). *But see Ledet v. Fischer*, 548 F. Supp. 775, 786 (M.D. La. 1982). *But see Dexter v. Kirschner*, 984 F.2d 979 (9th Cir. 1993) (holding that Medicaid Act gives discretion for covering organ transplants and state is within its discretion to fund one type of bone marrow transplant but not another).

[40]42 U.S.C. ' 1396a(a)(17).

[41]*DeSario v. Thomas*, 139 F.3d 80 (2d Cir. 1998).

[42]CMS, *Dear State Medicaid Director Letter*, Sept. 4, 1998, *available at* http://www.cms.hhs.gov/states/letters/smd90498.asp

[43]*Slekis v. Thomas*, 525 U.S. 1098 (1999).

[44]*See e.g. T.L. v. Colo. Dep't Health Care Policy*, 42 P.3d 63 (Colo. Ct. App. 2001) (striking down state exclusion of hot tubs from Medicaid coverage regardless of medical necessity); *Fred C. v. Texas Health and Human Services Comm'n*, 924 F. Supp. 788 (W.D. Tex. 1996), *vacated on other grounds* 117 F.3d 537, *on remand*, 988 F. Supp. 1032 (W.D. Tex. 1997), *aff'd without opinion* 167 F.3d 537 (5th Cir. 1998) (striking down denial of coverage of augmentive communicative device).

[45]*See e.g. Holman*, 757 N.E.2d at 386 (noting that Aby presuming non-coverage to all cosmetic surgeries, [the state Medicaid agency] erred as a matter of law.); *See also Allen v. Mansour*, 681 F. Supp. 1232 (E.D. Mich. 1986) (finding that requiring a two-year period of abstinence from alcohol before allowing a liver transplant for alcoholic cirrhosis arbitrary and unreasonable). *But see Smith v. Rasmussen*, 249 F.3d 755 (8th Cir. 2001) (upholding Iowa Medicaid agency's categorical exclusion of sex reassignment surgery as consistent with Medicaid Act).

[46]*Visser v. Taylor*, 756 F. Supp. 501 (D. Kan. 1990) (holding that state Medicaid agency's refusal to cover prescription drug Clozaril for beneficiary despite demonstrated medical necessity violated sufficiency requirement).

[47]42 C.F.R. '' 431.201, 431.211.

[48]42 C.F.R. '' 431.206, 431.210, 431.220.

[49]42 C.F.R. ' 431.210

[50]*Becker v. Toia*, 439 F. Supp. 324, 331 (S.D. N.Y. 1978).

[51]*Eder. v. Beal*, 609 F.2d 695 (3d Cir. 1979); *Toia*, 439 F. Supp. At 324.

[52]*See e.g. Jeneski*, 163 Cal. App. 3d at 31.

[53]5 U.S.C. '' 551-76.

[54]See e.g. Cal. Govt. Code. '' 6250-65

[55]For cases discussing challenges enforcing Medicaid requirements through 42 U.S.C. ' 1983, *see* Jane Perkins, *42 U.S.C. ' 1983 and Enforcement of the Medicaid Act*, available from NHeLP's Chapel Hill office.

[56]*See* 42 C.F.R. 440.120(a)*.*

Medicaid for New Attorneys

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National Health Law Program

December 2006

http://www.heathlaw.org

NATIONAL HEALTH LAW PROGRAM

Medicaid for New Attorneys[1]

This paper provides the new attorney with an overview of the Medicaid program—its administration, eligibility and service rules. While each state must adhere to the federal Medicaid Act's minimum requirements, there is much room for flexibility. Therefore, it is important to become familiar not only with the federal rules but also with the policies guiding the program at the state level.

Medicaid can be complex. For in-depth information about the program, please consult our *Advocate's Guide to the Medicaid Program.* We are also available to consult with you on any question that you have about the program's operation federally or in your state. Please do not hesitate to contact us.

Introduction

Medicaid is the program of medical assistance for individuals with limited incomes established by Title XIX of the Social Security Act.[2] Medicaid covers one in six people.[3] It is the largest source of insurance for children, covering nearly one in four.[4] This paper covers the following topics:

- Administration of the Medicaid program
- Medicaid eligibility
- The scope of covered benefits
- Provider participation and managed care
- Key issues and resources for dealing with them

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[1] Updated and revised from the original publication: National Center on Poverty Law, *Poverty Law Manual for the New Lawyer* (2002), Ch. 5, pp. 61-70.

[2] *See* 42 U.S.C. §§ 1396 *et seq.* 42 C.F.R. §§ 430 *et seq.*

[3] *See* THE KAISER COMMISSION ON MEDICAID AND THE UNINSURED, MEDICAID: A PRIMER i (July 2005), *available at* http://www.kff.org. [hereinafter MEDICAID: A PRIMER]; U.S. Bureau of the Census, www.census.gov.

[4] *Id.* at 3.

Sources of Information on Medicaid

- Medicaid Act – 42 U.S.C. §§ 1396 *et seq.*
- Medicaid Regulations – 42 C.F.R. §§ 430 *et seq.*
- CMS, State Medicaid Manual, *available at* http://www.cms.hhs.gov/Manuals/01_Overview.
- CMS, Dear State Medicaid Director Letters, *available at* http://www.cms.hhs.gov/SMDL/SMD/list.asp#TopOfPage and www.healthlaw.org
- CMS transmittals, *see* www.healthlaw.org
- Federal and state court cases
- State statutes and regulations, health plan and provider contracts, and policy letters
- State Medicaid Plan, link through http://www.cms.hhs.gov/medicaid/stateplans/
- State case worker and provider manuals

Administration of the Medicaid program

Since its enactment in 1965, Medicaid has been an “entitlement” program. This means that individuals who meet Medicaid eligibility requirements have a *legal right* to have payments made to their providers for the covered services they need.

While state participation in Medicaid is voluntary, all states participate. States also have an entitlement—to receive federal matching payments for all state spending on covered services. Federal payments do not come without strings attached, however, as states must adhere to minimum federal requirements when implementing their Medicaid programs.[5]

Administration of the Medicaid program at the federal level is the responsibility of the Centers for Medicare and Medicaid Services (CMS), of the United States Department of Health and Human Services.[6] In addition to promulgating Medicaid regulations, CMS publishes the *State Medicaid Manual* and *Dear State Medicaid Director* letters that announce federal Medicaid policy.

Federal law requires each state to designate a "single state agency" to administer its Medicaid program.[7] This means that each state must have in effect a written state Medicaid plan that has been approved by the federal government.[8] The state plan describes who is eligible for Medicaid, what services are covered, and how the program is administered. In general, the state's Medicaid program must conform to all requirements of federal law[9] and operate statewide.[10]

States must provide that all individuals wishing to apply for Medicaid can do so without delay and ensure that assistance will be furnished with reasonable promptness.[11] States must also establish a Medical Care Advisory Committee,

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[5] *See, e.g.,* Wilder v. Virginia Hosp. Ass'n, 496 U.S. 498, 502 (1990)("Although participation in the program is voluntary, participating States must comply with certain requirements imposed by the Medicaid Act (Act) and regulations promulgated by the Secretary of Health and Human Services."); Schweiker v. Gray Panthers, 453 U.S. 34, 36-37 (1981) ("An individual is entitled to Medicaid if he fulfills the criteria established by the State in which he lives. State Medicaid plans must comply with requirements imposed both by the Act itself and by the Secretary of Health and Human Services.").

[6] Until June 2001, CMS was known as the Health Care Financing Administration or HCFA.

[7] *See* 42 U.S.C. § 1396a(a)(5); 42 C.F.R. § 431.10.

[8] *See* 42 U.S.C. § 1396a ; 42 C.F.R. § 430.10.

[9] *See* 42 U.S.C. § 1396a (setting forth requirements states must meet).

[10] *See* 42 U.S.C. § 1396a(a)(1); 42 C.F.R. § 431.50.

[11] *See* 42 U.S.C. § 1396a(a)(8); 42 C.F.R. § 435.906.

which includes Medicaid beneficiaries and knowledgeable providers, to advise the single state agency on policy development and program administration and to review marketing materials of Medicaid-participating managed care organizations.[12]

Through matching payments, the federal and state governments fund the Medicaid program. In some states, counties or local governments also contribute toward the state costs. Federal matching payments can vary from fifty percent to eighty-three percent of the total expenditures, with poorer per capita income states receiving higher federal payments.[13] Federal spending accounts for 57 percent of all Medicaid spending.[14]

Medicaid Eligibility – Fitting into a category

An individual is not eligible for Medicaid simply because he or she has a low income. Rather, individuals must successfully pass through four separate screens before being awarded a Medicaid card. A Medicaid applicant must:

- Fit into a recognized eligibility category.
- Meet financial criteria by having limited income and resources.[15]
- Have appropriate immigration status—have United States citizenship or be a "qualified alien."[16]

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[12] *See* 42 U.S.C. § 1396a(a)(4); 42 C.F.R. § 431.12.

[13] *See* 42 U.S.C. §§ 1396d(a), 1396d(b).

[14] *See* MEDICAID: A PRIMER, *supra* at 11.

[15] *See* 42 U.S.C. § 1396a(a)(17). For example, possession of a car with an equity value of $1500, or less at state option, makes an applicant ineligible for Medicaid. *See*, *e.g.* Hazard v. Sullivan, 44 F.3d 399 (6th Cir. 1995) (upholding $1500 limit on automobile exclusion). Special financial eligibility rules apply when one spouse is in an institution, such as a nursing home, and the other still lives in the community, *see* 42 U.S.C. § 1396r-5.

[16] Most immigrants who arrive in the United States lawfully after August 22, 1996 are barred from receiving full-scope Medicaid benefits for at least five years, and Medicaid will only cover treatment of emergency medical conditions for these

- Be a resident of the state where the individual applies for Medicaid benefits.[17]

The first screen, fitting into an eligibility category, requires additional discussion. Of about 60 Medicaid eligibility categories currently, some are mandatory while others may be offered at state option.[18] The categories focus on four groups: children and their caretakers, pregnant women, the elderly, and people with disabilities. For example, states must cover children under age six whose family incomes are at or below 133 percent of the federal poverty level,[19] and children and adolescents between ages six and nineteen whose family incomes are at or below the federal poverty level.[20] In most states, individuals who are receiving Supplemental Security Income (SSI) on the basis of disability automatically qualify for Medicaid.[21] States must also use Medicaid to cover the Medicare Part A and Part B premiums, deductibles, and coinsurance of certain

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persons and other unqualified immigrants. *See* 8 U.S.C. § 1601 *et seq.*; 42 U.S.C. §§ 1320b-7, 1396b(v).

[17] *See* 42 C.F.R. § 435.403.

[18] *See* 42 U.S.C. § 1396a(a)(10).

[19] *See* 42 U.S.C. §§ 1396a(a)(10)(A)(I)(IV) and (VI), 1396a(l)(A)-(C) (Supp. 2001). The 2006 federal poverty level for a family of four is in the forty-eight contiguous states and the District of Columbia is $20,000. *See* 71 Fed. Reg. 3848 (Jan. 24, 2006). Federal poverty level figures are published annually in the Federal Register, usually during the month of February.

[20] *See* 42 U.S.C. §§ 1396a(a)(10)(A)(i)(VII), 1396a(l)(1)(D).

[21] *See* 42 U.S.C. § 1396a(a)(10)(A)(i)(II). SSI was created in 1972 to provide cash assistance to the aged, blind and disabled who have limited income and resources. Some states do not provide Medicaid automatically to persons receiving SSI. Under section 1902(f) of the Social Security Act, these states use their 1972 state assistance eligibility rules in determining Medicaid eligibility. *See* 1972 Social Security Amendments Act, Pub. L. No. 92-603, § 209(b), 86 Stat. 1381 (1972). These states, referred to as “209(b) states” after the provision of the Social Security Act enacting the option, are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

elderly or disabled individuals.[22] For example, states must provide Part A and Part B coverage to aged and disabled individuals who are entitled to receive Medicare Part A and who have incomes at or below the federal poverty level.[23]

States have the option to cover a number of other groups, including infants and pregnant women with incomes up to 185 percent of the federal poverty level,[24] noninstitutionalized disabled children,[25] working disabled individuals,[26] and elderly and disabled persons with incomes below the federal poverty level.[27] States can also cover the medically needy – persons who fit into a federal public benefit program category, such as SSI or families with children, but whose income or resources are above the eligibility levels for the benefit program.[28] Such individuals qualify for Medicaid once their income, minus incurred medical

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[22] Medicare Part A, called hospital insurance, includes inpatient hospitals services, skilled nursing, home health services, and hospice care, while Part B, called medical insurance, includes outpatient hospital services, physician services, ambulances, and medical equipment and devices. *See* 42 U.S.C. §§ 1395 *et seq.*

[23] *See* 42 U.S.C §§ 1396a(a)(10)(E), 1396d(p).

[24] *See id.* at §§ 1396a(a)(10)(A)(ii)(IX), 1396a(l)(A), (B).

[25] *See id.* at § 1396a(a)(e)(3).

[26] *See id.*. at § 1396a(a)(10)(A)(ii)(XV). States may impose premiums and cost-sharing requirements on this covered group. *Id.* at § 1396o(g).

[27] *See id.* at § 1396a(a)(10)(ii)(XIII).

[28] *See* 42 U.S.C. § 1396a(a)(10)(C). The following jurisdictions have medically needy programs: California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin. States electing the 209(b) option, *see supra* note 21, must have a medically needy program for the aged, blind, and disabled. *Id.* at § 1396a(f).

expenses, is less than the state's medically needy income level.[29] For example, assume that: (a) the state's medically needy income level is $500 per month; (b) the budget period is three months (states can use a one to six month budget period); and (c) the applicant has income of $700 per month. In this example, the applicant must incur a total of $600 in medical expenses over a three-month budget period before Medicaid coverage begins ($200 income exceeding the medically needy income level X 3 month budget period = $600 spend down).

Given the strict eligibility requirements, it is not surprising that not all poor people qualify for Medicaid. In 2003, Medicaid covered only forty two percent of non-elderly Americans with incomes below the federal poverty level.[30] Nonetheless, Medicaid is a crucial source of coverage for people with disabilities. In fact, Medicaid is the single largest source of insurance—public or private—for people with disabilities.[31]

The citizenship requirement also requires additional discussion. In February 2006, President Bush signed the Deficit Reduction Act, which addresses a wide range of issues including Medicaid.[32] Previously, states were permitted to grant eligibility to individuals who declared that they were citizens, without

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[29] *See* 42 U.S.C. § 1396a(a)(17). While states have a great deal of flexibility in how they operate their medically needy programs, states choosing this option must include prenatal and delivery services for pregnant women and ambulatory services for children under age 18. *Id.* at § 1396a(a)(10)(C)(ii), (iii).

[30] *See* THE KAISER COMMISSION ON MEDICAID AND THE UNINSURED, THE MEDICAID PROGRAM AT A GLANCE at 2 (May 2006), *available at* http://www.kff.org. The 2006 federal poverty level for a family of three is in the forty-eight contiguous states and the District of Columbia is $16,600; in Alaska, $20,750 and in Hawaii, $19,090. 71 Fed. Reg. 3849-3849 (Jan. 24, 2006).

[31] Medicaid covers about eight million people under age 65 with disabilities. *See* THE KAISER COMMISSION ON MEDICAID AND THE UNINSURED, MEDICAID'S ROLE FOR PEOPLE WITH DISABILITIES at i, 10 (Aug. 2003), *available at* http://www.kff.org.

[32] Pub. L. No. 109-171. For a detailed discussion of the Medicaid, Medicare and State Children's Health Insurance Program provisions of the DRA, *see* National Health Law Program, *Health Advocate* (Spring 2006), available at www.healthlaw.org.

requiring additional documentation.[33] The DRA requires that states document U.S. citizenship and identity or be denied federal funding for providing services to individuals for whom documentation is required.[34] The implementing interim regulations promulgated by CMS provide a closed-end list of documents that may be used to verify identity and require a hierarchical approach to verification.[35] For example, a passport can be used to prove both U.S. citizenship and identity. If the individual does not have a passport, a birth certificate may be used to verify citizenship, but another document must be used to prove identity, such as a driver's license.[36] If, and only if, an individual does not have a birth certificate, he may produce a document from the next category, such as a hospital record.[37] Moreover, copies are not acceptable – even notarized copies.[38]

The following recipients are not subject to these requirements: Individuals who are on Medicare,individuals who receive social security benefits based on disability and are in the two-year waiting period for Medicare eligibility, children who are receiving foster care or adoption assistance through either title IV-B or IV-E, and individuals who receive Supplemental Security Income (SSI) in states that grant automatic eligibility to SSI recipients.[39]

Even so, it is likely that this requirement will cause serious difficulties for the many individuals who will have trouble locating birth certificates or another document from the prescribed lists. [40] For a detailed discussion of these

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[33] 42 U.S.C. § 1320b-7(d).

[34] 42 U.S.C. § 1396b(i)(22).

[35] Centers for Medicare and Medicaid Services, "Medicaid Program; Citizenship Documentation Requirements," 71 Fed. Reg. 39214 (July 12, 2006).

[36] 71 Fed. Reg. at 39222 – 39224.

[37] 71 Fed. Reg. at 39223.

[38] 71 Fed. Reg. at 39216.

[39] *Id.*

[40] At the time this was written, final regulations had not been issued. Moreover, a challenge to the documentation requirements, filed by a nationwide class of

citizenship documentation requirements, including all of the individuals who are exempted, *see* NHeLP, *Health Advocate* (Spring 2006) at 26.

Medicaid Scope of Benefits

Under federal law, states must provide coverage for certain services and may choose to cover other types of services when needed by program beneficiaries. Included in the mandatory benefit package that is available to most beneficiaries are: inpatient and outpatient hospital services,[41] physician services,[42] laboratory and x-ray services,[43] family planning services,[44] and nurse midwife services.[45] States must cover home health services for any individual who is eligible to receive nursing facility services.[46] States must also cover Early and Periodic Screening, Diagnosis and Treatment (EPSDT) for children and adolescents under age twenty-one.[47] EPSDT includes periodic medical, vision, hearing and dental examinations, age-appropriate health education, and treatment services to "correct or ameliorate" physical or mental problems, including case management.[48]

States can choose whether or not to cover for adults, twenty-three optional

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applicants and beneficiaries, was ongoing in the Federal District Court for the Northern District of Illinois. *Bell v. Leavitt,* No. 06 C-3520 (N.D. Ill.).

[41] *See* 42 U.S.C. § 1396d(a)(1); 42 C.F.R. § 440.10(a).

[42] *See* 42 U.S.C. § 1396d(a)(5)(A); 42 C.F.R. § 440.50.

[43] *See* 42 U.S.C. § 1396d(a)(3); 42 C.F.R. § 440.30.

[44] *See* 42 U.S.C. § 1396d(a)(4)(C); 42 C.F.R. § 441.20.

[45] *See* 42 U.S.C. § 1396d(a)(17); 42 C.F.R. § 440.165.

[46] *See* 42 U.S.C. § 1396a(a)(10)(D); 42 C.F.R. § 440.70.

[47] *See* 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

[48] *Id.*

services, including prescription drugs,[49] dental services,[50] physical and related therapies,[51] home health services,[52] intermediate care facility services for the mentally retarded,[53] and personal care services.[54] States can also provide transportation as an optional Medicaid service, which includes expenses for transportation and "travel related expenses" necessary to secure medical examinations and treatment.[55] Notably, EPSDT requires these optional services for adults to be provided to children and adolescents when needed to correct or ameliorate a health problem.

Each service must be covered according to "reasonable standards" and "sufficient in amount, duration and scope to reasonably achieve its purpose."[56] Thus, while a state can limit coverage of inpatient hospital days to, for example,

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[49] *See* 42 U.S.C. § 1396d(a)(12); 42 C.F.R. § 440.120.

