



Hunger In America

A NATIONAL DISGRACE

About 4 million low-income children under the age of 12 experience hunger each year.



Photo essay by David Bacon
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ANALYSIS

California Must Protect Health Care for Medi-Cal Children

By Ben Siegel

According to recent figures, an estimated 22 million children are enrolled in Medicaid programs across the United States, with 3.2 million in California alone.¹ Children eligible for Medicaid are entitled to broad health care coverage under the statute's early and periodic screening, diagnosis, and treatment provision (EPSDT).² Congress established EPSDT in 1967, to address the shortage of medical services for impoverished youth.³ In 1989, Congress amended Medicaid by prohibiting states from restricting EPSDT benefits to those benefits offered under a state's Medicaid program.⁴

This established a broad entitlement to services for EPSDT-eligible children that often exceeds Medicaid services for adults. EPSDT services include health screening, vision, dental, and hearing services,⁵ as well as treatment that is "necessary ... to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan."⁶

¹ Kaiser Family Foundation, *2000 State and National Medicaid Enrollment and Spending Data (MSIS)*, <http://www.kff.org/medicaid/kcmu031104bpkg.cfm> (Published Mar. 11, 2004).

² See 42 U.S.C. §§ 1396a(a)(10), 1396a(a)(43), 1396(a)(4)(B), 1396d(r)(5).

³ See *S.D. v. Hood*, 2002 WL 31741240, at **3-4 (E.D. La. Dec. 5, 2002) (citing *Welfare for Children*, H.R. Doc. No. 54, 90th Cong., 1st Sess. (1967) for the proposition that the "1967 amendments were Congress's response to the lack of medical care for America's poorest children.").

⁴ *Omnibus Budget Reconciliation Act of 1989 ("OBRA")*, Pub. L. No. 101-239, § 6403, codified at 42 U.S.C. § 1396d(r).

⁵ 42 U.S.C. §§ 1396d(r)1-1396d(r)(4).

⁶ 42 U.S.C. § 1396d(r)(5).

Coverage for California Children at Risk

However, California's fiscal crisis is creating immense pressure to cut health care programs and placing EPSDT protections for children at risk. Early next year, Gov. Arnold Schwarzenegger is expected to ask the federal government for a sweeping Medicaid waiver that would allow California to fundamentally restructure Medi-Cal, the state's Medicaid program.⁷ A particular concern for children is a proposal to redefine the range of "medically necessary" services that must be provided to children through EPSDT.⁸ Under the proposed waiver, the state no longer would be required to provide medical assistance that a doctor believes is necessary to "ameliorate" a Medicaid-eligible child's physical or mental illnesses.⁹

Our analysis makes clear that courts have relied on the ameliorate language to define a broad entitlement to Medicaid services. Limiting treatment to corrective measures could lead to a significant narrowing of the EPSDT entitlement and a reduction in the range of services available to children in California.

Medicaid Waivers Signal Major Changes

Medicaid is a federal-state program that assists states that wish to provide medical assistance to low-income families and individuals.¹⁰ State participation in Medicaid is

voluntary, but once a state chooses to participate and receive federal matching funds, its Medicaid program must comport with federal requirements.¹¹

In recent years, the federal government has been receptive to state requests for increased flexibility in administering their Medicaid programs, as is demonstrated by the federal government's increased willingness to grant Section 1115 waivers.¹² Section 1115 of the Social Security Act gives the U.S. Secretary of Health and Human Services (HHS) authority to waive various provisions of the Medicaid statute.¹³

These waivers permit a state to implement demonstration projects that are "likely to assist in promoting [the] objectives" of the Medicaid statute.¹⁴ The legislative history of Section 1115 indicates that one goal was to allow for "small-scale policy experimentation."¹⁵ However, many states have viewed these demonstration waivers as an opportunity to implement overarching systemic changes.¹⁶

Broad waiver program reforms are often well-intentioned. For example, waivers have allowed states to extend Medicaid coverage to previously ineligible groups such as childless adults.¹⁷ However, advocates for children and low-income families are concerned that budget neutrality requirements for waiver proposals might encourage states to cut benefits for current beneficiaries in order to expand coverage more generally.¹⁸

These concerns are heightened by the fact that federal courts have been reluctant to challenge HHS waiver decisions, despite the fact that waiver programs may allow changes to state Medicaid plans that are inconsistent with the objectives of the Medicaid statute.¹⁹ Courts have interpreted Section 1115 as granting broad discretion to HHS to determine if a waiver meets statutory objectives.²⁰ Courts have enjoined waivers when the HHS decision-making process proved to be flawed,²¹ but this is a narrow legal avenue for advocates wishing to challenge waivers.