[50] *See* 42 U.S.C. § 1396d(a)(10); 42 C.F.R. § 440.100.

[51] *See* 42 U.S.C. § 1396d(a)(11); 42 C.F.R. § 440.110.

[52] *See* 42 U.S.C. § 1396d(a)(7); 42 C.F.R. § 440.70.

[53] *See* 42 U.S.C. § 1396d(a)(15); 42 C.F.R. § 483.400 *et seq.*.

[54] *See* 42 U.S.C. § 1396d(a)(24); 42 C.F.R. § 440.167.

[55] *See* 42 U.S.C. § 1396d(a)(27); 42 C.F.R. § 440.170(a). The Deficit Reduction Act authorizes states to establish non-emergency medical transportation brokerage programs. Pub. L. No. 109-171, § 6083 (adding 42 U.S.C. § 1396a(a)(70)). Transportation is also included as an administrative obligation of states. State Medicaid plans must describe how states will ensure necessary transportation for beneficiaries to and from providers. *See* 42 U.S.C. § 1396a(a)(4)(A); 42 C.F.R. § 431.53.

[56] *See* 42 U.S.C. § 1396a(a)(17) (requiring states to use "reasonable standards"); 42 U.S.C. § 1396b(i) (requiring sufficient amount, duration and scope); 42 C.F.R. § 440.230(b) (same). *See, e.g.* Lankford v. Sherman, 451 F.3d 496, 511 (8th Cir. 2006) (finding that state's failure to provide Medicaid coverage for non-experimental, medically-necessary services within a coverage Medicaid category is both "per se unreasonable and inconsistent with the stated goals of Medicaid.").

twenty-one days per year, it should not be able to limit these services to one day per year.[57] States cannot arbitrarily deny or reduce the amount, duration or scope of services to an otherwise eligible individual solely because of the diagnosis, illness or condition.[58] For example, a state should not be able to exclude drugs needed by people because they are suffering from HIV/AIDS.[59]

The DRA offers states the option of providing Medicaid to certain groups by enrolling them in pre-existing health insurance plans.[60] This would enable the state to ignore traditional rules requiring coverage of mandatory and optional services, statewideness, freedom of choice and comparability. These groups must receive coverage through a "benchmark" or "benchmark equivalent" plan. The benchmark plans are (1) the standard Blue Cross Blue Shield preferred provider option under the Federal Employee Health Benefit Plan; (2) the HMO plan with the largest commercial, non-Medicaid enrollment in the state; (3) any generally available state employee plan; (4) any plan that the Secretary of HHS determined to be appropriate.[61] States are not permitted to require certain individuals to obtain benefits through this option, including pregnant women with incomes less than 133 percent of poverty and many individuals with disabilities.[62]

While some children can be required to enroll in these benchmark plans, the DRA also requires states to provide for "any children under 19 years of age [other than the medically needy] wrap around benefits to the benchmark coverage that consist of early and periodic diagnosis and treatment services."[63] For a detailed discussion of the benchmark requirements, including all of the individuals who are exempted, *see* NHeLP, *Health Advocate* (Spring 2006) at 26.

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[57] *See, e.g.*, Charleston Memorial Hosp. v. Conrad, 693 F.2d 324 (5th Cir. 1982) (upholding 12 day annual limit on inpatient hospital services).

[58] *See*. 42 C.F.R. § 440.230(c).

[59] *See* Weaver v. Reagan, 886 F.2d 194 (8th Cir. 1989) (discussing impermissible exclusion of AZT for individuals with AIDS-related condition).

[60] DRA, § 6044.

[61] DRA § 6044.

[62] DRA, § 6044(a).

[63] *Id.*

Medicaid Cost Sharing

The Medicaid Act has authorized states to impose cost sharing on some Medicaid beneficiaries. The DRA of 2005 added an entirely new section to the Medicaid Act, 42 U.S.C. § 1396oA, that vastly expands the states' options to impose cost sharing on Medicaid beneficiaries. See DRA, § 6041. This new provision leaves the existing premium and cost sharing provision, § 1396o, on the books untouched, but, in effect, largely repealed.[64] Children, the elderly, and persons with disabilities are all affected by the changes.

The DRA allows states to generally increase beneficiary cost sharing and establishes separate options for prescription drugs and non-emergency use of the emergency room. However, whether using the new DRA option or the previous cost sharing authorization, states may not impose copayments on certain beneficiaries, including children and youth with incomes below the federal poverty level and nursing home residents, or on certain services, including pregnancy-related services for pregnant women, emergency services, family planning services, and hospice services.

These DRA provisions became effective on March 31, 2006, except for the emergency room provisions, which are effective on January 1, 2007. For a discussion of the new cost sharing rules, see NHeLP, *Health Advocate* (Spring 2006) at 21-25.

Provider participation and managed care

States have much flexibility to decide how they will deliver services to Medicaid beneficiaries and how providers will be paid. However, the federal law requires states to assure that Medicaid payments to providers are sufficient to attract enough providers so that services are available to the Medicaid population at least to the extent they are available to the general population in the service

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[64] Before the DRA, states could only impose “nominal” cost sharing on beneficiaries by, for example, requiring beneficiaries to pay a small amount to the provider, up front, before services are received (called a “copayment”). *See* 42 U.S.C. § 1396o (Supp. 2001); 42 C.F.R. § 447.50 *et seq.* (2000)..

area.[65] In addition, Medicaid participating providers must accept Medicaid payment as payment in full.[66] In other words, they must agree not to seek payment from Medicaid beneficiaries.

Traditionally, states paid a fee to providers for each service rendered, called "fee-for-service" reimbursement. Over the last twenty years, however, Medicaid has shifted toward managed care delivery that emphasizes prepaid or discounted services and utilization controls, such as prior authorization requirements before providers can render services. In many managed care programs, beneficiaries select or are assigned to a specific managed care plan and, except in emergencies, must obtain all of the services included in the managed care program from this managed care plan. If services are obtained "out of plan," the beneficiary may be billed for them. Over half of all Medicaid beneficiaries are enrolled in managed care.[67]

Managed care will bring significant changes to the care seeking patterns of Medicaid beneficiaries. Rather than dealing directly with state and local eligibility workers, beneficiaries will be directed to the managed care plan (often to consumer services) when questions arise regarding providers and services. The contract between the managed care plan and the state Medicaid agency becomes a critical document because it provides the details of the plan's obligations to enrolled beneficiaries. The payment dynamics (in particular, prospective, pre-set payments) create an incentive for managed care plans and providers to limit services. These limitations should not go so far as to prevent the beneficiary from obtaining services that are medically necessary. Moreover, managed care plans that have previously served only commercial markets may not adhere to the Medicaid requirements for coverage. For example, the plan may provide check ups to Medicaid children and adolescents that do not include all of the required components of the EPSDT screens.[68]

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[65] *See* 42 U.S.C. § 1396a(a)(30)(A).

[66] *See id.* at § 1396a(a)(25); 42 C.F.R. § 447.15.

[67] CMS, "Medicaid Managed Care: Overview," http://www.cms.hhs.gov/MedicaidManagCare/ (May 19, 2006)

[68] The EPSDT medical screen must include five components: an unclothed physical exam, developmental assessment, appropriate immunizations, laboratory testing (including lead blood tests for children at 12 and 24 months and otherwise

Medicaid Resources on the World Wide Web

The National Health Law Program

- http://www.healthlaw.org
- Provides updates and analysis on federal legislation and policy developments, federal and state case law, major state activities, and academic research; provides access to model pleadings' provides extensive links to other organizations working on Medicaid issues

The Kaiser Commission on Medicaid and the Uninsured

- http://www.kff.org
- Provides extensive Medicaid facts and figures, nationally and by state; publishes extensive analysis on Medicaid trends

Center on Budget and Policy Priorities

- http://www.cbpp.org
- Provides research and advocacy support on Medicaid issues

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for children at high risk), and health education. *See* 42 U.S.C. § 1396d(r)(1) (Supp. 2001).

Avoiding Cruel Choices

A guide for policymakers and family organizations on Medicaid's role in preventing custody relinquishment

Bazelon Center for Mental Health Law

November 2002

Acknowledgments

The Bazelon Center wishes to acknowledge the generous support of the William T. Grant Foundation in supporting the production of this guide and some of the underlying research upon which it is based. The guide relies heavily on research conducted in 2001-2002 by the Bazelon Center under grants by the Center for Mental Health Services (which funded a study of states' use of the TEFRA option) and the Grant Foundation (which funded surveys of states regarding the barriers to using the TEFRA option or the home- and community-based waiver for children with mental or emotional disorders).

This family guide was written by Chris Koyanagi, the Bazelon Center's policy director, in consultation with staff attorney Mary Giliberti, edited by communications director Lee Carty and designed by deputy communications director Christopher Burley. Callie Schlippert and Lisa Conlin, parents of children with serious emotional disturbance, commented on the draft. The analysis is based on research directed by Rafael Semansky, senior policy analyst, with the assistance of interns Ellen Lupinski, Leigh Ann Simons and Andy Mack.

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November 2002
$10.00

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Introduction

Nationally, the public mental health system for children is in crisis.[1] As a result of its sorry state, many children are placed in the custody of child welfare or juvenile justice systems because that is the only way they can gain access to care that should have been available to them through a healthcare delivery system.

Public-policy alternatives exist that could rescue families from the awful choice of giving up custody to the state or seeing their child go without needed care. The federal government gives states several ways for these families to access services through the federal-state Medicaid program, but to date most states have failed to take advantage of them.

This guide is designed to assist advocates in educating policymakers about the problem and available policy options to significantly alleviate it. It describes devastating consequences of the country's failing public mental health system for children and investigates the causes of the problem. The guide also details federal policy options that could be used to fill the gaps in private insurance coverage. We report which states are taking advantage of these programs and which are not, and discuss the issues that state officials say prevent them from implementing these solutions. We also provide recommendations for advocates and policymakers who want to encourage their states to do more.

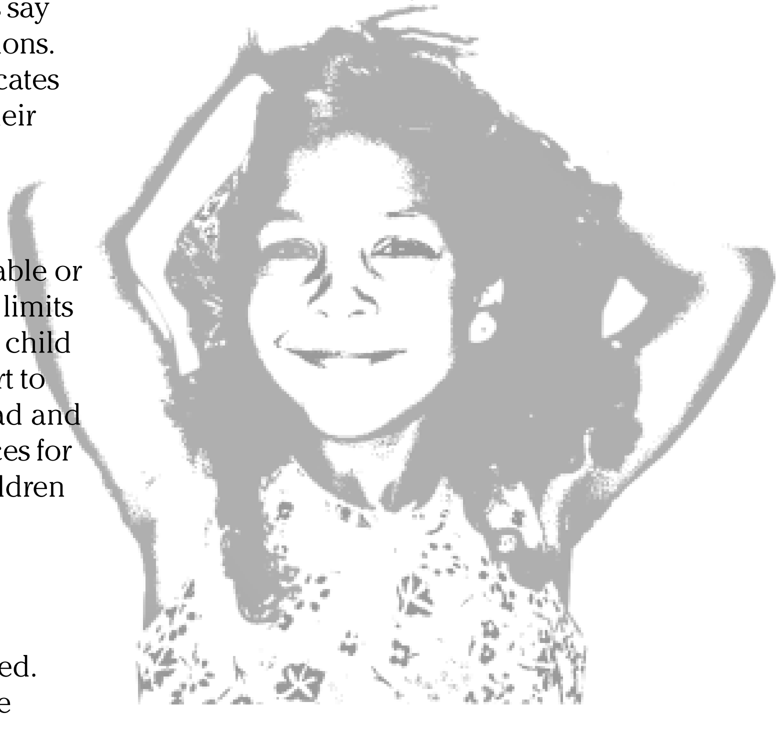
The Problem

When private insurance coverage is unavailable or inadequate and family income exceeds the limits for public programs, children often enter the child welfare or juvenile justice systems in an effort to access treatment. This practice is widespread and has long-lasting and devastating consequences for families. Unfortunately, large numbers of children in this country are either uninsured or have insurance with minimal coverage for mental health care.

A significant number of children are uninsured. The Kaiser Commission on Medicaid and the Uninsured, which compiles these data, estimated the uninsured rate for children at 15. 6 percent in 1998. With the slowdown in the economy, this rate has likely risen since then. The uninsured rate is slightly higher for adolescents than for younger children. Nearly a third of uninsured children live in families where both parents work and 85 percent live in families with at least one working parent. These children have no coverage for mental health care—either private insurance or Medicaid.[2]

Children who do have private health insurance almost always encounter caps on their mental health coverage. Both inpatient and outpatient services are limited. Data show that 94 percent of health maintenance plans and 96 percent of other plans have restrictions on mental health benefits, such as the number of outpatient sessions and inpatient days covered. And these limits have risen over time.[3]

Moreover, private insurance plans do not cover the full array of intensive, community-based rehabilitative services that children with the most severe mental or emotional disorders need. In this respect, coverage of mental health services is similar to coverage for physical health care, where rehabilitation or services designed to maintain an individual's functioning are often not covered.



However, children with the most severe mental and emotional disorders require a range of community services usually offered only through public child-serving systems, such as intensive in-home services, day treatment, behavioral aides or mentors, structured services and activities after school and during the summer, and independent-living skills training.

The major public program covering mental health care for children is the federal-state Medicaid program for low-income individuals.[4] Medicaid is supplemented by the State Child Health Insurance Program (S-CHIP), which covers children up to a slightly higher level of family income. The federal government shares in the cost of Medicaid and S-CHIP services, at a slightly higher rate for S-CHIP than for Medicaid. States may provide S-CHIP children with either Medicaid coverage or coverage under a heath plan based on a private insurance plan in the state.[5] To date, about half the states have chosen Medicaid (either putting all their S-CHIP children into Medicaid or having a mix of Medicaid for some children and a private plan for others). States that choose a private-plan approach give children policies that have the same restrictions as other private insurance.

Families soon find that only Medicaid offers the comprehensive array of intensive services needed

What Is Medicaid?

Medicaid finances health and mental health care for eligible low-income people. It is a means-tested program, and children and adults must have low income to qualify. Medicaid is run and financed jointly by the federal government and the states. Thirty-seven million people, including one quarter of all children, are covered by Medicaid. Children normally qualify either because they live in a family with very low income or because they have a disability severe enough to qualify them for federal disability benefits and live in families who are financially eligible for SSI (generally, SSI financial eligibility standards are somewhat higher than the state's ceiling for other low-income families).

Once on Medicaid, children are eligible for a significant range of mental health services: inpatient hospital care, residential treatment center services, outpatient clinical care (including therapy, medications and visits to a physician), crisis services, intensive in-home services, day treatment, substance abuse counseling, social and daily living skills training, case management, behavioral aide services and other intensive community-based care. This broad array provides more comprehensive, and more appropriate, coverage than a typical private insurance plan.

The federal government requires that states cover certain individuals on Medicaid, including children, pregnant women and caretaker adults with the lowest incomes, those with low incomes who also have a disability and elderly individuals who meet certain financial-eligibility criteria. In addition, the federal law permits but does not require states to expand Medicaid eligibility to certain other groups. The TEFRA option discussed in this report is one of those eligibility groups. Finally, states have the ability to apply to the federal government to alter their Medicaid program in certain ways, provided the federal government approves of the changes. This authority to "waive" federal rules can be used to expand the use of managed care in the state, to try out and evaluate new approaches to health care coverage or to provide home- and community-based services to individuals who would not otherwise be able to access them. The home- and community-based waiver for children with mental disorders discussed in this report operates only when a state has permission to waive federal rules in this manner.

Medicaid Coverage of Institutional Services for Children with Higher Incomes

Even for families who are not normally eligible for Medicaid, hospital and other medical institutions' services are a covered Medicaid service when a child with a mental or physical disability resides there for more than 30 days. This is because, once 30 days of care have elapsed, the income and resources of the child's family are no longer considered. As a result, many children with disabilities from higher-income families become eligible, but only as long as they reside in an institution.

by a child with a serious mental or emotional disorder. However, since Medicaid is a program designed to cover low-income individuals, its rules on financial eligibility keep many families from qualifying. Their family income— while far short of the level needed to pay for their child's care— is still above the very low levels required for Medicaid eligibility.

Families who do not qualify for Medicaid or S-CHIP due to their income and resources have no alternative but to try to pay out-of-pocket for services not covered through their private insurance. However, these children generally have a long-term and consistent need for services and some of those services can be prohibitively expensive. Eventually, many families reach the end of their resources.

In at least half the states, such families are told to place their children in state custody in order to access the services covered through the public programs.[6] The National Alliance for the Mentally Ill reported that approximately one of every five families of children with mental or emotional disorders were advised to give up custody to get help.[7] When they do, the families risk losing their children altogether, since under federal law states must work to place children who are in custody in adoption or back with their families within strict time limits.

Other parents are told to call the police and turn their children over to the juvenile justice system to get mental health care. Thirty-six percent of families surveyed reported that their children were in the juvenile justice system because mental health services were not available.[8]

This reliance on the child welfare and juvenile justice systems tears families apart and misuses public funds. The Federation of Families for Children's Mental Health lists the following consequences of such policies:[9]

- Children are led to believe they have been abandoned by their family. This irreparably damages the bond between child and family.
- Parents are forced to make an unthinkable choice between retaining the responsibility for and relationship with their child or giving over decision-making authority and control to a state agency in order to get the help their child desperately needs.
- Public funds are wasted by keeping children as wards of the state when the families who love them could provide for their basic needs.
- Children are forced into expensive residential placements rather than living in supportive families and receiving less costly community-based services.

State Options for Providing Access to Care

Medicaid is a safety-net program for children and adults with disabilities who have no other means to obtain the specialized, long-term services they require. This role is enhanced by eligibility rules designed to allow children with mental or physical disabilities to become eligible in certain circumstances without regard to their family's income.

For children whose family income makes them ineligible under standard Medicaid rules, certain institutional services are nonetheless covered in all state Medicaid plans (see box, page 3).

Most families do not wish to place a child with a serious mental disorder in an institution for a long time. Their child needs community-based services and if they had access to these services the family would be able to keep the child at home. To help these families, federal law gives states two options:

- The TEFRA option, [10] also sometimes known as the Katie Beckett option after the child whose situation led to this policy, and

- The home- and community-based services waiver under section 1915(c) of Medicaid law.

TEFRA

The TEFRA option allows states to cover home- and community-based services for children with disabilities living at home. These are children who would otherwise need the kind of skilled care provided in a medical institution. Eligibility for TEFRA is based on the child's disability and care needs, not on family income. For the child to be eligible, certain conditions must be met:

- The child must be a child with a disability, as defined in federal disability policy under Supplemental Security Income (SSI) or the Social Security Disability Insurance (SSDI) program.

- The child must need the level of care normally provided in a hospital, nursing home or Intermediate Care Facility for Mental Retardation (ICF-MR).

- The child must be able to be cared for at home instead of in the institution.

- The cost of care in the community must not be more than the estimated cost of the institutional care.

- The child, without regard to family income, must not have income or assets in his or her own name that exceeds the state's financial eligibility standards for a child living in an institution.[11]

Children who qualify under TEFRA will be given a Medicaid card and all state Medicaid program rules will apply. For example, these children are eligible for the same array of services as other Medicaid-eligible children.

Home- and Community-Based Services Waiver

Generally, states must follow all federal Medicaid rules in order to receive federal Medicaid funds. However, Medicaid law allows certain federal rules to be waived, or set aside, so that states can have the flexibility to make changes to their Medicaid programs. To do this, states need to submit a request to the federal Centers for Medicare and Medicaid Services (CMS) central office in Baltimore and have it approved before operating a waiver program.

One of the waivers permitted under federal law allows an expanded array of home- and community-based services to be furnished to children or adults with physical or mental disabilities as an alternative to institutional care that would otherwise be paid for by Medicaid. In addition to offering an expanded array of services, these waivers, known as home- and community-

How TEFRA Works

Families interested in applying for TEFRA should contact the local agency responsible for Medicaid (generally the social or human services agency). They should make clear they are applying through TEFRA, not through the regular Medicaid eligibility categories.

To complete the application, families will need to:

- present evidence documenting the child's disability (from treating physicians, psychologists or others who work with the child; information from school and other sources is also often helpful);

- provide information on the child's income and resources, if any; and

- furnish other information the state may request, such as their willingness and ability to care for the child at home.

Once the child is approved, the child will be on Medicaid and all state Medicaid rules will apply:

- The child will be eligible for all community-based clinical, rehabilitative and case management services covered by Medicaid law (this includes in-home services, day treatment, therapy, medications, case management and other services).

- The child has the right to appeal if a request for a service is denied.

- Medicaid will pay for services only as the last payor. This means if the family has private health insurance that covers a service their child needs, their insurance will be billed first. Medicaid will only pay for what is not covered in the child's insurance plan.

- The child must use providers who are certified by Medicaid in order for Medicaid to pay.

- States are not permitted to charge parents co-payments for services their child receives.

Some states have systems to help families as they apply for TEFRA. For example, in Wisconsin there is a "Katie Beckett consultant" who will talk with the family about the program and help them apply. Check with your local Medicaid agency. In many states with TEFRA, parent groups representing children with physical and/or mental disabilities have information and can assist parents with TEFRA issues.

Children who have received services in the three months prior to applying for TEFRA may be eligible for retroactive payment for those services. Check with the Medicaid agency.

Children must be re-certified every year as being eligible for TEFRA, as they must for any other Medicaid eligibility category.

Additional Services Offered to Families Under Home- and Community-Based Waivers

Kansas: Wraparound facilitation, parent support and training, respite care and independent living services

Vermont: Flexible supports, including respite care, home supports, family supports, community/ social supports and crisis supports, and transportation, environmental modification and adaptive equipment

New York: Individualized care coordination, respite care, skill building, intensive in-home services, crisis-response services and family support services

based care waivers, permit states to provide Medicaid coverage to some children who would not otherwise be eligible for Medicaid.

The waiver gives states considerable flexibility. States can open the program to children who would otherwise be excluded because of their parents' income and resources and can expand the array of services these children receive. However, states are also allowed to limit the number of children in the waiver. They can restrict services to parts of the state, target certain populations, such as children with mental disorders, and set overall limits on the number of children who are included. As a result, many of these waivers have very small numbers of children enrolled.

For a child to be eligible under a home-and community-based waiver, certain conditions must be met:

- The child must require care in a medical institution (a hospital, nursing home or institution for mental retardation, but not a residential treatment center), and

- home- and community-based services must be an appropriate option for the child.

As with the TEFRA option, children are eligible for home- and community-based waivers without regard to family income.

In order to receive federal approval for a home- and community-based waiver, the state must show that the average cost of community care for all children in the waiver will not exceed the average cost of the institutional care that would be paid by Medicaid. In making this calculation, the state must use the costs of institutions defined in federal law— psychiatric or general hospitals, nursing homes and ICF- MRs— and show that children will be diverted from these institutions into community care that is, on average, no more expensive.

A significant advantage of a home- and community-based waiver is that the state may expand the array of services for the children in the waiver. In the three states that now have home- and community-based waivers for children with mental or emotional disorders, these services include respite care for the families caring for these children at home, other family support services and skill building (*see box, above*). The state can also use waiver funds to pay for one-time setup expenses for the child to transition from the institution to home.

Unfortunately, in many states the home- and community-based waiver is not a practical option for children with mental or emotional disorders. The problem is the federal definition of a "medical institution". In many states children with mental or emotional disorders are at risk of long-term placement in a residential treatment center, but these facilities are not referenced in the federal definition. As a result, home- and community-based waivers cannot be used to divert children from a residential treatment center placement. In some states, where Medicaid-eligible children are rarely placed in a psychiatric hospital for any substantial length of time, the waiver may not be a practical possibility.

Differences Between TEFRA and Home- and Community-Based Waivers

The TEFRA option has an important advantage over the home- and community-based waiver. TEFRA creates an entitlement for all children who qualify, while under the home- and community-based waiver the state may limit the number of children who benefit. No one can be excluded from the TEFRA option based on limited state resources, diagnosis or for any other arbitrary reason.

The advantage of the waiver over the TEFRA option is that the state can expand the array of services available to children and families. The waiver may also be more attractive to states because they can accurately estimate its costs and can limit costs to funds available for their match of federal Medicaid dollars.

The process of developing a waiver application involves public input, so there is greater awareness around the state of the waiver's availability. In contrast, parents are often totally unaware of TEFRA.

States selecting the TEFRA option can receive federal approval promptly through their CMS regional office. Obtaining approval for a home- and community-based waiver, on the other hand, can be more time-consuming and complicated because it involves demonstrating to the CMS central office that the proposed community services will, on average, cost the same or less than institutional care for the targeted population.

The differences between these two approaches are summarized in the box below.

Comparing TEFRA and Home- & Community-Based Waivers

TEFRA Option	**Home- and Community-Based Waiver**
· Children qualify without regard to family income.	· Children qualify without regard to family income.
· All children who qualify are eligible regardless of whether their disability is physical or mental.	· The waiver can be limited to children with certain disabilities, such as serious emotional disturbance. The state can establish a limited number of slots.
· Children are covered for the same array of Medicaid services as all other Medicaid-eligible children.	· Children can receive additional services as well as those covered in the regular Medicaid program.
· Children from all parts of the state are eligible.	· Eligibility can be limited to particular geographic area.
· The TEFRA option can be approved by the federal regional office.	· The CMS Central Office in Baltimore must approve the waiver.

State Response

With few exceptions, states have failed to adopt the necessary policies to use either the TEFRA option or the home- and community-based services waiver. Only 12 states use either approach to improve access to services for families whose children have a serious mental or emotional disorder and even in these states, the number of children who benefit from these policies is very small.

Use of the Home- and Community-Based Waiver

Only three states have elected to seek a federal waiver to cover home- and community-based services for children with mental or emotional disorders. In contrast, 49 states have such waivers for people with developmental disabilities.

Many other states have considered, but rejected, applying for a home- and community-based waiver for children with mental or emotional disorders. According to a study by the Bazelon Center, more than half of states without these waivers considered developing a waiver but stopped when they faced barriers. The most significant barriers they cited were:

- lack of state funds to pay the state's share of Medicaid costs;
- the federal rule that prevents children in or at risk of placement in a residential treatment center from being eligible; and
- the requirement that community services be no more expensive than the alternative institutional placement.

However, experience from the three states that have the waiver shows that the other states' cost-related concerns can be addressed. In fact, per-child costs of a home- and community-based services waiver for children with mental or emotional disorders are quite low. Moreover, since the state can limit the number of slots, a home- and community-based waiver can be initiated with a relatively small state investment. For example, first-year costs for the Kansas waiver were only $1 million. Initially, New York began by serving 25 children (now up to 354). In addition, the costs of the waiver services can be offset by institutional savings. Kansas closed one of its psychiatric hospitals in coordination with the waiver.

Use of the TEFRA Option

Twenty states have the TEFRA option for children with disabilities. Yet half of these states have no children on TEFRA who qualified as a result of a mental or emotional disorder.[12] This means that the potentially very important TEFRA option is currently unavailable to children with mental disorders in 40 states and the District of Columbia.

Even in the states with the TEFRA option, very few children participate, and in most of these states children with mental or emotional disorders are a small percentage of these small numbers. Compared to total enrollment in the Medicaid program, TEFRA enrollment is minimal. It varies widely between states, ranging from extremely low (10 children in Michigan) to large (4, 300 children in Wisconsin). Moreover, children with mental or emotional disorders are a small percentage of TEFRA enrollment— less than 21 percent, except

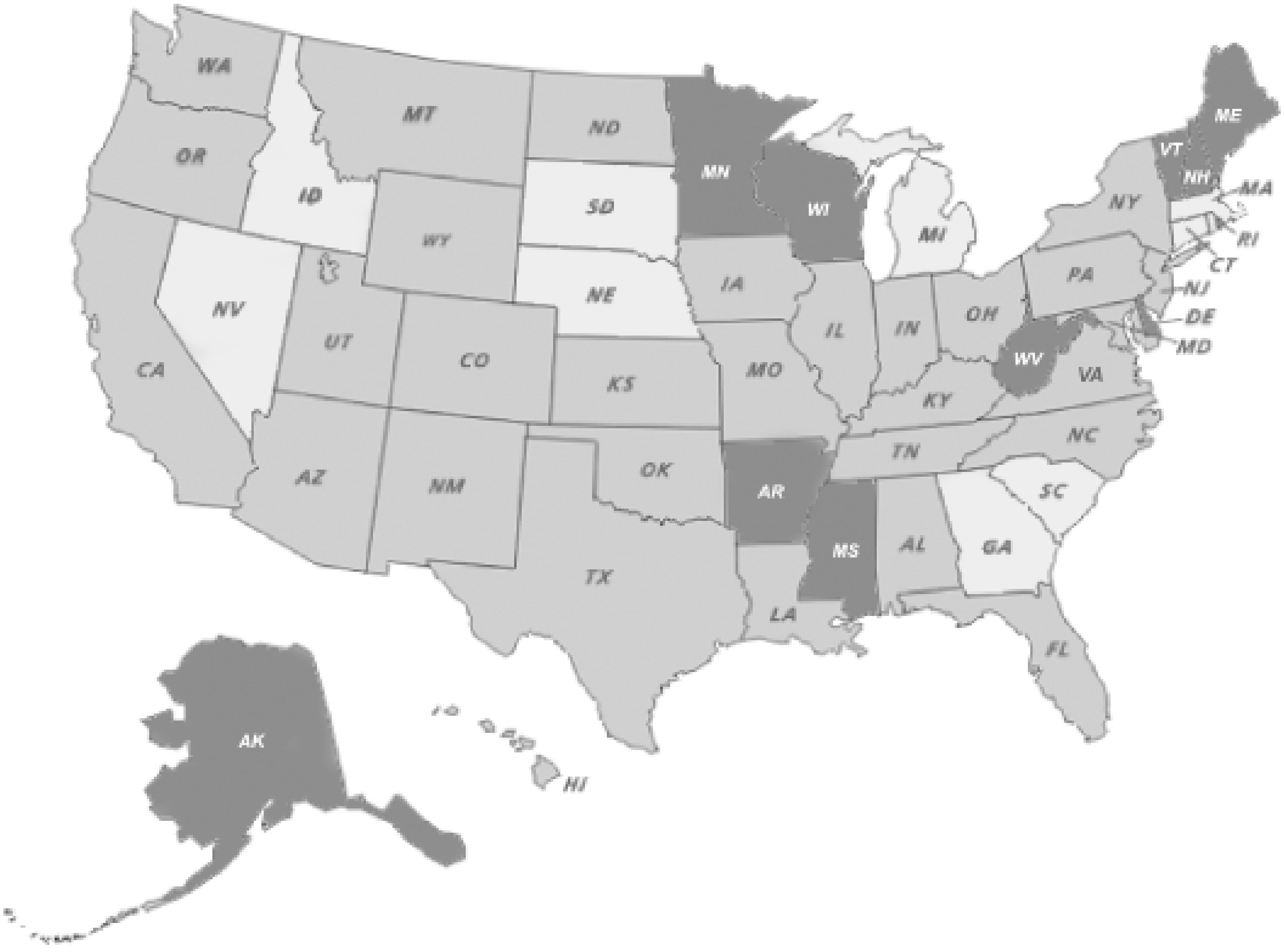
*Experience of States with Home- and Community-Based Waivers: Per-Child Costs**

Kansas: Average annual per-child costs $12, 900, compared with institutional costs of $25, 600.

Vermont: Average annual per child costs $23, 344, compared with inpatient costs of $52, 988.

New York: Approximate annual per child costs $40, 000, compared with institutional costs of $77, 429.

*2001 data



▩ *States with TEFRA Option Where Children with Mental and Emotional Disorders Qualify*

□ *States with TEFRA Option Where Children with Mental and Emotional Disorders Do Not Qualify*

▨ *States without the TEFRA Option*

in Vermont, where 52 percent of TEFRA children have mental or emotional disorders.

It is surprising that 30 states and the District of Columbia have not adopted the TEFRA option for children with disabilities, especially given the likelihood that in most states many of the families of children with mental or emotional disorders who could qualify will be faced with the option of giving up custody to the state. At that point the entire cost of the child's care falls on the state, whereas if the TEFRA option is used the federal government will pay a substantial part of the cost.

Lack of knowledge about TEFRA may partially explain why so few states have adopted it. Information collected by the Bazelon Center suggests that many state officials believe that additional information on implementation of TEFRA would help them determine whether or not their state should use this option. The information these state officials would like to have from states that already use the TEFRA option is:

- the number of children who have qualified;
- expenditures on services for these children;
- specific TEFRA rules used;
- characteristics of children who use TEFRA;

- source of funds for state match;

- plans and proposals developed in order to justify use of TEFRA.

The Fact Sheet, *States Using the TEFRA Option for Children with Serious Mental Disorders* (page 23), attached to this report provides a summary of some of this information. Further data are available to state officials and advocates in a Bazelon Center report prepared for federal officials that can be accessed at www. bazelon. org.

In some states with the TEFRA option, it is not meeting the needs of children with mental and emotional disorders. Among possible reasons:

- Families are unaware of the option and do not apply.

- State rules are written in such a way that they either exclude children with mental or emotional disorders or discourage their inclusion.

- State practice emphasizes that only children with a qualifying physical disability can become eligible and other families are discouraged from applying.

Federal Center for Medicare and Medicaid Services, Policy Manual for States

"If you elect this option you will need to provide coverage to all disabled children who meet the conditions. This is unlike the situation that exists for home- and community-based waivers, for which the law authorizes a waiver of the statewideness and comparability requirements. "*

* Centers for Medicare and Medicaid Services, State Medicaid Manual §3589

Regardless of the cause, denying access to the TEFRA option to children with mental disorders is a direct violation of federal Medicaid policy, which specifically states that all qualified children must be eligible if the state takes this option (*see box, center*).

State TEFRA Rules Often Deny Access

Even in the 20 states that have the TEFRA option, children with mental or emotional disorders are often not included. Although federal law requires inclusion of all eligible children when the TEFRA option is adopted, families of children with mental and emotional disorders do not believe TEFRA works for them.

One reason is the history of TEFRA. The option was initially developed in response to the publicized problems of Katie Beckett, a child with physical disabilities. From the first day, many state officials assumed that the option was designed to help only children like Katie, and the family groups publicizing the option were those focused on the needs of children with physical or developmental disabilities.

Another reason may lie in inappropriate or inadequate state rules. Federal rules for TEFRA implementation leave it to the states to develop many of the details of how the option will operate. For example, the federal government leaves to the states the development of rules that:

- clarify the federal definition of the medical institutions to which a child would otherwise need to be admitted without the community services of TEFRA;

- define the level of care considered "normally provided" in these institutions;

- clarify how the state will decide that home care is appropriate for the child;

- determine how the state will calculate that home care does not cost more than the alternative care in the medical institution.

It is important for these state rules to reflect policies that lead to the inclusion of children with mental or emotional disorders.

The Bazelon Center's review of states' TEFRA rules found that children with mental and emotional disorders are qualifying in only 10 of the 20 states with the option. References to children with mental disorders or to psychiatric facilities or other programs relevant to them are an indication of whether these children will be able to qualify in the state.

Of the 10 states where children with mental and emotional disorders do not qualify under the TEFRA option, only one[13] has an explicit provision in its rules that would tend to eliminate these children from its program. In the other nine, a combination of factors results in the exclusion of children with mental and emotional disorders. The rules in seven of these states[14] have no reference to children with mental disorders and do not suggest that children who would otherwise be placed in a psychiatric hospital can qualify. These two omissions suggest that it is state policy to exclude these children—a conclusion strongly supported by the states' failure to enroll even one child with a mental disorder in TEFRA. [15] In contrast, most of the states that do include children with mental or emotional disorders specifically cite psychiatric hospitals in their definition of medical institution.

In addition, many of the states where children with mental and emotional disorders do not qualify do not mention the fact that children with mental disorders can qualify for TEFRA in their materials for parents. [16] This would discourage families with these children from applying.

State rules and criteria for measuring whether a child needs the level of care provided in an institution might also be problematic, as may rules on determining whether home care is appropriate and whether it is less expensive than institutional care. However, the Bazelon Center study did not find any specific problems in these parts of the TEFRA rules it reviewed. In the 10 states where children are qualifying, the approval rates for children with a primary diagnosis of mental or emotional disorder ranged from 50-100%, comparable to the approval rates for children with physical disabilities. This suggests that these aspects of state rules are generally not as problematic.

The Fact Sheet entitled *TEFRA (Katie Beckett) Medicaid Option: State Policies* (page 25), summarizes the issues in TEFRA rules that are important for children with mental disorders and presents information that can guide a state in developing appropriate TEFRA rules.

Information for Parents

The availability of information on the TEFRA option plays a critical role in whether parents of children with mental or emotional disorders apply. The Bazelon Center study found significant problems in the sample of parent materials it reviewed.

States have provided booklets with information on TEFRA and many have also included information on their web pages. In several states, parent organizations have produced materials. These materials generally describe the way the option works, the eligibility criteria, how to apply and the services for which a child may be eligible. Some include a copy of the application forms or forms for physician assessments.

The Bazelon Center was able to secure parent materials on TEFRA from 10 states. Nine others reported that they had no parent materials on TEFRA.

Parent materials in three states[17] had no specific references to 1) the fact that children with mental or emotional disorders were eligible, 2) mental disability as a qualifying disabling condition, and 3) the availability of mental health services. Materials in seven states[18] referenced at least one of these three elements.

Materials are useful, but without outreach and other educational efforts they will not ensure that families of children with mental or emotional disorders are aware of TEFRA. The study found that states where children with mental and emotional disorders qualify often conducted outreach to parent organizations or conducted training for the staff of community mental health programs or for their Medicaid-eligibility workers. In some states, materials on TEFRA were widely distributed to physician offices, children's hospitals, county offices and other places where families are likely to pick them up.

Some states designate individuals to help families fill out the application, while in others local mental health programs will provide such assistance. In addition, particularly in states with significant numbers of children with mental and emotional disorders on TEFRA, the family organization itself plays a significant role in reaching potentially eligible families through workshops, educational materials and outreach.

Despite state efforts, parent groups in the states where children with mental or emotional disorders qualify for TEFRA report that parents still face several problems:

- difficulty in understanding how to provide the appropriate documentation of disability;
- long and complex application forms;
- significant delays before a decision is made on an application;
- requirements for re-application yearly or at other intervals; and
- denials of applications because of missing information of which the parent was unaware.

Parents also had a hard time finding help to complete the application. Given the problems parents face in dealing with the application process, it would seem important for the state to ensure they have this assistance.

Clearly, all states could do much more to make the TEFRA option more effective— even the states whose rules allow children with mental or emotional disorders to be covered.

Improving State Systems

TEFRA and the home- and community-based waiver are underused resources for helping families of children with mental disorders avoid having to relinquish custody or place their children in institutions far from home.

State officials contacted for the Bazelon Center study confirm the importance of TEFRA. Officials in seven of the 10 states where children with mental or emotional disorders qualify for TEFRA said that availability of the option has reduced the number of parents relinquishing custody to the state. The experience in Vermont shows the potential: More than half of TEFRA children in Vermont are children with mental or emotional disorders.