The federal government's willingness to grant waivers, coupled with the substantial deference courts have given the Secretary to decide whether a waiver proposal meets statutory objectives, suggest that best opportunity to influence the nature and scope of a waiver is during the design stage. For California, that time is now.

California's Waiver Proposal

Like many states, California faces budgetary problems, and it has responded with cost-cutting strategies. A primary target of these efforts is the Medi-Cal program, which since 1999 has seen a more than \$3 billion (41 percent) increase in its cost to the state general fund.²² The Schwarzenegger administration contends that its waiver would save money by enabling "programmatic reforms and operational efficiencies"²³ that

⁷ Aurelio Rojas, *California's Medi-Cal Health Insurance Revisions Are Shelved Until January*, The Sacramento Bee, Aug. 3, 2004.

⁸ See California Budget Project & Center on Budget and Policy Priorities, *California's Proposal to Restructure Medi-Cal is Financially Risky and Could Increase State Costs 2*, <http://www.cbpp.org/2004/0407medicalrestructure.pdf> (Revised July 21, 2004).

⁹ See 42 U.S.C. § 1396d(r)(5).

¹⁰ See 42 U.S.C. § 1396 et. seq.

¹¹ 42 U.S.C. § 1396a(a).

¹² See generally, Jonathan R. Bolton, Student Author, *The Case of the Disappearing Statute: A Legal and Policy Critique of the Use of Section 1115 Waivers to Restructure the Medicaid Program*, 37 Colum. J.L. & Soc. Probs. 91 (2003).

¹³ 42 U.S.C. § 1315.

¹⁴ *Id.*

¹⁵ Bolton, 37 Colum. J.L. & Soc. Probs. at 99.

¹⁶ *Id.*

¹⁷ *Id.* at 100.

¹⁸ "Budget neutrality" means that total costs to the federal government cannot increase as a result of the waiver. See e.g. National Health Law Project, *What is HIFA and Why Should We Be Concerned?* <http://www.nhelp.org/pubs/waivers/waiverhillsummary3.doc> (Feb. 9, 2002).

¹⁹ See Bolton, 37 Colum. J.L. & Soc. Probs. at 100.

²⁰ *Id.* at 100, n. 62 (citing *C.K. v. N.J. Dept of Health & Human Servs.*, 92 F.3d 171 (3d Cir. 1996); *Aguayo v. Richardson*, 473 F.2d 1090 (2d Cir. 1973); *Crane v. Matthews*, 417 F. Supp. 532 (N.D. Ga. 1976); *Cal. Welfare Rights Org. v. Richardson*, 348 F. Supp. 491

(N.D. Cal. 1972) for the proposition that courts have granted the Secretary broad discretion to decide whether a waiver proposal meets the objectives of "relevant [Social Security Act] titles," including the Medicaid statute.)

²¹ *Id.* at 100 (citing *Beno v. Shalala*, 30 F.3d 1057 (9th Cir. 1994), as an example of a successful challenge to the granting of a Section 1115 waiver).

²² Arnold Schwarzenegger (Governor) & S. Kimberley Belshé (Secretary), *Medi-Cal Redesign Update* (Health and Human Services Agency, August 2004).

²³ *Id.*



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Medicaid's early and periodic screening, diagnosis, and treatment provision has helped guarantee important medical care for children.

currently are not possible under the Medicaid statute.

When California announced plans in January 2004 to restructure Medi-Cal, the administration proposed a number of restructuring options, including a plan to eliminate “ameliorate” from the EPSDT entitlement.²⁴ If ameliorate were eliminated, only services that are medically necessary to “correct” a child’s defect or physical or mental illness would be mandatory under § 1396d(r)(5).