Advocates for families of children with mental or emotional disorders should therefore review their state's policies with respect to TEFRA and the home- and community-based waiver. State policymakers should be urged to make the changes needed to help families keep their child with a mental disability at home. Table 1, which can be found on page 20, shows details of state policies on TEFRA and the home- and community-based waiver for children with mental disorders. Using data in that table, advocates should:

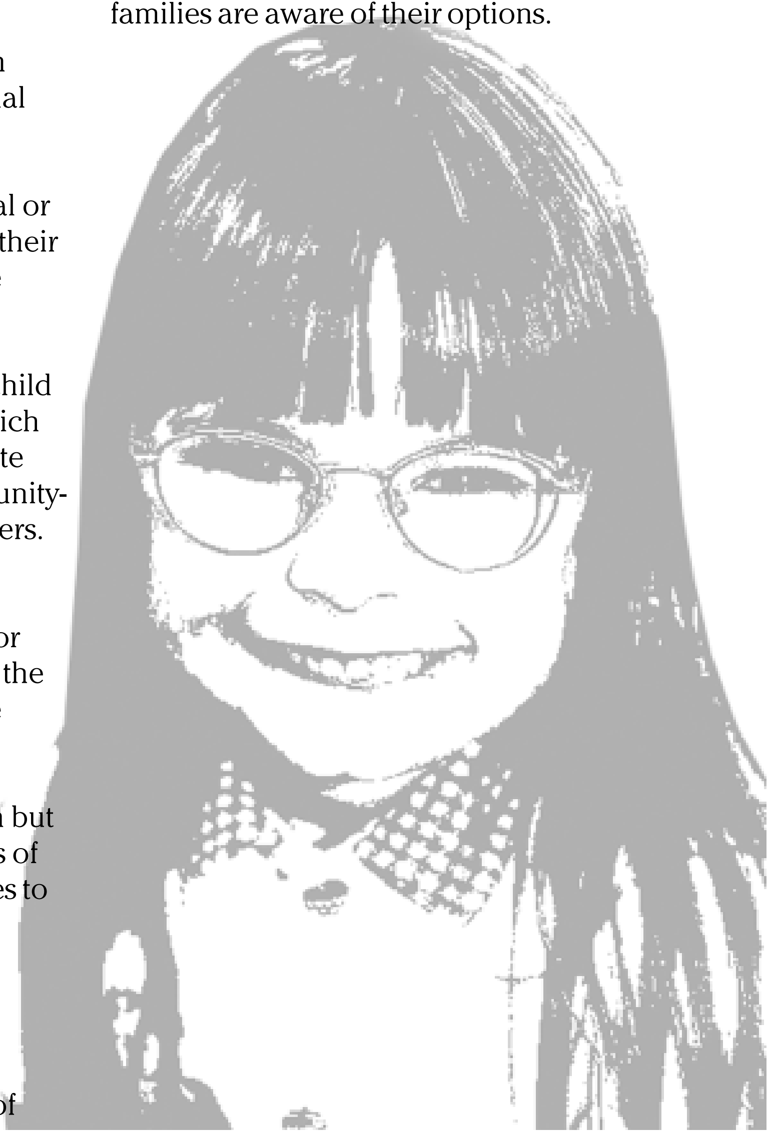
- Urge adoption of either the TEFRA option or the home- and community-based waiver in the 29 states that have adopted neither of these approaches.

- In the 10 states that have the TEFRA option but where no children with a primary diagnosis of mental disorder are qualifying, urge changes to state TEFRA rules and criteria and greater effort to publicize the option to potentially eligible families.

- In states with the TEFRA option that do include children with a primary diagnosis of mental disorder, check the number of these children currently qualifying. If it seems low, urge state officials to make greater efforts to publicize the option to potentially eligible families.

- In states without the home- and community-based waiver, urge policymakers to review the practicality of this waiver for children with mental and emotional disorders.

If the state already has the TEFRA option for children with mental or emotional disorders, advocates may wish to find ways to get the word out to families. In addition to developing appropriate parent materials, it is important to give this information wide circulation. Both the state and parent groups should work to ensure that families are aware of their options.



Advocating for TEFRA and the Home- and Community-Based Care Waiver

To accomplish these goals, advocates will need to present information to legislators and other policymakers in the state. The attached fact sheets will help begin this process. Policymakers will want:

- information that explains the federal rules on TEFRA and the home- and community-based waiver, the advantages to a state of adopting one of these approaches and the impact on families and children of failing to act (see Fact Sheet, *Families Need Choices: Lack of Access Results in Custody Relinquishment to the State*, page 21);

- information on why the TEFRA option is a good policy choice, including data from states with the option (see Fact Sheet, *States Using the TEFRA Option for Children with Serious Mental Disorders,* page 23);

- explanations of specific TEFRA rules that states need to adopt to ensure appropriate eligibility for children with mental and emotional disorders (see Fact Sheet, *TEFRA (Katie Beckett) Medicaid Option: State Policies,* page 25); and

- information regarding why the home- and community-based waiver is a good policy choice, including data from states with the waiver (see Fact Sheet, *Rules on Home- and Community-Based Waivers for Children with Mental and Emotional Disorders,* page 27).

Advocates will have to overcome inertia at the state level in adopting either of these Medicaid policies. Although lack of funding is often cited as a major impediment, states are already paying a high cost for services to children with mental health needs in their child welfare and juvenile justice systems. Moreover, both the waiver and the TEFRA option are more extensively used for children with developmental or other disabilities. The real issue is priority-setting, not an overall lack of funds.

Children with mental health care needs are victims of the continued stereotypes that their disorders are not real or that they will outgrow their behavior problems. Parents continue to be blamed, children's needs remain ignored and services are denied. This pattern inevitably leads both to bad outcomes for the children and to high costs in other sectors of the state system. Advocacy and education are essential to overcome the stereotypes and encourage states to fill the gaps in mental health care coverage with a healthcare delivery system (Medicaid), instead of through the punitive systems of child welfare and juvenile justice. Some strategies to do this are presented on the facing page.

Strategies for Advocacy

TEFRA Option

- In states without the TEFRA option, advocates for children with mental disorders may find that other organizations representing children with developmental or physical disabilities would be interested in joining with them to urge the state to adopt this option.

- Additional allies may be community mental health providers and their state association. These organizations will understand the problem and the impact of current policy on families, and may have special knowledge of cost and other data policymakers will want, such as how the state's rules need to be written and how much the alternative community services would cost.

- Other mental health and child advocacy groups may also join with families in making the case for keeping children at home.

Home- and Community-Based Waiver

Kansas was successful in securing a home- and community-based waiver in 1997, and it now has the largest such waiver program for children with mental and emotional disorders, with 1,150 children. This success was the result of several factors:

- cooperation between state policymakers, children's advocates, families, service providers and Medicaid officials;

- inclusion of parents, providers, state agencies, research and policy experts and state Medicaid staff on a task force that planned and designed the waiver;

- use of a consultant experienced in writing waiver applications;

- the experience of state staff in successfully securing a home- and community-based waiver for individuals with developmental disabilities;

- conducting a review of waiver applications from other states.

The application process was not costly or unduly burdensome and federal CMS staff were helpful and encouraging. The waiver was approved about three months after its submission.

Conclusion

States can use policy options under Medicaid to alleviate the problems for families of children with mental and emotional disorders who cannot obtain the services they need to keep their child at home. However, these tools—the TEFRA eligibility option and the home- and community-based waiver—are greatly underutilized.

Many more states could utilize the home- and community-based waiver, and state concerns about implementation of such a waiver are not borne out in practice by the three states that have them. Waiver costs can be modest and controlled, and can easily offset alternative institutional costs, while helping families who might otherwise be forced to give up custody of their child to the state.

The TEFRA option provides another important tool to avoid custody relinquishment. It could benefit even more families than a home- and community-based waiver because it is an entitlement for all eligible children. Yet few states have the TEFRA option and even those that do could improve their policies to help more families. Few children benefit from TEFRA and children with mental or emotional disorders benefit even less, whether because of state rules, omissions in state policy, deficient parent-education materials or misinformation from state officials who do not understand the program.

The purpose of this guide is to give family advocates and policymakers the information they need to change this bleak picture. We hope they will use this report, and the attached fact sheets and other information, to educate state decision-makers on how TEFRA or a home- and community-based waiver can benefit many children and families while still being a cost-effective approach for the state.

Federal Medicaid law offers the states options that could greatly alleviate the inhumane practice of sending parents and children to court and putting them on trial for their inability to get help for a mental health problem. Children and their families should not be punished for having a mental health condition. Instead, states should make full use of federal Medicaid options and waivers to serve children with mental and emotional disorders in their homes and communities.

Notes

1. Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States' Public Mental Health Systems*. Washington, D.C. 2001; and *State Mental Hospital Continuity of Care Study: Preliminary Report*, Louis de la Parte Florida Mental Health Institute, University of South Florida. Tampa. 2002.

2. Kaiser Commission on Medicaid and the Uninsured (May, 2000). *Uninsured in America: A Chart Book, Second Edition*.

3. P. Peele, J. Lave, Y. Xu, Benefit Limitations in Behavioral Health Carve-Outs: Do They Matter? *Journal of Behavioral Health Services and Research*, 26(4): 430-441 (1999).

4. Generally, up to 200 percent of federal poverty level.

5. Generally, up to 200 percent of federal poverty level.

6. S-CHIP plans can be based on the state employees' health plan, the federal employees' Blue Cross/Blue Shield plan or the plan of the largest commercial HMO in the state, or they can be private plans that are created especially for S-CHIP but are the actuarial equivalent of any one of the above plans. However, states may limit the mental health benefit under these options to only 75 percent of the actuarial value of the mental health benefit in the plan on which the state has modeled its S-CHIP plan. Thus, mental health benefits in S-CHIP private insurance plans are generally quite limited.

7. TEFRA Medicaid Option Leaves Children with Disabilities in the Lurch, a report on TEFRA by the Bazelon Center for Mental Health Law produced for the Center for Mental Health Services. 2002.

8. National Alliance for the Mentally Ill, *Families on the Brink* (1999) at 10.

9. Relinquishing Custody to Obtain Necessary Treatment, Fact Sheet, Federation of Families for Children's Mental Health, November 1999.

10. TEFRA, the Tax Equity and Fiscal Responsibility Act of 1982, created this option. This replaced a previous authority for state waivers which had accomplished the same goal. The TEFRA option is sometimes known as the Katie Beckett option after the child whose plight came to the attention of President Reagan.

11. These levels are set by the state, but will only exclude children with significant assets or who have income. However, sometimes child support payments can exclude a child from TEFRA eligibility.

12. Some children who qualify due to a physical disability may also have a serious mental disorder, and so may be receiving TEFRA health and/or mental health services.

13. Massachusetts has a rule that defines a hospital level of care as addressing only the needs of children with physical disabilities, thus making it impossible for a child with a mental or emotional disorder to qualify.

14. Georgia, Idaho, Michigan, Nevada, Rhode Island, South Carolina and South Dakota.

15. Two other states also fail to identify any children due to their mental disorder, but two (Nebraska and Connecticut) did not share copies of their rules for review.

16. These seven states are: Connecticut, Georgia, Idaho, Massachusetts, Michigan, Nevada and Rhode Island. In South Carolina and South Dakota there is mention of mental health issues for TEFRA children in the parent materials, but the state identifies no children based on their mental or emotional disorder.

17. Arkansas, Connecticut and Idaho.

18. Minnesota, Mississippi, New Hampshire, South Carolina, South Dakota, Vermont and Wisconsin.

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Appendices

Table 1: TEFRA and Home- and Community-Based Waivers by State

State	Eligibility Expansion	Total number of TEFRA children	Children Qualify for TEFRA Based on Mental Disorder	Number of Children with Primary Mental Diagnosis	% of Children on TEFRA with Primary Diagnosis of Mental Disorder	Level of Care Criteria Includes Psychiatric Hospitals	Information Materials Refer to Mental Disorder
Alabama							
Alaska	TEFRA	272	x	16	6%	x	
Arizona							
Arkansas	TEFRA	3,334	x	700	21%		
California							
Colorado							
Connecticut	TEFRA	125		--	--	not available	
Delaware	TEFRA	1,500	x	not available	not available	x	
District of Columbia							
Florida							
Georgia	TEFRA	4,086		--	--		
Hawaii							
Idaho	TEFRA	887		--	--		
Illinois							
Indiana							
Iowa							
Kansas	H&CB waiver						
Kentucky							
Louisiana							
Maine	TEFRA	1,157	x	not available	not avaialble	x	
Maryland							
Massachusetts	TEFRA	250		--	--		
Michigan	TEFRA	10		--	--		
Minnesota	TEFRA	3,603	x	581	16%	x	x
Mississippi	TEFRA	708	x	123	17%		
Missouri							
Montana							
Nebraska	TEFRA	42		---	--	not available	not available
Nevada	TEFRA	204		--	--		
New Hampshire	TEFRA	1,125	x	165	15%	x	x
New Jersey							
New Mexico							
New York	H&CB waiver						
North Carolina							
North Dakota							
Ohio							
Oklahoma							
Oregon							
Pennsylvania							
Rhode Island	TEFRA	800		--	--		
South Carolina	TEFRA	2,012		not available	not available		x
South Dakota	TEFRA	49		--	--		x
Tennessee							
Texas							
Utah							
Vermont	TEFRA H&CB waiver	309	x	160	52%		x
Virginia							
Washington							
West Virginia	TEFRA	164	x	5	3%	x	
Wisconsin	TEFRA	4,302	x	262	6%	x	x
Wyoming							

[1] States that specify the standard level of care–hospitals, nursing facilities, and intermediate care for the mentally retarded.

Fact Sheet

Access to Services for Children with Serious Mental Disorders

Families Need Choices: Lack of Access Results in Custody Relinquishment to the State

Issue

Families of children with mental and physical disabilities are often unable to obtain the specialized and intensive services their children need through their private insurance policy. Most policies limit coverage of the rehabilitative and other care needed by individuals with disabilities and chronic illnesses, and few families can afford to pay out-of-pocket.

This problem is especially acute for children with mental and emotional disorders. Insurance coverage of mental health services is extraordinarily limited. Coverage of acute hospital and physician care is generally far below what these children require and private insurance does not pay at all for many essential rehabilitative services. The result is that most children with mental or emotional disorders have no access to the services they need. Their families then face the choice whether to leave their child untreated—with horrible,even fatal,consequences—or give up custody to the child welfare system so their child can access services through Medicaid.

Medicaid's Role

Medicaid can be a lifesaving resource for these families because it covers the range of services that children with disabilities need. Families whose children with physical or mental disabilities are on Medicaid are much more satisfied with their child's care than are families with only private insurance coverage. Seventy-one percent of families rated Medicaid good or excellent and 54 percent had no problems getting the mental health services their child needed. In contrast, only 51 percent of families with private insurance thought their plan was good or excellent and only 38 percent reported no problems getting mental health services for their child.[1]

State Options

Federal Medicaid law gives states two policy options that allow children with a mental or physical disability to be enrolled in Medicaid even when their family income would normally exclude eligibility. These children can qualify if the state adopts either:

- the eligibility option authorized by the Tax Equity and Financial Responsibility Act of 1988, TEFRA (also known as the Katie Beckett option) Sect. 1902(a)(ii)(VI) of Medicaid law; or
- a Home- and Community-Based Services waiver under Section 1915(c).

TEFRA

The Medicaid TEFRA eligibility option permits states to enroll children with disabilities who live at home and need extensive care but who would not otherwise qualify for Medicaid due to their family income and resources.[2] In order to be eligible:

- The child must be a child with a disability as defined in federal disability rules (Supplemental Security Income, SSI, program).
- The child must need the level of care normally provided in a medical institution.
- Home care for the child must be appropriate and the cost of home care must not exceed the cost of the alternative institutional care.

Compared to the total enrollment in the Medicaid program, the TEFRA option covers a small number of children and enrollment varies widely between states. The average number of children qualifying under TEFRA per state is 1,230 (the range is from 10 to 4,300 children). The average

TEFRA (cont'd.)

number of children with a primary diagnosis of mental or emotional disorders is 250, or between 3% and 21% of total TEFRA enrollment, except in Vermont, where 52% of the TEFRA children are estimated to have a primary diagnosis of serious emotional disturbance.[3]

A study of Minnesota's TEFRA option[4] found that, while costs for children with physical disabilities averaged $43, 000, costs for children with mental health diagnoses averaged only $17, 900. Since TEFRA is the payer of last resort and many children have other insurance, the cost per child for Medicaid was only $8, 100.[5] Children on TEFRA with a mental disorder come from families with lower incomes and were also less likely to have supplemental insurance than other TEFRA children.

Home- & Community-Based Waiver

The home- and community-based waiver, authorized under Section 1915(b), allows states to cover under Medicaid children who would otherwise be excluded because of their parents' income and resources and to expand services beyond those listed in federal law. For a child to be eligible under this waiver, certain conditions must be met:

- The child must require care in a medical institution (a hospital, nursing home or institution for mental retardation, but excluding residential treatment centers).
- Home- and community-based services must be an appropriate option for the child.

Families in states with these waivers are very pleased with the array of community services available to them. For example, Kansas offers respite care, independent living skills services and parent training and support. Vermont offers various flexible supports, include respite and other services. New York provides individualized care coordination, respite and family support services.

Although federal rules require that states show the waiver to be budget neutral for the Medicaid program, federal rules are not onerous. States need only show that the average cost of community care for all children in the waiver will not exceed the average cost of the alternative institutional care otherwise payable by Medicaid. It is not necessary for the state to require such a showing for every waiver child.

Federal rules also provide another level of flexibility for states, in that children need not be placed in an institution to qualify under the waiver. The costs of institutional care for children at risk of placement may also be used to offset the costs of community services.

One limiting factor for home- and community-based waivers for children needing mental health care is that federal rules do not allow states to consider the costs of institutionalizing the child in a residential treatment facility. In many states children with mental or emotional disorders are at risk of long-term placement in residential treatment centers. But because these facilities are not considered a medical institution under the law, home- and community-based waivers cannot be used to divert children from such a placement.

States may limit the number of children in the waiver in order to reduce their costs. Funding for the waiver may also be linked to state appropriations for services. As a result, states can control the number of children in a home- and community-based waiver and costs are readily controlled.

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[1] *Your Voice Counts! The Health Care Experiences of Children with Special Health Care Needs*, Brandeis University, Center for Child and Adolescent Health Policy, MassGeneral Hospital for Children and Family Voices, Boston, MA. 1999. [2] The Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 created the TEFRA state option. This replaced a waiver authority that had accomplished the same goal (and was known as the Katie Beckett waiver after a child whose plight came to the attention of President Reagan). [3] Bazelon Center for Mental Health Law (2002) Report to the Center for Mental Health Services on the Implementation of the TEFRA Option. [4] Chan, Benjamin., Jahnke, Lola., Thorson, Sarah., Vanderberg, Nancy (1988). *Caring for Our Children: A Study of TEFRA in Minnesota. Minnesota Children with Special Health Needs.* St. Paul, MN: Minnesota Department of Health. [5] Chan, Benjamin., and Vanderburg, Nancy. (1999). Children *with Disabilities, Managed Care Plans, and Medicaid TEFRA Option in Minnesota– Implications for Patients' Rights.* Paper presented at the 16th Annual Meeting, Academy for Health Services Research and Health Policy, Washington, DC.

Fact Sheet

States Using the TEFRA Option for Children with Serious Mental Disorders

TEFRA Option for Children with Serious Mental Disorders

Issue

Twenty state Medicaid programs use the eligibility option known as TEFRA or Katie Beckett to expand eligibility to certain children with physical and mental disabilities.

In other states, policymakers have indicated that more information on TEFRA implementation would help them make a decision about whether to adopt this option.

TEFRA

The TEFRA option permits children with physical or mental disabilities (as defined in SSI regulations) to be offered home-based services instead of placement in an institution. Under current law, these children are covered under Medicaid while in the institution after the first 30 days; at that time their family's income and resources are no longer counted and so the child becomes financially eligible. If these children meet the federal definition of disability, they then become Medicaid-eligible.

State Concerns

A 2002 survey of states without the TEFRA option by the Bazelon Center for Mental Health Law identified the following as the major reasons why the state had not considered or had not adopted this option:

- lack of information on implementation of TEFRA by states with the option;
- concern over raising funds for the state match;
- overall costs, concern over budget-neutrality and ability to control the number of children who would become eligible; and
- mistaken belief that other Medicaid options will address this need;

TEFRA Implementation

The Bazelon Center for Mental Health Law recently conducted a study of the implementation of TEFRA in the 20 states with the option. Data from this study show:

- The overall number of children who qualify is low.
- The costs per child on TEFRA are low. A Minnesota study of TEFRA found that TEFRA only pays 23% of total health care costs for the children (private health insurance, families and schools pay the rest).
- Half the states with the option have rules that enable children with serious mental and emotional disorders to qualify; the other 10 states have rules or practices that create barriers for these children.

Other Medicaid Options

Other Medicaid options that state officials believe may meet the needs of these children do not, in fact, address the same issues. The Medicaid options cited by state officials as alternatives to TEFRA were:

- Medically needy option: This requires a family to spend down into poverty for their child to be eligible. But these families are seeking home- and community-based services only available through the public sector—services that cannot be purchased—and so they will not be able to "spend down" by accessing community care. Instead, the families are forced into paying for residential services in order to meet medically needy standards. In addition, families must frequently re-establish eligibility under the medically needy option. For these

Other Medicaid Options (cont'd.)

reasons the medically needy option is impractical as a means of covering the community care these children need.

- Home- and community-based waivers: A home- and community-based waiver could be an alternative to TEFRA for these children. However, only three states have home- and community-based waivers for children with mental and emotional disorders; in no other state does this alternative Medicaid eligibility approach exist.

Costs

States had concerns over both the cost of the TEFRA option and the budget-neutrality of its implementation. These concerns were heightened by a fear that the state could not control the number of children who might be eligible (as it can with a home- and community-based waiver), and that this too would drive up overall costs to the state.

- Data from Minnesota (the only state that has studied this issue) show that the actual costs of providing home- and community-based services to TEFRA children are not high. Moreover, the costs for children with mental disorders were less than for other children.
- Budget-neutrality is a federal requirement for TEFRA, and states make the essential calculations themselves. Concern over budget-neutrality can be addressed by states by ensuring accurate assessments of the costs of institutional care and accurate assessments of whether the child truly needs the level of care provided in an institution. These are state decisions, controlled by the Medicaid agencies.
- Overall, few children qualify. First, all children must meet the stringent SSI definition of disability and second, they must need the level of care furnished in an institution. This greatly reduces the total number of potential eligibles, and the data confirm this.

State Match

Mental health officials were concerned about the need for state matching funds for services to these children. In most states, mental health authorities provide the Medicaid match for community-based mental health services. Accordingly, this is of concern. However, when parents of these children are forced into giving up custody to the state, the costs of their care will still fall on the state and the Medicaid match must still be paid. In these situations, the child becomes the responsibility of child welfare (not mental health), but the service furnished will be residential care that is far more expensive for the state than the TEFRA community-based services. Thus, while the mental health system "saves" the match, the state itself pays an even higher match.

State policymakers need to examine the full impact of policies designed to "save" the match. More effective would be to offer these families family-friendly community-based services that are available through the public mental health system by ensuring that the child becomes Medicaid-eligible through TEFRA.

The advantage of TEFRA for the child is obvious. Families on TEFRA in Minnesota (the only state with data) have incomes that are average for the state. If they have private insurance, mental health coverage is limited and the intensive community services their children need are typically not part of an insurance policy benefit package. The options facing these families are to place their child in an institution (Medicaid will pay after 30 days), give up custody to child welfare (child welfare will pay the Medicaid match and the costs of residential care), or continue to struggle along until their child will, most likely, enter the juvenile justice system and become a state responsibility. Families want their children to have access to services before such dire outcomes occur. TEFRA is an obvious policy option for states that wish to address these families' needs.

Fact Sheet

For States Interested in Using the TEFRA Option for Children with Serious Mental Disorders

TEFRA (Katie Beckett) Medicaid Option: State Policies

Issue

Families of children with serious mental or emotional disorders are often unable to obtain the specialized and intensive services their children need through their private insurance policy or by paying out-of-pocket. Medicaid provides the range of services children with disabilities require and can be a life-saving resource for these families. However, many such families have incomes too high to be covered under normal Medicaid rules.

State Option

Under federal law, states have the option to cover children with physical and mental disabilities in the community if the child would be eligible for Medicaid institutional services but can be cared for at home. This option was authorized by the Tax Equity and Financial Responsibility Act of 1982 (TEFRA); it is sometimes called the Katie Beckett option after the child whose situation inspired it.

Children Who Are Not Covered

In half the 20 states that have the TEFRA option, no children with mental or emotional disorders have qualified for the program. While federal law does not permit states to exclude qualified children based on their disability, these states' policies have effectively done just that. The states are: Connecticut, Georgia, Idaho, Massachusetts, Michigan, Nebraska, Nevada, Rhode Island, South Carolina and South Dakota.

State Policy Issues

State rules in these 10 states may be causing children with mental disorders to be in appropriately excluded under TEFRA. When states set policy for their TEFRA option they must do the following:

- clarify the definition of a medical institution that the child would need to be admitted to without the community services of TEFRA;
- define the level of care the state considers to be "normally provided" in these institutions;
- clarify how the state will decide that home care is appropriate for the child; and
- explain how the state will calculate that home care does not cost more than the alternative care in the medical institution.

In setting these policies, states can affect the degree to which children with mental disorders access the program. For example, state rules defining a medical institution and the level of care a child needs in order to be at risk of placement in such an institution can be problematic for children with mental and emotional disorders. A number of states include reference to "psychiatric hospitals" in their definition of medical institution. These states have children with mental disorders on TEFRA, while most of those that do not reference psychiatric hospitals do not. (See the box on the next page for more details on the TEFRA rules as they relate to children with mental disorders.)

Parent Information

Parents need information about TEFRA and assistance in applying. States where children with mental and emotional disorders qualify under TEFRA have parent booklets and other materials that reference the eligibility of children with mental and emotional disorders. Often this information is also featured on a web page. Materials need to be short and easy to read, but must include appropriate information on the option and how to apply.

Fact Sheet for States Interested in Using the TEFRA Option for Children with Serious Mental Disorders

State TEFRA Rules Relevant for Children with Mental Disorders

None of the 10 states with the TEFRA option where no children with mental disorders qualify explicitly cite psychiatric hospitals in their definition of a medical institution. Most of the states that do include children with mental disorders refer to psychiatric hospitals in their rules.

Level-of-care criteria may also be inappropriate for children with mental disorders. For example,one state explicitly defines a hospital level of care as addressing only the needs of children with physical disabilities and another requires a child to need nursing home level of care,an inappropriate standard for a child with a mental disability.

The way states calculate the cost of home care versus the cost of institutional care may also be a barrier. The methods used by states vary widely, and in some states it is the counties that make these calculations.

In contrast, none of the states reviewed have rules that appear to exclude children with mental disorders from being considered appropriate for home care instead of institutional care. In fact, in most states children are able to qualify for TEFRA while still at home because they are found at risk of institutional placement. Accordingly, this aspect of state rules is not a barrier to including children with mental disorders.

From: *Avoiding Cruel Choices, Report of a Study on TEFRA* for the Center for Mental Health Services, Rockville, MD, Bazelon Center for Mental Health Law, Washington, D.C. 2002

Parent Information (Cont'd.)

Materials, while useful, are not sufficient to ensure that families learn of TEFRA. Families in states with the TEFRA option complain of:

- difficulty understanding how to provide the appropriate documentation of disability;
- long and complex application forms;
- significant delays before a decision is made on an application;
- requirements for re-application yearly or at other time intervals;
- denials resulting from missing information when the parent was unaware of this fact;
- difficulty finding assistance to help them complete the application.

Several states have engaged in outreach and other educational efforts to overcome these barriers, such as:

- outreach to familiy organizations;
- in-service training on TEFRA for community mental health program staff and training and orientation about TEFRA for Medicaid eligibility workers;
- distribution programs to provide materials to pediatrician offices, children's hospitals, county offices and other places where families may pick them up.

Some states also designate individuals to help families fill out TEFRA applications. For example, Wisconsin has regional Katie Beckett consultants.

Fact Sheet

For States Interested in Creating a Home- and Community-Based Waiver for Children with Serious Mental Disorders

Rules on Home- and Community-Based Waivers for Children with Mental and Emotional Disorders

Issue

Despite the value of the home- and community-based services waiver under Section 1915(c) for children with mental and emotional disorders whose families might otherwise be forced into giving up custody to the state because they can no longer manage their child at home without supports, only three states have such waivers in their Medicaid programs. In contrast, 49 have waivers for individuals with developmental disabilities.

Home- and Community-Based Waiver

A home- and community-based waiver permits children with mental disabilities (as defined in SSI) to be offered home-based services in lieu of placement in an institution. The waiver allows the state to expand the number of children eligible for Medicaid because children may be included regardless of family income if they would otherwise require care in an institution.

The waiver also allows the state to offer these children and their families an expanded package of home- and community-based services that may include the all-important service of respite care for the family, along with other family-support services that enable the child to remain at home. This is a far better option for the child and family and less expensive for the state. With support services, the child's own family is able to care for the child. Without such services,costly therapeutic foster care or institutional services are the only option.

One potential problem in the federal rules for home- and community-based waivers is the definition of the institutions from which the covered child would be discharged or diverted. Federal law defines these institutions as only "hospitals, nursing homes and Intermediate Care Facilities for Mental Retardation." The federal Centers for Medicare and Medicaid Services (CMS) has made it clear that a residential treatment center for a child with a mental or emotional disorder does not fall within this definition. This makes it more difficult for states to use the waiver. However, states can still estimate the number of children with serious mental disorders whose condition requires the level of care provided in a hospital and use cost estimates of hospital care to document their potential savings through a waiver.

State Concerns

A recent survey of selected states without the home- and community-based services waiver found that more than half of states had considered developing a waiver for children with mental or emotional disorders, but faced barriers in doing so.[1] These states identified the following as the most significant barriers (percentage of states where officials cited these barriers in parentheses):

- lack of state funds to furnish the state's share of Medicaid costs (65%);
- the federal rule which does not permit children in or at risk of placement in a residential treatment center to be eligible (59%);
- the requirement that community services be no more expensive than the alternative institutional placement (47%).

Modest Cost

Experience in the three states that have these waivers shows that the cost-related concerns of other states can be addressed. In fact:

- The costs of a home- and community-based services waiver for children with mental or emotional disorders are quite low per child, e. g. $12,900 per child for the home- and community- based

Modest Cost (Cont'd.)

services in Kansas (2001), $23,344 in Vermont (2001) and $40,000 in New York (2001). In comparison, per child institutional costs in these states were: $25,600 in Kansas, $52,988 in Vermont and $77,429 in New York.

- Since the state can limit the number of slots, a home- and community-based waiver can be initiated with a relatively small state investment. For example, first-year costs for the Kansas waiver were only $1 million. Initially, New York began by serving 25 children.

The three states with these waivers did not find the state match difficult to raise. All started small and expanded the waiver after the state had some experience. In New York, the legislature was supportive of increasing access to community care. In Vermont, total costs are low and several agencies contribute funds for the match. In Kansas, tobacco settlement resources were initially used for the match and experience with waivers for individuals with developmental disabilities encouraged state officials to apply for a waiver for children with mental disorders.

These three states have had little trouble meeting the cost-neutrality requirements. The high costs of institutional care easily offset the average waiver costs. Each state found it had an adequate level of funding and none have average costs that approach the institutional costs. States also did not find it difficult to gather the data to demonstrate cost neutrality to the federal government. They used existing data systems, and one supplemented this through a survey of providers.

Other Barriers

The states with the waiver found it a helpful source of funding for home- and community-based services and a catalyst to build the necessary infrastructure. However, states needed to address the issue of workforce development and training. One state provided incentives for participating agencies by providing start-up funds for new services.

Federal rules on the institutions to which children are at risk of placement are a more serious barrier. Only hospitals, nursing homes and Intermediate Care Facilities for Mental Retardation are included in the federal definition. In some states very few children on Medicaid are placed in a psychiatric or other hospital settings, but are instead in residential treatment centers (RTCs). In these states, a home- and community-based waiver can still be developed but the state will have to prepare documentation showing that a significant number of children have conditions that require a hospital level of care (even if the child is not placed in a hospital) and the costs of such care. A home- and community-based waiver can be developed in this manner.

Legislation to include RTCs within the definition of institution under Section 1915(c) is pending in Congress and CMS has announced plans to develop a demonstration program along these lines. However, pending federal action some states may not be able to use the home- and community-based waiver to help parents of children with mental or emotional disorders.

States can also control the size of the population covered (and thus the costs) and the home- and community-based services families need to keep their child at home are significantly less expensive than the costs of alternative institutional care.

Action Needed

All 47 states[2] without the waiver should examine the pattern of institutional placements for children with mental and emotional disorders to determine whether a home- and community-based services waiver can help families struggling to find services for their child.

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[1] Survey conducted in 2001 by the Bazelon Center for Mental Health Law, Washington, D.C. [2] And the District of Columbia

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A BAZELON CENTER ISSUE BRIEF

Mix and Match

Using Federal Programs to Support Interagency Systems of Care for Children with Mental Health Care Needs

CONTENTS

INTRODUCTION

The importance of cross-system collaborations to address the needs of children with mental or emotional disorders who receive services from various child-serving agencies—most commonly, mental health and substance abuse, child welfare, education and juvenile justice—is increasingly recognized. Over the past decade, the federal government has provided resources to encourage states to develop interagency systems of care to meet these children's needs. As states develop such collaborations, they need to draw on various federal funding programs while also using their own resources to support the comprehensive array of services necessary to meet the needs of children with serious mental and emotional disorders.

All states have now developed some level of cross-system collaboration. However, these collaborations vary widely in extent and effectiveness. Many states have had considerable difficulty bringing systems of care to scale in the state. Local systems have often floundered once their special funding from foundations or government sources has ended.

Yet the need for such interagency collaborations is great. The way resources for children's mental health services are distributed, organized and funded often makes little sense. Most funds are still directed to the most restrictive forms of care in response to escalating crises—crises that could have been avoided, had adequate resources been available to serve these children in the community. Families face significant gaps in services due to funding constraints. Some are assigned several case managers (one from each system), and the goals of different agencies often conflict. In extreme cases, families are forced to give up custody to the child welfare system in order to obtain care for their child.

Clearly, much more can be done to increase coordination and expand families' access to needed services. Federal programs can be improved to assist states, and the Bazelon Center has made recommendations to this effect.[1] However, states and localities can also use existing federal programs in a coordinated manner to finance the widest possible array of services for children of all ages and income groups. This issue brief is produced to help them do so.

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LAW

ABOUT THIS ISSUE BRIEF

The brief was written by Chris Koyanagi, Ron Boudreaux and Elizabeth Lind, and edited and designed by Lee Carty and Christopher Burley. Its development, production and distribution were funded by the William T. Grant Foundation, with additional support provided through the Bazelon Center's general program by the John D. and Catherine T. MacArthur Foundation, the Evenor Armington Fund and the Public Welfare Foundation.

The Bazelon Center is the leading national legal advocate for adults and children with mental disabilities. The staff uses a coordinated approach of litigation, policy analysis, coalition-building, public information and technical support for local advocates to end the segregation of children and adults with mental disabilities and assure them of the opportunity to access needed services and supports.

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The information presented here comes from officials in states with a history of interagency collaboration—in particular, from individuals representing state mental health, child welfare, juvenile justice, education and Medicaid agencies, along with families and national experts, who met in the Fall of 2002. The group discussed how states and communities can create sustainable statewide systems of care and how they can use existing federal programs to fund them. This report is based both on their recommendations and on a separate set of conversations with officials in 10 other states, held prior to the meeting.

FEDERAL PROGRAMS FOR CHILD MENTAL HEALTH SERVICES

Financing an interagency system of care requires that state and local officials make effective use of all relevant resources. Much of the funding for services to children with mental and emotional disorders comes from the federal government. Unfortunately, these monies come from numerous complex programs. These programs are hard to understand individually and even harder to understand as parts of a comprehensive revenue stream for state and local systems of care.

The rules for the various federal programs are designed to ensure accountability. These programs target resources to address specific needs of children and achieve specific federal policy objectives. However, participants stressed that both the number of federal programs that fund services for children and the fact that federal dollars flow through several separate federal agencies create significant difficulties for state and local officials who are designing comprehensive interagency systems of care to meet the range of needs that children with serious mental and emotional disorders have.[2]

Those interviewed were most frustrated by the fact that individual children may be eligible for some federal programs, but not others. This creates gaps in funding for the continuum of needed services. Families may have limited choices and experience delays in accessing appropriate services because their children fall between the cracks of federal programs. In the worst situations, children are provided the services that can be funded rather than the services that could best meet their needs. At a minimum, disjointed funding streams force families to go from place to place to seek care and undermine efforts to provide continuity in services. Inconsistent accounting standards, including different data-collection and reporting requirements, can further frustrate state and local efforts to provide a coordinated system of care.

While these are all significant obstacles, states contacted for this study have found ways to address many of them and to use federal funds effectively and in a coordinated manner. These states have achieved more success in this than many other state and local officials realize. Their combined experiences are reflected in the recommendations that follow.

PRINCIPLES FOR A SUCCESSFUL FUNDING STRATEGY

A study of the Robert Wood Johnson project that led the way in demonstrating the effectiveness of interagency systems of care found that successful systems use resources from various sources, often in ways that less successful collaborations do not. Successful systems integrate resources behind a common plan for each child and family, to which all the collaborating agencies are committed. Rather than tightly controlling expenditures through overly restrictive regulations and burdensome cost-accounting at the provider level, these systems have set up an extensive provider network, which operates in a flexible manner, focuses on performance and outcomes, and makes continuous efforts to improve the quality of services. Flexibility is supported either by blending various funding streams and/or by braiding major program funding or by doing some of both (see box on page 4 for discussion of these mechanisms). Under this approach, each family has one care plan that is coordinated through a single accountable entity but funded with resources from various programs.[3]

To ensure a successful funding strategy, those interviewed suggested that state and local planners need to:

- have a clear vision of what they are trying to finance;
- engage in collaborative planning across agencies and with families;
- understand resource options. Planners must determine in what way federal funds can be used, under what timetable, how and by whom, and what are reporting requirements. In doing this, it is important to avoid a rigid and conservative interpretation of federal rules, particularly Medicaid;
- create a funding strategy that merges and takes maximum advantage of different funding sources—federal and other—so that child and family needs drive agency decisions on which services to provide;
- focus on outcomes but recognize the need for accountability – in particular, cost-accounting must be rigorous to demonstrate how program requirements are being met. It is necessary to track, document and account for funds as well as demonstrate outcomes;
- engage families in the service and provider monitoring process;
- possess a data infrastructure that can provide the essential information needed to ensure accountability; and
- provide training and cross-training of staff.

BLENDING OR BRAIDING FEDERAL FUNDS

Blending or braiding federal funds allows decisions on services to be made with the family and by those working most closely with the family. Both strategies offer local flexibility and allow providers to focus on outcomes. However, this flexibility must be accompanied by accurate measurement of outcomes.

BLENDED AND BRAIDED FUNDING ARRANGEMENTS

Blended funding pools have been used for many years, while the concept of braiding funding is a more recent approach. Both approaches combine funds from different federal agencies or programs into a single funding stream so they are indistinguishable at the point of service delivery.

Blended funding: Funds are combined into a single pool from which they can be allocated to providers.

Braided funding: Funds from various sources are used to pay for a service package for an individual child, but tracking and accountability for each pot of money is maintained at the administrative level. The funds remain in separate strands but are joined or "braided" for the individual child and family.

To local providers of care and for families, blended and braided funding streams should look the same. However, braiding avoids some potential difficulties with blended funding pools in that it recognizes the categorical nature of how we fund services in this country.

Those interviewed stressed that systems of care must track, document and account for the funds they spend, whether using a blended or a braided funding approach. To collect the information needed to demonstrate effective outcomes for children served and accountability to taxpayers, systems of care must coordinate monitoring across agencies and strive to demonstrate total costs and benefits across systems.

Blended funding—even on a small scale – has advantages over braiding of funds because it offers significant flexibility for state and local agencies and reduces the work required for reporting and accountability measures. Blended funding can allow systems to fund activities that are not reimbursable through specific categorical programs. In so doing, blended funds can help plug funding gaps in the services continuum. This is particularly true when blended funding includes flexible dollars such as those available through a state's general fund.

Braiding, on the other hand, allows resources to be tracked more closely for the purpose of accounting to federal program administrators. It thus recognizes the categorical nature of existing programs and avoids some of the conflicts that can arise in blended funding pools.

Blending funds is often more politically difficult than the newer approach of braiding because agencies lose control; the ability to track funds to the service-delivery point may also be lost. Those interviewed pointed out that agencies are often reluctant to contribute to a blended pool or, if they do, contribute only small sums, which they generally expect will be used to pay for activities that cannot be billed to a specific funding source. Braided funding approaches tap into the larger funding sources in a manner that allows both for accountability and local flexibility in meeting individual children's needs.

Implementing a braided funding approach involves significant attention to administrative issues, according to those interviewed. It requires that states or communities ensure that there is a single point of responsibility for assessing services and the funding stream that can pay for them. Large provider agencies may be able to handle the fiscal accounting of braided funding themselves, but small providers cannot. To implement a braided funding approach, states may wish to make available to smaller providers a skilled fiscal agent who is responsible to all agencies participating in the braided funding approach. This agent would address the various requirements of funding programs, such as different funding cycles, different payment arrangements (prospective, retrospective) and different reporting requirements. This approach would provide a single point of accountability for funders, but would also require its own administrative funds. Braided funding can be a cost-accounting challenge, but it can be done and ultimately is an important strategy for making the best use of the significant federal resources available for children's services.

We use woven funding. Financing streams in the state are mapped out. (State *mental health official*)

EXAMPLES OF BLENDED AND BRAIDED FUNDING

Wraparound Milwaukee, Wisconsin is a county-based managed care program operating with a blended funding pool. Medicaid, child welfare, juvenile justice and mental health agencies all contribute resources. Medicaid pays on a capitated basis, the other agencies pay case rates. Thus each agency knows the cost of services to children it refers to the system.

Vermont has operated a braided funding system for the past 15 years, using child welfare, juvenile justice, mental health and special education funds to develop innovative community-based treatment plans for children, adolescents and their families with the most intensive and complex needs. For the past 10 years, mental health, juvenile justice and child welfare have blended funds to operate a comprehensive immedi-ate- response system in each of the 12 regions of the state.

Michigan, in 17 counties, uses a case-rate and wraparound approach to blend funding from mental health, juvenile justice, child welfare and education to serve children with serious mental or emotional disorders. Funding is separately tracked for accounting purposes, but at the child-family level the source of appears to be a single pool.

(continued on the next page)

USING FEDERAL FUNDS EFFECTIVELY: ENTITLEMENTS AND PERMANENT AUTHORITIES

Whichever system of merging funds is adopted, it is important to understand fully the rules that govern the financing of services through federal programs and use them in the most advantageous ways. The interviewees urged system planners, when designing a sustainable funding strategy, to consider different ways of using two categiories of federal programs:

◆ ongoing funding streams such as block grants or entitlement programs that provide resources year after year in a reliable fashion, and

◆ discretionary grants, which are time-limited and often require state or local matching funds.

No state or local system of care can be sustained effectively without ongoing financial support from both state/local and federal sources using reliable funding streams. This means that the first and most important step for planners is to review federal programs that provide ongoing support without arbitrary federal time limits. Such programs exist to fund the activities of all core child-serving agencies. For example:

◆ Medicaid supports all agencies—mental health, child welfare, education and juvenile justice.

◆ Programs under the Individuals with Disabilities Education Act, the Elementary and Secondary Education Act and Vocational Education Act are available to school systems.

◆ Department of Justice Juvenile Justice and Delinquency Prevention Act programs can support a wide array of activities.

◆ Title IV-B and Title IV-E of the Social Security Act provide resources to child welfare systems.

◆ The mental health, substance abuse and Maternal and Child Health block grants fund specific services through three state agencies.

◆ Temporary Assistance for Needy Families (TANF) pays for services for low-income families.

◆ The Social Services block grant (Title XX) funds a range of services for many children.

The matrix on pages 8-9 offers an overview of the services and other activities that can be funded through these and other major federal entitlement or block grant programs. All programs in this matrix provide ongoing resources without arbitrary time-limits, although the level of funding available may vary, depending on federal appropriations and the state and local resources available to provide a match.

The matrix is intended as a guide to specific opportunities for funding services and activities with these federal programs. Each program has its own restrictions on eligibility and on what can be funded, but it is impossible to show

such level of detail in a chart. For example, Medicaid is shown as funding both therapeutic foster care and supported housing. However, Medicaid will fund only some of these activities' costs (those related to services) and not others (such as rent or reimbursement to a foster family). Title IV-E funds certain expenses, but only when children are in foster care and only if costs are built into the foster care rate. Each program in the matrix, similarly, has limitations. Table 1, on pages 24-25, presents a few of the most important caveats regarding these programs.

Interviewees strongly recommend that to use these programs effectively, states and, to a lesser degree, localities should charge individual staff with the task of becoming experts on federal rules. Without a full understanding of federal program rules and what can be done with particular federal funds, significant opportunities to support the system of care with federal resources may be lost. Given the complexity of many federal programs, this is most effectively done by a team consisting of staff from all relevant agencies. The matrix identifies the potential of the various funding streams and can facilitate such work.

The first several lines of the matrix identify key aspects of eligibility rules, and can help planners identify whether:

- the program is means-tested, meaning that program eligibility is tied to family income and/or resources;
- only children and youth of a certain age range are eligible. Programs where no such limit is indicated may nonetheless define the end of childhood differently, such as at age 18, 20 or 21;
- children must have a certain level of impairment or disability before they can qualify for the program; or
- other eligibility criteria exist, such as being in foster care.

This allows system planners to see how certain children may qualify for some services through one program and other services through another. It thus shows planners which services are not adequately supported by federal sources and where alternative funding approaches will be needed.

The matrix also shows the services and activities that can be funded for eligible individuals under each of the listed federal programs. These are grouped into:

- screening and assessment;
- services for children and families (medical and clinical services are shown first, followed by rehabilitation and support services); and
- infrastructure funding (training, transportation, etc.).

Because this matrix is for use by interagency systems of care serving children whose mental health care needs have already been identified, it does not include the preventive programs that have a broad population-based public health approach.[4]

The matrix is based on federal rules governing the use of funds and on state efforts to fund specific mental health services or activities through the programs.

EXAMPLES (continued)

New Jersey, in a new statewide initiative, combines blending and braiding approaches. The payment source for a specific service is unknown to providers and families, who see only a flexible pot of funds available for the child's services. The state contracts with an administrative services organization to address payment issues and to support individualized service planning at the local level. The ASO identifies the payment source for each identified service or support for the child and family. This is facilitated through the creation of a single electronic record. Funds for the initiative (Medicaid and non-Medicaid funds) are held by the state Medicaid agency and the Medicaid agency handles all reimbursement through its existing financial management system.

The Dawn Project in Indiana has braided funds from mental health, special education, child welfare and juvenile court to create a case rate paid per member per month to be used flexibly by providers in the system to finance an individualized and comprehensive plan of care for each child and family. Agencies contribute to the case rate based on established eligibility criteria. The project uses clinical-management software which can integrate clinical and fiscal data. These data are used to handle cost approval and analysis and claims adjudication.

With respect to Medicaid, services checked include those incorporated in a number of states' definitions of rehabilitation services, even though, because of Medicaid's reliance on state flexibility, there may be no federal rules defining these services.

Action step: The interviewees suggested that states set up a review process to consider the services they wish to fund and the eligibility status of the group of children they intend to serve, and to identify existing budget assets. The matrix can then be used to identify gaps in their current use of potential federal funding sources.

To replicate this matrix at the state level—to show what is now funded through these various federal sources—key information is needed on who is eligible, who can provide services, how funds must be accounted for, and what are the administrative requirements. Administrative requirements include the rules on reimbursement (prospective and retrospective), reporting requirements and more. It is also important to identify the state and local agencies that can draw down funds from the various federal programs.

Interviewees suggested that one way to gather information is to send a questionnaire to agency personnel and to families, asking what works well in the current system of mental health service delivery and what does not. This can help identify services that require expansion and those viewed by key players in the system as not helpful.

Once the funding for various services and activities is mapped, it is then possible to engage in a meaningful process to identify opportunities in the major federal programs by matching the funding stream to the programmatic goals of the system of care. It is also important to consider how programs can work together to fund particular services. For example, Title IV-E can fund room and board for therapeutic foster care while Medicaid can fund training and services for the therapeutic foster family.

Such a comparison can also help states develop a strategy to divert residential-service spending to community care. Over the years, a number of states have found this an important tool for improving systems. Recently, New Jersey, as part of its statewide child services reform, was able to leverage federal funds for residential services that had been 100-percent state-funded. This enabled dollars previously used for long-term residential care to serve as the state Medicaid match in order to extend the array of services provided through local community-care organizations. As a result, children and families have access to a more diverse array of appropriate, individualized community-based services.

Part of this process should be the identification and removal of state and local barriers to tapping into federal resources in appropriate ways. The end result should be a coherent set of policies that allows programs to work together as much as is feasible under federal law. In some cases, this may require changing state rules and regulations or even state statutes.

> You need the skill to identify rules you can change. Then change those rules you can through legislation, policy bulletins or whatever. It's a skill to identify what you can change and what would be wasted energy. (State mental health official)

Matrix of Federal Entitlement and Block Grant Programs to Support Systems of Care for Children with Serious Mental and Emotional Disorders

	Title IV-E Foster Care	Title IV-E Training	Title IV-E Administration	Title IV-B/ Promoting Safe & Stable Families Prog.	IDEA, Part B	IDEA, Part C	IDEA Pre-School Grants	Sliver Grants	Vocational Rehabilitation, State Grants	ESEA, Title I used for special education students	Community Development Block Grants	Section 8 Housing	Juvenile Justice & Delinquency Prevent. Form. Grant	Delinquency Prevention Block Grant (Part C)	Medicaid: Clinic Services	Medicaid: Rehabilitation Services	Medicaid: EPSDT Administration	Medicaid: Targeted Case Management	Medicaid: Psychiatric hospital services for children	Medicaid: Home & community-based waiver	Medicaid: Other*	S-CHIP	Community mental health block grant	Substance abuse block grant	Maternal and Child Health Block Grant	Social Services Block Grant	TANF	Child Care Block Grant
ELIGIBILITY																												
Income	X	X	X							X		X			X	X	X	X	X	X	X	X					X	X
Severity of child disorder				X	X	X	X	X	X														X					X
Age	X	X	X	X				X																				
Other factors	X	X	X																								X	
SERVICES																												
Screening	X		X	X	X	X	X	X					X	X	X	X			X		X	X	X		X	X	X	
Assessment/evaluation/diagnosis	X		X	X	X	X	X	X					X	X	X	X			X		X	X	X		X	X	X	
Anticipatory guidance				X									X	X	X	X			X	X	X	X	X		X	X	X	
Individual, group and family therapy				X	X	X	X	X					X	X	X	X			X	X	X	X	X		X	X	X	
Crisis intervention				X	X	X	X	X					X	X	X	X			X	X	X	X	X		X	X	X	
Mobile crisis services				X									X	X	X	X			X	X		X	X		X	X		
Medication management				X									X	X	X	X			X	X	X	X	X		X			
Prescription medications													X	X							X		X		X			
Substance abuse outpatient treatment				X	X	X		X					X	X	X	X				X	X	X		X	X	X	X	
Parental education on child disorder				X	X	X		X					X	X	X	X			X	X	X	X	X		X	X	X	X
Home visits for new borns			X	X		X		X					X	X	X	X				X	X	X	X		X	X	X	
Family services for 0-6				X		X		X					X	X									X		X	X	X	
Intensive in-home services				X		X							X	X		X				X		X	X		X	X	X	
School-based day treatment				X	X		X	X					X	X	X	X				X		X	X					
School-based mental health services				X	X		X	X					X	X	X	X				X		X	X					
Other day treatment				X	X		X	X					X	X	X	X				X		X	X		X	X	X	
Behavioral aide	X			X	X	X	X	X					X	X		X				X		X	X		X	X	X	
Social skills daily living skills training	X			X	X	X	X	X					X	X		X				X		X	X		X	X	X	
Therapeutic nurseries/preschools				X		X	X	X								X				X		X	X		X	X	X	
After-school programs	X			X	X	X	X	X					X	X		X				X		X	X		X	X	X	X
Summer day programs	X			X	X	X	X	X					X	X		X				X		X	X		X	X	X	X
Parent hotlines				X		X		X					X	X		X				X		X	X		X	X	X	
Therapeutic recreation				X	X	X	X	X					X	X		X				X			X		X	X	X	
Service team meetings	X		X	X	X	X	X	X					X	X									X		X	X	X	

Matrix of Federal Entitlement and Block Grant Programs to Support Systems of Care for Children with Serious Mental and Emotional Disorders (continued)

	Title IV-E Foster Care	Title IV-E Training	Title IV-E Administration	Title IV-B/ Promoting Safe & Stable Families Prog.	IDEA, Part B	IDEA, Part C	IDEA Pre-School Grants	Sliver Grants	Vocational Rehabilitation, State Grants	ESEA, Title I used for special education students	Community Development Block Grants	Section 8 Housing	Juvenile Justice & Delinquency Prevent. Form. Grant	Delinquency Prevention Block Grant (Part C)	Medicaid: Clinic Services	Medicaid: Rehabilitation Services	Medicaid: EPSDT Administration	Medicaid: Targeted Case Management	Medicaid: Psychiatric hospital services for children	Medicaid: Home & community-based waiver	Medicaid: Other*	S-CHIP	Community mental health block grant	Substance abuse block grant	Maternal and Child Health Block Grant	Social Services Block Grant	TANF	Child Care Block Grant
Wraparound facilitation	X		X	X	X	X	X	X					X	X		X							X		X	X	X	
Case management	X		X	X	X	X	X	X					X	X	X	X		X		X		X	X		X	X	X	
Intensive case management/ACT			X	X									X	X		X		X		X			X		X	X	X	
Supported employment (adolescents)				X	X			X	X				X	X									X		X	X	X	
Supported education (adolescents)	X			X	X			X	X				X	X									X		X	X	X	
Supported housing (adolescents)	X			X							X	X	X	X									X		X	X	X	
Education and consultation					X	X	X	X					X	X		X							X		X	X	X	X
Respite services	X			X		X							X	X									X	X	X	X	X	X
Parent-to-parent support groups	X			X	X	X	X	X					X	X									X	X	X	X	X	
Engaging natural supports	X		X	X									X	X		X				X		X	X		X	X	X	
Transportation	X			X	X	X		X					X	X							X				X	X	X	
Inpatient psychiatric hospitalization																			X									
Residential treatment center services**	X			X	X			X											X					X				
Crisis residential services**	X			X												X			X					X	X			
Group homes**	X			X							X	X				X							X	X	X			
Therapeutic foster care**	X			X												X							X	X	X	X		
Purchase of goods/opportunities for child	X				X	X		X					X	X											X		X	
Recruitment of personnel	X		X	X	X	X	X	X					X	X											X	X		
Pre-service training	X	X	X	X	X	X		X																	X	X		
Multi-discipline & cross-discipline in-service train	X	X		X	X	X	X	X					X	X											X	X	X	
Resources for family organization				X									X	X											X			
Resources for family partic. in policy & program	X		X	X									X	X									X	X	X			
Advocacy services			X	X			X						X	X											X		X	
Mediation of disputes				X	X	X	X	X					X	X											X		X	
Technical assistance to providers	X		X	X			X	X					X	X							X		X	X	X			
Management information system	X	X	X	X			X	X					X	X							X		X	X	X		X	
Provider networking	X			X	X	X		X					X	X									X	X	X		X	
Systems collaboration (agency level)	X		X	X	X			X					X	X							X		X	X	X		X	

*Medicaid: Other category includes physician, home health, transportation, administration

** Under Title IV-E, only room, board, and care can be covered; under Medicaid, only services can be covered

Those interviewed stressed that, while addressing all state-created barriers at once may not be manageable, states should begin this process by dealing with the most problematic constraints.

> It is important to drop rules when they are out-of-date. (State mental health official)

Interviewees stressed that the process of removing program barriers and simplifying rules should not diminish accountability. Instead, the aim is to create flexibility and improve continuity of funding for systems of care. Systems of care should adopt appropriate performance measures to measure their outcomes.

How States Use Federal Entitlement and Block Grant Funds

Without exception, interviewees had found Medicaid to be the backbone of their funding strategies. Although federal Medicaid law allows states to fund a wide range of services, the interviewees knew that in many states either the state Medicaid agency or the federal regional office resists efforts to take full advantage of federal options. But not all states are so reluctant. New Jersey's representatives described a strategy where several state officials—including those from the state Medicaid agency—went to the federal regional office to explain their plan for funding community mental health services for children, showing how it would make services more accessible and improve child outcomes. Federal approval of most of the state's Medicaid proposals followed.

A second significant yet often underutilized federal entitlement for children with mental and emotional disorders is the Individuals with Disabilities Education Act (IDEA). The IDEA funds services for children of all income groups and is thus a critical adjunct to Medicaid funding. In Vermont, negotiations with the education system have led to school systems' contributing to the state Medicaid match in order to support more than 300 school-based clinicians. Mental health centers provide significant backup once children are identified under the IDEA.

Child welfare resources are typically used to fund room-and-board costs for children in care (Title IV-E) or to support adoption and reunification. Federal funds for prevention of out-of-home placements (Title IV-B) are much scarcer, but the rules are very flexible as to the range of services that can be funded and more flexible than Title IV-E regarding the low-income children who can be targeted.

Juvenile justice funds flow in large formula-grant programs to states, which must funnel most of them to localities. As the matrix shows, very few restrictions are placed on the use of these funds for children with mental or emotional disorders. However, mental health and other eligible activities often compete for these funds locally. Ultimately, juvenile justice typically provides fewer dollars to a system of care than mental health, child welfare or Medicaid, but these funds can be used for activities other federal sources will not support.

Discretionary Programs Plug the Gaps

Interviewees reported using a number of federal categorical programs for children's services to strategically supplement funds from entitlements and block grants. They suggest that states review the most relevant categorical programs to determine whether these dollars can fill gaps in funding of a particular system of care, provide start-up money for new services, underwrite infrastructure, support training or retraining, or finance strategy-planning processes.

Major discretionary programs authorized through each of the four core child-serving federal systems (mental health and substance abuse, child welfare, education and juvenile justice) are shown in Table 2 on pages 26-28. This is not a definitive list, but a listing of programs considered most relevant and useful by the officials who participated in the Bazelon Center study. Most of these programs are funded by the Department of Health and Human Services—particularly the Substance Abuse and Mental Health Services Administration—but the Departments of Education and Justice are also important sources to which state and local systems can look for discretionary funds.

Because it is important not to rely too heavily on discretionary programs that will inevitably end within a prescribed number of years, one strategy, according to those interviewed, is to use such programs to initiate the most critical services missing in the current system. In some cases, a federal entitlement program may pay for the service once it is in place, but it will not pay development costs. In other cases, once demonstrated effective, such services may be more readily funded through state or local sources. In adopting this approach, it is important to develop a strategy for how a reliable funding stream will eventually pay for the services or activity once discretionary funds are terminated

Other activities that can often be best funded through federal discretionary programs are time-limited, such as planning, technical assistance, training or building data infrastructure.

Such time-limited activities can also be funded with private resources, such as grants by national and local foundations, corporations and community organizations. The interviewees pointed out that, while private grants or contributions provide lower funding levels than most government sources, they can be extremely flexible and therefore valuable to system planners.

Those interviewed saw many opportunities for states and localities to use federal programs to fund an expansive array of services for children with mental disorders who receive services through various child-serving systems. However, these funds will be more efficiently used if the core child-serving agencies collaborate around both service delivery and funding issues. The remainder of this report reflects the perspectives of these officials with respect to forging meaningful and long-lasting cross-agency collaborations better to meet children's mental health care needs.

COLLABORATIONS FOR INTERAGENCY SYSTEMS OF CARE

Those interviewed for this study have had considerable success in forging interagency collaborations and they offered tips and suggestions for colleagues who are struggling to find the resources and political will in their states to establish collaborations that promote effective systems of care. Although the interviewees did not feel that a single model for establishing a system of care could be uniformly applied in all cases, they believe their experiences can guide others seeking to develop such systems.

Several excellent publications also discuss in detail how systems of care can be organized (see resources section on pages 22-23). *Building Systems of Care: A Primer,* by the Human Services Collaborative for the Georgetown University National Technical Assistance Center for Children's Mental Health, is particularly informative.

Who Collaborates?

Leadership has been a key factor in every collaboration that has achieved long-term viability and success in improving child outcomes.

> All of the agencies are jointly committed to the best care for each child… commitment of the agencies at middle management (responsible bureaucrats near the top of each of the child agencies) is what worked in our state. (State juvenile justice official)

Finding and supporting people who will play these leadership roles is not always easy. Participants at the meeting identified three key barriers that must be overcome:

- Leadership in an agency may be turf-oriented and self-protective.
- The system could be about to lose critical leadership or leadership combinations.
- Personnel shortages may limit the time that can be devoted to the required meeting/planning for system change or individual child/family planning.

To overcome these barriers, commitment from a high level of government has generally been necessary. The officials interviewed for this study stressed that top leaders must either buy into the concept or, at a minimum, support the collaboration's broad goals and empower agency personnel to collaborate in new and effective ways.

Some states establish separate committees, task forces or a children's cabinet to bring about high-level collaboration. Other states have less formal, but nonetheless effective, strategies.

> Find champions to carry the message and exemplify it. (State juvenile justice official)

Leaders must remain engaged. In the experience of those interviewed, the greatest success was achieved when high-level leadership stayed informed on

progress and had regular contact with those who were designing and implementing the system of care. At the same time, leaders must allow agency personnel the flexibility to think creatively and "out-of-the-box" in order to develop new ways of doing business.

The interviewees also stressed the importance of identifying individuals who can act as effective leaders within each agency (such as the state mental health authority's children's staff or the child welfare staff responsible for foster care), in family groups and in the stakeholder community. These individuals must do the actual work of collaboration on a month-by-month basis. In a few states, leaders at this level have achieved long-lasting and effective collaboration despite minimal involvement of higher-level leadership.

> You need people who have informal leadership, not necessarily formal leadership, to be engaged—people who are on your wavelength. (State mental health official)

While the exact structure varies to suit state dynamics, generally a core leadership group has formed in all successful states to sustain the collaboration through changes in political leadership. Another large, inclusive group often exists as well, to keep everyone informed and to collect feedback from a broad group of stakeholders.

> You can't be dependent on one person. It must be a culture of collaboration. (State child welfare official)

Collaborative relationships are built on trust among people who have shared ideas of system needs. According to the officials interviewed for this study, one way to assess who will be a strong partner is to look for willingness to make compromises when necessary. Rigid thinking will undermine collaborative efforts. People in the collaboration should be accessible to their colleagues and be ready to give up some control in order to further the collaboration.

> The skills you need to look for (in agency personnel) are facilitation skills, not diagnostic skills. (State mental health official)

Those interviewed felt strongly that family members need to be brought into such collaborations at the earliest possible stage, to work alongside agency personnel and help guide the collaboration so that outcomes are acceptable to families. This is unlikely unless public agencies provide resources for family members to participate, such as payment for their time and reimbursement for travel or other related costs and child care.

> What works is having families as allies...this enhances the vision that kids belong in communities and reduces turf issues. (State child welfare official)

All parties must make a real commitment, not just give lip-service to collaboration. The group needs to be action-oriented to avoid promoting reforms that

will exist only on paper. Participants pointed out that each participating agency must be willing to commit to the collaboration in a meaningful way so as to purchase results.

> The ingredients that make the system work are leadership and money as an incentive. If you play (collaborate) you get the money/resources to have your children served; if you don't, you don't. (State mental health official)

Action step: Establish a common mission and vision. Mental health systems commonly develop mission statements using the principles of the Child and Adolescent Service System Program (CASSP), on page 29. However, it is important to build a mission statement across agencies. This mission statement may need to be broader in some respects or narrower in others. Most state interagency mission statements incorporate many of the basic values of CASSP, but do not adopt the principles in their entirety.

First Steps to Take

Leaders must subscribe to the same important values. In particular, they must agree that children's and families' needs must be prioritized and must always override agency issues and staff needs.

> What brings people together is a shared commitment to do the right thing. (State juvenile justice official)

This philosophy should be clarified in a collaborative process and be in writing.

An important aspect of the mission, and one that should be dealt with by the highest level of leadership, is the definition of children to be served. Is it all children, all children with mental health care needs, children of all ages, children with serious mental or emotional disorders? Decisions on system-building vary greatly depending on this choice. Regardless of this decision, leaders must also focus on how the most complex cases will be resolved without disputes, because a failure to deal with the most difficult cases will undermine agencies' commitments to work together in the future.

> We have state review teams for very complex children. The directors of all agencies come together to deal with these children's issues. (State juvenile justice official)

Action step: As a group, establish a change-management plan, with a long-range view of perhaps five to 10 years to implement reforms. Such long-range change-management plans should take into account the potential impact of a change in political leadership.

Collaborators need to be clear not only on their mission and purpose but how they will accomplish their goals and the timeline for making the various changes needed. It is unreasonable to expect quick results.

To build long-lasting collaborations, the proposed system must both address children's and families' needs and serve each agency's goals. Participants believed that no single solution could guide collaborators, but that it is possible in each case to determine how the system of care will help agencies stay true to their basic mission. For example, many agency goals can be satisfied in a system of care whose articulated objectives include preventing children's involvement with juvenile justice, helping children behave appropriately in school or improving their academic performance, and keeping children safe either in their own home or in an alternative placement when necessary.

Action step: Prepare a marketing plan as part of the group collaborative process to address the issues for various stakeholders: agencies, families and policymakers.

Experience has shown participants that systems of care can readily be marketed to all agencies—and to legislators or senior policy officials who oversee such agencies—by showing how the collaboration will satisfy each agency's existing goals and improve outcomes. They stress that successful collaborations

do not result from mental health agencies' dictating to other child-serving systems what must be done by the group, but from mental health agencies' learning what other agencies require better to serve children with mental health care needs in their systems.

> What's clear from this is that the system's objections to change were taken seriously and dealt with effectively from the beginning, so they were invested in the process. (State child welfare official)

> Child welfare has been relieved of the sole responsibility for deep end kids' mental health issues. (State child welfare official)

Getting Down to Business

The process must begin with individuals' spending time to learn about each of the other systems—their language and goals, the data they collect and the products they want. This enables the group to acknowledge and respect the differences between agencies and to identify commonalities.

Action step: Engage in a process to identify what is working and what is not. This will identify gaps, overlaps, conflicts and poor outcomes to be avoided in the future.

The group should share detailed information about each agency, including budget information. Planning groups should be mixed, with policy experts, administrators and direct-care staff.

Frequent contact and a willingness to respond to problems of colleagues can facilitate this process. In time, informants had found, the group will begin to share power and control as well as the burden of running overextended systems with too few resources. All agencies may not be prepared to "play" and the collaboration must be prepared to proceed.

Action step: Determine where funds currently exist in the system, then identify how some of these dollars might be redirected to more effective strategies.

> Our primary systems are mental health, child welfare and Medicaid. Juvenile justice is a partner, but no funds yet. Education is involved to a lesser degree and substance abuse has a long way to go. (State mental health official)

Policy changes should allow for some top-down reform, such as a state's setting broad policy reform goals, designing new initiatives and providing funding, infrastructure and training. But they also should allow for bottom-up reform through local design and built-in flexibility at the local level, within the framework established by the state.

Particularly successful strategies to foster closer working relationships between mental health and other agencies are:

- Mental health staff volunteer to work on other agency committees—for example, to help write state regulations on IDEA regarding mental health issues.
- Mental health line staff are outplaced into other child-serving agencies.
- Cross-agency job shadowing is arranged for those working in all the collaborating agencies.

Action step: Create and implement a plan that addresses the need for integrated cross-agency financing, clinical practice and training of staff.

Action step: Early in the collaboration process, create a plan for how to obtain useful data and a plan for developing the necessary data infrastructure so that cross-system data can be compiled and analyzed.

> Mental health staff are co-located in [the] child welfare agency to resolve issues quickly. We co-fund certain services and share supervisory responsibility and jointly certify wraparound coordinators. (State child welfare official)

Collecting good data is critical for monitoring, evaluating and demonstrating success. Interviewees urged collaborations to address data-system issues early in the reform process. Unless it is clear what is happening to children and families from the outset, the effect of the collaboration will be difficult to determine. Without evidence that collaboration makes a real difference, resistance to change and other obstacles may soon overwhelm reform efforts. Collaborators must continue to evaluate the outcomes achieved by the system of care and must constantly work to improve its responsiveness and effectiveness.

Action step: Recruit diverse professionals and para-professionals for service delivery, engage and support families of color, assure that cultural competence is a value included in all agencies' programming and maintained through the use of cultural competence consultants for planning and training.

> We use Medicaid MIS now for some non-Medicaid services so we can identify all the funds for the child in one place. (State mental health official)

Data should focus on outcomes and speak for itself. That is, collaborations should avoid over-interpretation. Data might include:

- drop outs/school discipline incidents;
- child welfare residential-placement rates;
- use of inpatient psychiatric hospitals or residential treatment centers (RTCs);
- family views on services;
- number of children in juvenile justice because mental health services are inaccessible elsewhere.

As system reform is designed, it is critical to address the broad range of issues raised by the families who are to benefit from the provision of more effective services for their child. Each reform will need to infuse cultural competence throughout its systems of care.

Barriers to be Overcome

Long-standing suspicions, misunderstandings and different views of children and families in different systems can work against collaboration. Participants reported that the organizational culture in some agencies can also work against collaboration. They point out that these barriers should be recognized, so they can be addressed and agencies can remain focused on the child and family.

> Different values, beliefs, funding, "blaming and shaming" need to be dealt with early in the collaboration process and gotten out of the way. (State child welfare official).

> Teachers are invested in the status quo. A system of cross-agency staff training has been used to assist in implementing the [new] system. (State special education official.)

Keeping Collaborations Going

In addition to having formal processes for discussing key issues, participants reported, collaborations are often most successful when people get to know each

other in less formal ways. Deliberate plans to get together outside meetings—over lunch, for example—enhance the sense that all are engaged in a common task and walk the same path. This can help a group overcome the inevitable and difficult clashes of agency needs. Accordingly, said the officials interviewed, a sense of shared ownership, shared burden and shared leadership must exist within the group.

> In spite of legislation and policy, we were able to build strong relationships based on trust. (State education official)

Consultants can be helpful in developing and implementing these steps, according to participants. Outside experts can create trust when, as often happens, people within the state know each other too well and are unable to hear new ideas from their in-state colleagues. To get the most value from such outside consultants, it is best to work with only one or two individuals over time, so that the consultant becomes familiar with state-specific issues and problems.

An ongoing training program for administrators and direct staff is necessary to ensure success and maintain collaboration at both state and local levels. Cross-training is the most effective approach. Training must be ongoing, due to staff turnover and because the pressures of everyday work can overwhelm staff. If that happens, collaborative work, despite its long-term payoff, will be dropped.

> We have had wraparound training universally. Even correctional officers in the juvenile justice institution have received wraparound training (State juvenile justice official)

> Two trainers train staff from mental health, child welfare, juvenile justice and education with families for a week. (State mental health official)

Family engagement at the implementation stage is key, according to the officials interviewed. Family engagement can help maintain constant pressure for real improvement. It can also help motivate policymakers and legislators to support a process that may not immediately demonstrate its efficacy.

As time passes, participants warned, it is easy to allow day-to-day pressures to reduce the time spent continuing to build and nurture the collaboration process and the essential relationships. Strong collaborations are built on frequent contact and must involve individuals who are willing to spend time going beyond their normal responsibilities.

Managing Change in Difficult Times

Managing change is the difficult task facing a collaborative effort at systems reform. Those interviewed stressed that it is critically important to be strategic about what can be changed, and not to overreach in the early stages of reform. This is an evolutionary process and there will inevitably be stages to the relationships between agencies.

Interviewees reported that they had faced and overcome several challenges

to successful interagency system-of-care reforms, including:

- resource issues—a continuing and sometimes overwhelming barrier;
- changes in leadership, particularly at the highest levels;
- lack of advocacy and support from child agencies, families or various other child advocates in the state; and
- already overworked staff's becoming overwhelmed.

Those interviewed also highlighted four specific resource issues of concern:

- To be successful, systems of care must be able to serve all children who qualify, regardless of the funding source. Currently, mental health and, increasingly, other state systems focus almost exclusively on Medicaid-eligible children.
- Short-range cost concerns too often drive state and local rulemaking. This creates difficulties for the system of care and hampers long-range improvements in outcomes for children and families.
- Reformers are constantly threatened by potential funding cuts—a problem that is particularly acute as this study goes to print.
- Different values between the systems about what should be funded can lead to cost-shifting and blaming.

> Less money can cause more gate guarding and people retrenching. (State child welfare official)

Participants reported that funding constraints are often created by one system or another either out of ignorance of a particular program's spending rules or out of a desire to limit spending in a particular agency's budget. For example, there is great confusion over the use of Medicaid funds and some state officials may erroneously believe that federal rules prohibit certain types of spending. Those interviewed urged efforts to overcome bureaucratic resistance to examining all funding streams and devising ways to use existing funds appropriately in a collaborative manner to achieve the same goals and outcomes for children.

> Escalating costs can result in cost-monitoring and cost-containment measures. When this is a motive and drives rulemaking, the less the system is oriented to child services and therefore the less effective it is. (State education official)

On the other hand, some interviewees pointed out that budget crises have often driven successful reforms and that the lack of resources can help advance reforms. Resource shortages force officials to think out of the box and devise more cost-efficient ways of using limited funds. Interagency systems of care are efficient and, if appropriately designed and implemented, can reduce wasted expenditures and improve child outcomes, resulting in significant future savings for many state systems. In times of fiscal crises, policymakers are often open to such new ideas.

> Economic downturn is an asset in that it forces more efficiency and effectiveness in planning and execution. In our state it caused entities to come together and blend whatever they had to contribute. (State juvenile justice official)

A strategy that might be used in difficult fiscal times would be for agencies to join together on major initiatives, such as applications for a federal waiver. An application in one system (Medicaid or child welfare) could involve partner agencies who would make policy changes in their own systems to support the waiver. In this way, the waiver can be designed to support the interagency system-of-care goals and objectives, and working together strengthens the collaboration as well as the system of care.

Besides the obvious opportunities presented by demonstrating successful outcomes, positive resource benefits can result for every agency once a system of care begins to show results. Individual agency budgets may be increased as policymakers see the success of this approach. Data sharing and improved data infrastructure can produce information to help policymakers view the total costs of serving children. Cost-savings can then be appropriately considered to include savings in various other state systems.

When state administrations change and new high-level leadership takes over, the value, goals and objectives and system-of-care outcomes must be explained all over again. This can be done successfully, but must be a focus for those engaged in the reform initiative; collaborators cannot assume that new leadership will buy into the principles underlying reform.

A split among agency-level participants over key issues, such as reform goals, is a constant threat to collaborative efforts and can reduce agencies' commitment to the process. The officials interviewed for this study repeatedly emphasized that these reforms are constant and evolving processes and that collaborators need to remain focused on how each agency can gain from the collaboration and to work at building relationships within the collaboration.

Finding time for sustained collaboration can be difficult. The commitment to carve out the hours necessary for interagency discussions and new planning can become burdensome.

Many states have developed successful local collaborations in some areas of the state, but have had great difficulty in stimulating similar reforms in others. An examination of why these areas are doing so much better in collaboration can be useful. For example, is it due to better collaborative structures, personnel or other factors? Other strategies might include states' supporting local collaborations by forging common approaches to children's and families' needs. For example, state-level collaborations can design core competencies across child-serving systems. They can arrange a common schedule for training (and retraining) to reorient direct-care staff to a systems-of-care approach. States can also assist local system-of-care sites by providing technical assistance directly and furnishing flexible funds that can be used locally for planning or training.

Another threat identified by the group is lack of advocacy to create pressure for a single agenda. This, it was observed, has undermined many reforms. Lack of advocacy also affects the ability of reformers to sell their approach to the

state's political leadership. If families are fully involved and committed to the system-of-care reforms, they must also recognize their important role as advocates and spend time and resources to learn how to present a case to policymakers. To do so, families and advocates need access to key information and data and should be fully engaged in a meaningful, ongoing way in the design and implementation of reform.

Those interviewed pointed out that working first to solve a specific problem or to provide useful, timely information to others can be helpful in creating a sense early on of the successes that can come from collaboration.

CONCLUSION

Above all, said participants, all state and local officials engaged in designing and implementing interagency systems of care for children who need mental health services must be willing to be flexible, to work at these issues over a considerable period of time, to be critical of their own agency's role and policies, and to engage and work with families and youth in design, implementation and oversight of the system. According to officials interviewed for this study, successful programs:

- ensure that the child's needs drive program and funding, not the other way around;
- make certain that each child and family has a single service plan;
- blend and/or braid funding;
- use significant federal resources in a manner that supports the system's goals;
- create new services to ensure that all essential child and family needs can be met;
- establish a range of performance measures and standards that make systems focus on outcomes;
- engage in continuous quality improvement;
- keep senior policymakers informed and engaged to enable the successful adoption of sustainable reforms around the state.

Those who are engaged in these processes report substantial rewards.

> It has been the most exciting thing I have ever worked on. (State child welfare official)

NOTES

1. Bazelon Center for Mental Health Law (2003). *The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders: Help or Hindrance?* Washington, DC: Bazelon Center for Mental Health Law.

2. For more information on federal rules that pose a barrier to state and local officials designing systems of care for children who need mental health services, as well as proposals for changes to those rules, see *The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders: Help or Hindrance?* (2003). Washington, DC: Bazelon Center for Mental Health Law.

3. Cole, Robert F., Poe, Stephanie, L. (1993). *Partnerships for Care: Systems of care for Children with Serious Emotional Disturbances and their Families, the Mental Health Services Program for Youth*. Washington, DC: Washington Business Group on Health.

4. Wischman, Amy, Kates, Donald and Kaufmann, Roxane (March 2001) *Funding Early Childhood Mental Health Services and Supports* (EI07) National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Workbook for states, communities and programs to navigate federal programs and tax provisions providing benefit to children and families. Based on a meeting of stakeholders and experts. Provides: a blank matrix that can be used to consolidate the services and funding source inventories into a single, two-dimensional depiction; Tables listing services and financing resources; and a description of funding sources outlining eligibility criteria, services and activities covered, provider qualifications, and any special features or unique issues to consider.

FURTHER READINGS

Building Systems of Care

Pires, Sheila A., *Building Systems of Care: A Primer*. (Spring, 2002). Washington, DC: Human Service Collaborative for (and available from) the National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000).

Child, Adolescent and Family Branch, Center for Mental Health Services, *Systems of Care: Promising Practices in Children's Mental Health Series* (1999, 2000 and 2001). CMHS Child, Adolescent and Family Branch, Substance Abuse and Mental health services Administration, U.S. Department of Health and Human Services. (301/433-1333).

Cole, Robert F., Poe, Stephanie, L. (1993) *Partnerships for Care: Systems of Care for Children with Serious Emotional Disturbances and their Families, The Mental Health Services Program for Youth*. Washington DC: Washington Business Group on Health.

Medicaid

Bazelon Center for Mental Health Law (1999). *Making Sense of Medicaid*. Washington DC: Bazelon Center for Mental Health Law.

Pires, Sheila A., (2002). Health Care Reform Tracking Project: Promising Approaches for Behavioral Health Services to Children and Adolescents and Their Families in Managed Care Systems—Managed Care Design and Financing. Tampa, FL: Research & Training Center for Children's Mental Health, Dept. of Child & Family Studies, Florida Mental Health Institute, University of South Florida. (FMHI Publication #211-1)

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Hepburn, Kathy & McCarthy, Jan, (2003). Health Care Reform Tracking Project: Promising Approaches for Behavioral Health Services to Children and Adolescents and Their Families in Managed Care Systems–Making Interagency Initiatives Work for Children & Families in the Child Welfare System. Washington, DC: Georgetown University Center for Child and Human Development. Available at: gucdc.georgetown.edu.

Meeting the Health Care Needs of Children in the Foster Care System (2002) National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Summary of a three-year study to identify and describe promising approaches for meeting the physical, mental, emotional, developmental and dental health care needs of children in the foster care system.

Stark, Deborah (September, 1999). *Collaboration Basics: Strategies from Six Communities Engaged in Collaborative Efforts Among Families, Child Welfare and Children's Mental Health* CW05 National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Describes practical strategies for mental health and child welfare systems to work together with families on issues that require the attention and commitment of families and both systems. This document provides a summary of lessons learned from three national organizations representing child welfare, mental health, and families. Reviews successes and struggles of six state and community sites, lists principles to guide collaboration, elements of effective collaboration, and gives a checklist to guide the collaborative process.

Meyers, Judith, McCarthy, Jan and Vivian Jackson, (May 1999) *The Adoption and Safe Families Act: Exploring the Opportunity for Collaboration between Child Mental Health and Child Welfare Systems*

(CW03). National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). A resource technical assistance guide tool for child welfare and children's mental health systems about the Adoption and Safe Families Act exploring creative ways for child welfare and children's mental health systems to work together.

Education

Wischman, Amy, Kates, Donald and Kaufmann, Roxane (March 2001) *Funding Early Childhood Mental Health Services and Supports* (EI07) National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Workbook for states, communities and programs to navigate federal programs and tax provisions providing benefit to children and families. Based on a meeting of stakeholders and experts. Provides: a blank matrix that can be used to consolidate the services and funding source inventories into a single, two-dimensional depiction; Tables listing services and financing resources; and a description of funding sources outlining eligibility criteria, services and activities covered, provider qualifications, and any special features or unique issues to consider.

Feinberg Edward and Fenichel, Emily (September 1996). Who *Will Hear My Cry? Developing a System of Care to Meet the Mental Health Needs of Infants, Toddlers, Preschoolers and Their Families*. (EI04) National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Describes an invitational meeting where states, communities, and national experts shared promising policies and strategies for developing an early childhood system of care that meets the social/ emotional needs of young children and their families. Defines mental health needs of infants, toddlers, preschoolers and their families; looks at the key components of a system of care to meet the needs of young children; and addresses barriers to system development and strategies for change.

Family Partnerships

Adams, Jane, Biss, Charles, Burrell Mohammad, Valerie, Meyers, Judith & Slaton, Elaine (September 1998). *Learning From Colleagues: Family/ Professional Partnerships: Moving Forward Together A product of the Peer Technical Assistance Network*. National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). (FAM03) A monograph reflecting dialogue between professionals and family advocates on issues of power, empowerment, interdependence, mutuality, and reciprocity. Presents research and commentary on issues related to a systems approach to family/ professional partnership.

Tannen, Naomi, *Families at the Center of the Development of a System of Care* FAM02 (April 1996). National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Describes Families First initiative in Essex County, New York, a service system designed and implemented by families for families. Provides a philosophical framework, principles, strategies, and materials for developing a family-driven service system.

Human Resources

Pires, Sheila A., (April, 1995). *Resources for Staffing Systems of Care for Children with Emotional Disorders and their Families*. National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center (202/687-5000). Manual to help identify strategies and resources for recruiting, retaining, training and developing a workforce to deliver community-based, family-focused services to children and their families within the context of an interagency system of care.

TABLE 1: PURPOSES OF AND CONSTRAINTS IN MAJOR FEDERAL PROGRAMS

Program	Purposes	Limitations
Title IV-E	Title IV-E Foster Care and Adoption Assistance Program supports the maintenance and associated administrative child welfare functions for children in foster care (first column in the matrix). Title IV-E administrative and training funds can be used to supplement these funds as well as for additional specific purposes (second and third columns in the matrix). A separate fixed annual appropriation provides additional funds for independent living services (not separately listed in the matrix).	Children must meet certain low-income guidelines to benefit from Title IV-E. For costs to be funded through Title IV-E those activities must be included in the foster care rate. Title IV-E can support a family organization or family participation in policy and program, but only when the families are designated as volunteers supporting the appropriate department's foster care or protective services program. Finally, use of training funds in university settings is limited to those who work, or agree to work in the future, in a public or private non-profit agency.
Title IV-B and Promoting Safe and Stable Families Program	Child welfare systems can use Title IV-B funds for children and families where problems may result in neglect, abuse, exploitation or delinquency of children. There are two pots of funds under Title IV-B, the standard IV-B program which can support both families in care and families at risk and the Promoting Safe and Stable Families Program (formerly the Family Preservation Act) targeted specifically to keeping children with families, reunifying children with their families and providing adoption promotion and support services.	Most Title IV-B spending must be allocated to services that prevent child welfare placement. Title IV-B appropriations are significantly lower than Title IV-E.
IDEA	Children from all income levels are eligible for special education and related services under IDEA. Under federal law, if a service in a child's IDEA special education plan (IEP) is covered by Medicaid, Medicaid pays first.	To qualify, children must meet the education system's criteria as a child with a disability (usually children with mental disorders qualify as a child with emotional disturbance, other health impairments or learning disabilities).
Medicaid	Medicaid eligibility for children is primarily based on family income, and income levels vary by state as states have the option to raise the basic federally-mandated income level (federal poverty level). Children may also qualify due to the severity of their disorder, but in this case must also come from low-income families.	Only through certain optional eligibility categories (such as a home- and community-based waiver or the TEFRA option[1]) can children from some higher income families qualify. Medicaid pays for health-related services; it will not pay the non-service costs of certain mental health programs, such as housing costs, job training or academic teaching.
State Child Health Insurance Program (S-CHIP)	S-CHIP benefits vary by state. Some states provide these children with Medicaid coverage, some with a Medicaid-like benefit and others with a benefit modeled on private insurance plans.	States using the option to provide S-CHIP children with a benefit modeled on private insurance have placed significant restrictions on the amount of service covered (day and visit limits) and on the type of services paid for (rehabilitation and other intensive community services are rarely covered).

[1] TEFRA is the Tax Equity and Fiscal Responsibility Act of 1982, which created this eligibility option. TEFRA replaced a previous authority for state waivers that had provided a similar eligibility expansion. The TEFRA option is sometimes known as the Katie Becket option after the child whose plight came to the attention of Ronald Reagan, who then proposed the waiver.

TABLE 1 (continued)

Program	Purposes	Limitations
Maternal & Child Health Block Grant (Title V)	These funds support a wide array of family-centered, community-based services as well as training, family-to-family support and other activities. Funds can be used for direct services, enabling services, population-based services or infrastructure building. The matrix presents the broad array of services that states are permitted to cover.	States have the flexibility to determine children who will qualify as well as services and activities to be funded. Many states specifically exclude mental health as a covered service under the Maternal and Child Health program. These funds may not support inpatient or residential care. If a service is covered by Medicaid or the State Child Health Insurance Program, those programs must pay and Title V funds may not be used.
Social Services Block Grant	Services are provided to low-income individuals and families and children and adults who have been abused or neglected and other vulnerable populations.	There is considerable variation in states' use of these funds for mental health services. These funds rarely support a service entirely but are used to supplement other resources.
TANF	TANF is a capped block grant with no required state match, although there are maintenance-of-effort requirements. Services can be funded for needy families with children and can include services for family reunification, parenting education, in-home services and crisis intervention. Children removed from home and placed with a relative are also eligible for a range of services.	Medical services are not covered. States can transfer some funds from TANF to their social services block grant.

TABLE 2: DISCRETIONARY FEDERAL PROGRAMS SUPPORTING SERVICES AND ACTIVITIES OF INTERAGENCY SYSTEMS OF CARE FIR CHILDREN WITH MENTAL HEALTH NEEDSACTIVITIE

Administering Agency	Program	Eligible Applicants	Description
DEPARTMENT of HEALTH and HUMAN SERVICES			
Substance Abuse and Mental Health Services Administration www.samhsa.gov	Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances and Their Families	States, county or local governments, Indian Tribal governments	Six-year grants to provide community-based system of care for children with a serious emotional disturbance and their families. Ensures that services are provided collaboratively across child-serving systems.
Substance Abuse and Mental Health Services Administration www.samhsa.gov	Starting Early Starting Smart	Public and private nonprofit organizations	Grants provide integrated behavioral health services for very young children and their families and inform practitioners and policymakers of successful interventions.
Substance Abuse and Mental Health Services Administration www.samhsa.gov	Youth Violence Prevention Grants	Public and private nonprofit organizations	Two-year grants for collaborations of community organizations and constituencies to foster prevention of youth violence, substance abuse, delinquency, suicide or other mental health problems through a public health approach.
Substance Abuse and Mental Health Services Administration www.samhsa.gov	State Training and Evaluation of Evidence-Based Practices	State mental health authorities and tribal organizations	Grants to conduct evidence-based practices training and evaluation programs.
Substance Abuse and Mental Health Services Administration www.samhsa.gov	Strengthening Communities in the Development of Comprehensive Drug and Alcohol Treatment Systems	Public and private nonprofit entities	Provides funds to assist communities in strengthening their drug and alcohol abuse identification, referral and treatment systems for youth.
Substance Abuse and Mental Health Services Administration www.samhsa.gov	Statewide Family Network Grants	Statewide focused, family-controlled private nonprofit entities composed primarily of family members	Supports coalitions of family members, policymakers and service providers to strengthen families' capacity to influence services provided to them and to their children
Administration on Children and Families www.acf.hhs.gov	Head Start	Local governments, federally recognized Indian tribes or nonprofit agencies	Funds comprehensive health, educational, nutritional, child care and social services primarily to economically disadvantaged preschool children.
Administration on Children and Families www.acf.hhs.gov	Early Head Start	Local governments, federally recognized Indian tribes or nonprofit agencies	Funds family-centered services for low-income families with very young children to promote child development.

Administering Agency	Program	Eligible Applicants	Description
Administration on Children and Families www.acf.hhs.gov	Adoption Opportunities Program	Public and private nonprofit agencies	helps find permanent families for children who would benefit by adoption.
Administration on Children and Families www.acf.hhs.gov	Child Welfare Training Program	Nonprofit institutions of higher learning	Provides funds to upgrade the skills and qualifications of child welfare workers.
Administration on Children and Families www.acf.hhs.gov	Child Abuse Prevention and Treatment Act Research and Demonstration Projects	State and local agencies and organizations	Funds research on causes, prevention and treatment of child abuse and neglect, demonstration programs to identify means of preventing maltreatment and treating troubled families.
Administration on Children and Families www.acf.hhs.gov	Child Abuse and Neglect Discretionary Activities	Public agencies, nonprofit organizations and universities	Funds activities to prevent, assess, identify, and treat child abuse and neglect through research, information and dissemination.
Administration on Children and Families www.acf.hhs.gov	Transitional Living for Homeless Youth	States, localities, Indian organizations, and private entities	Grants for transitional living projects, and to promote self-sufficiency and avoid long-term dependency
Administration on Children and Families www.acf.hhs.gov	Runaway and Homeless Youth (Basic Center Program)	States, localities, Indian tribes and private entities	Assists community programs that address immediate needs of runaway youth and their families.
Health Resources and Services Administration www.hrsa.gov	Maternal and Child Health Federal Consolidated Projects (SPRANS)	Nonprofit institutions of higher learning or public or private nonprofit organizations	Carries out special maternal and child health projects of regional and national significance and projects to conduct training and research.
Health Resources and Services Administration www.hrsa.gov	Healthy Start Initiative	State or local health departments or other publicly supported organizations	Targets communities with high infant-mortality rates to support efforts to improve access to, utilization of and full participation in comprehensive maternity and infant care services.
Health Resources and Services Administration www.hrsa.gov	Healthy Schools, Healthy Communities	Public and private entities, including community- and faith-based organizations	Increases access to primary and preventive health care for underserved children, adolescents and their families.
DEPARTMENT of JUSTICE			
Office of Juvenile Justice and Delinquency Prevention www.ojjdp.hcjrs.org	Drug Prevention Program	Public and private organizations, states and local units of government	Seeks to reduce drug use through multiple approaches for young adolescents, e.g., life-skills training, education and motivation for a healthy lifestyle, fostering interpersonal and decision-making skills.
Office of Juvenile Justice and Delinquency Prevention www.ojjdp.hcjrs.org	Drug-Free Communities Support Program	Anti-drug coalitions	Supports community coalitions to help reduce substance abuse among children and at-risk youth, and to reduce substance abuse among adults.

TABLE 2 (continued)

Administering Agency	Program	Eligible Applicants	Description
Office of Justice Programs www.ojp.usdoj.gov	Youth Offender Initiative Reentry Grant	State, local and tribal units of government and nonprofit organizations	Enhances community safety by helping young offenders to reintegrate into the community.
Office of Justice Programs www.ojp.usdoj.gov	Safe Start Initiative	States, localities and tribal governments applying on behalf of a collaborative group of public or private agencies or organizations	Creates comprehensive community service- delivery systems by expanding partnerships and improving access to services for young children at high risk of exposure to violence and their families.
Office of Justice Programs www.ojp.usdoj.gov	Crime Victim Assistance Grants	Native American tribes and tribal organizations, states, eligible victim service agencies and private nonprofit agencies	Supports training and technical assistance to crime victim-assistance programs, funds demonstration projects and support services provided to victims of federal crimes assistance programs.
DEPARTMENT of EDUCATION			
Office of Safe and Drug-Free Schools www.ed.gov/offices/OSDFS	Safe Schools/Healthy Students	Local educational agencies	Provides comprehensive educational, mental health, social service, law enforcement and, as appropriate, juvenile justice system services to students, schools and communities
Office of Safe and Drug-Free Schools www.ed.gov/offices/OSDFS	Elementary and Secondary School Counseling Grants	Local educational agencies	Enables local educational agencies to establish or expand elementary and secondary school counseling programs
Office of Safe and Drug-Free Schools www.ed.gov/offices/OSDFS	Alternative Strategies to Reduce Student Suspensions and Expulsions Grants	Individuals, nonprofit organizations and public and private nonprofit organizations	Funds projects to enhance, implement and evaluate strategies to reduce suspensions and expulsions and ensure continued educational progress through challenging coursework for students who are suspended or expelled
Office of Elementary and Secondary Education www.ed.gov/offices/OESE	Even Start	State educational agencies, with various local sub-grantees	Funds to integrate early childhood education, adult literacy and parenting education in family literacy program
Office of Special Education and Rehabilitative Services www.ed.gov/offices/OSERS	State Program Improvement Grants Program	State education agencies	Funds to reform and improve systems for providing educational, early intervention and transitional services to children with disabilities
Office of Special Education and Rehabilitative Services www.ed.gov/offices/OSERS	Special Education-Personnel Preparation to Improve Services and Results for Children with Disabilities	Institutions of higher education	Funds to help address state-identified needs for qualified personnel in special education, related services, early intervention and regular education, to work with children with disabilities.

PRINCIPLES FOR A SYSTEM OF CARE FOR CHILD AND ADOLESCENT SERVICES

Developed by the Child and Adolescent Service System Program (CASSP)

Core Values

- The system of care should be child-centered and family-focused, with the needs of the child and family dictating the types and mix of services provided.
- The system of care should be community-based, with the locus of services as well as management and decision-making responsibility resting at the community level.
- The system of care should be culturally competent, with agencies, programs and services that are responsible to the cultural, racial, and ethnic differences of the populations they serve.

Principles

- Children with emotional disturbances should have access to a comprehensive array of services that address the child's physical, emotional, social and educational needs.
- Children with emotional disturbances should receive individualized services in accordance with the unique needs and potential of each child and guided by an individualized service plan.
- Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
- The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
- Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing and coordinating services.
- Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that the children can move through the system of services in accordance with their changing needs.
- Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
- Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
- The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and youth with emotional disturbances should be promoted.
- Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability or other characteristics and services should be sensitive and responsive to cultural differences and special needs.

SELECTED BAZELON CENTER PUBLICATIONS ON PROGRAMS AND SERVICES FOR CHILDREN WITH MENTAL OR EMOTIONAL DISORDERS

May be purchased on the Bazelon Center's website, www.bazelon.org. Some are available to print or download from the site (linked from the page on children's issues). To order by mail, email pubs@bazelon.org or call 202-467-5730 ext. 110 for information.

Suspending Disbelief—Moving Beyond Punishment to Promote Effective Interventions for Children with Mental or Emotional Disorders
Examines provisions of the Individuals with Disabilities Education Act (IDEA) targeting services and supports for students with emotional or behavioral problems; compares the mandate with its implementation, as shown by administrative and judicial decisions. Includes discussion of research supporting positive interventions. May 2003, 28 pages.

Failing to Qualify—The First Step to Failure in School
Issue brief discusses federal policy changes needed to encourage earlier and more accurate identification of children with mental or emotional disorders under the IDEA. January 2003, 21 pages.

Help or Hindrance?—The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders
Issue brief examines how federal programs and their rules have contributed to the fragmentation of services for children and explores ways to harmonize some of the differences to foster coordination of the services and supports needed by children and their families. February 2003, 15 pages.

Avoiding Cruel Choices—A Guide for Policymakers and Family Organizations on Medicaid's Role in Preventing Custody Relinquishment
Describes the TEFRA option and the home- and community-based services waiver—two Medicaid provisions that states can use to fill the gap in private insurance coverage that forces families to relinquish custody of their children to get them access to mental health services and supports through Medicaid. November 2002, 28 pages.

Merging System of Care Principles with Civil Rights Law—Olmstead Planning for Children with Serious Emotional Disturbance
Questions, answers and recommendations for state policymakers and advocates involved in implementing the Olmstead mandate of integrated services and developing a comprehensive plan for children that is responsive to their civil and human rights. November 2001, 20 pages.

Covering Intensive Community-Based Child Mental Health Services Under Medicaid
A set of issue briefs explaining Medicaid definitions of key rehabilitation services for children with serious mental or emotional disorders. July 2001, folder with six 4-page briefs and introduction.

Making Sense of Medicaid for Children with Serious Emotional Disturbance
A review of how states provide access to the most effective community-based services for children on Medicaid who need mental health care. September 1999, 89 pages.

Where to Turn—Confusion in Medicaid Policies on Screening Children for Mental Health Needs
Report on states' ineffective use of EPSDT to identify children who need mental health services, with recommended state policy changes and advocacy approaches to help families secure appropriate assessments for their children. September 1999, 18 pages.