Despite the broad reach of EPSDT, many California children still do not receive adequate health care services. Many children are eligible but not insured,²⁵ while other enrollees simply cannot overcome the bureaucratic barriers to

care imposed by the Medicaid system. For example, the state Little Hoover Commission’s October 2001 report, “Young Hearts and Minds: Making a Commitment to Children’s Mental Health,” found that of the “[m]ore than 1 million children in California [who] will experience an emotional or behavioral disorder this year, . . . more than 600,000 will not receive adequate treatment.”²⁶

In addition, there is concern that California’s waiver will reduce services already provided to Medicaid children, and prevent the state from extending services to eligible youth who are currently not receiving adequate—or any—care. The Schwarzenegger administration has not yet presented information on the expected im-

pact of eliminating the EPSDT entitlement to treatment that ameliorates a child’s illness or condition.

The distinct value of the “ameliorate” entitlement under EPSDT is evident in cases where courts have held that ameliorative services recommended by a doctor must be provided if they are “medically necessary.”²⁷ Courts have also used the ameliorate language in conjunction with the description of “medical assistance” in § 1396d(a), to broadly construe Medicaid’s treatment obligation to include services not listed in a state’s service plan.²⁸ These cases demonstrate that removing ameliorative treatment from § 1396d(r)(5) may significantly weaken the EPSDT entitlement.

²⁴ Adolescent Health Collaborative, *EPSDT in the Budget and the Medi-Cal Redesign*, http://www.californiateenhealth.org/AMHPN_EPSDT_june.asp (Updated June 2004).

²⁵ Almost two thirds of California’s 1 million uninsured children are eligible for public health insurance. See Quick Facts About Children’s Health Coverage, 100% Campaign, <http://www.100percentcampaign.org/resources/publications/fs-health-coverage-facts-031201.htm> (last visited Oct. 6, 2004).

²⁶ Michael E. Alpert (Chairman), *Young Hearts & Minds: Making a Commitment to Children’s Mental Health* (Little Hoover Commission 2001).

²⁷ *E.g.* *S.D. v. Hood*, at **7-8.

²⁸ *E.g. Collins v. Hamilton*, 231 F. Supp. 2d, 840, 848-49 (S.D. Ind. 2002), *aff’d* 349 F.3d 371 (7th Cir. 2003).



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Program waivers are a threat to children’s ability to receive critically important medical services.

Ameliorate Standard Offers Strong Protections

Webster’s Third New International Dictionary Unabridged defines ameliorate as “to make better” or “to improve.”²⁹ Correct is defined as “to make or set right” or “to remove the errors from.”³⁰ Courts have used the “ameliorate” language from 42 U.S.C. § 1396d(r)(5) to delineate a broad entitlement for Medicaid children to EPSDT services that “make better” or “improve” a child’s defect, illness, or condition. Case law, however, reveals that many services needed by children to address their illness or condition may not be considered medically necessary. For example, providing a child with a wheelchair does not correct a severed spinal cord, even though it does make the condition less debilitating by improving mobility. Several cases provide evidence of the value of the term “ameliorate” as an important and separate source of entitlement.

In *S.D. v. Hood*, the U.S. District Court for the Eastern District of Louisiana granted summary judgment to S.D., a 16-year-old Medicaid recipient afflicted with spina bifida.³¹ The court held that the state violated the Medicaid Act by refusing to provide S.D. with incontinence underwear that had been found “medically necessary [through EPSDT screenings] to ameliorate [his] condition . . .”³² The court rejected the state’s arguments that the underwear was “merely a convenience, not a medical necessity,” relying on statements by Dr. Ernest Edward Martin, Jr. that the underwear was necessary to “ameliorate [S.D.’s] condition.”³³

The court did not determine if the incontinence underwear would correct S.D.’s condition within the meaning of 42 U.S.C. § 1396d(r)(5). Instead, the court supported its holding by pointing to the ameliorative effects of the incontinence underwear, rejecting claims by a defense expert to the contrary.³⁴ The court accepted Dr. Martin’s testimony on the physically ameliorative effects of the underwear, including decreasing the risk of irritation and infection, as well as its ameliorative social and mental health aspects that included allowing S.D. to leave the home and attend school.³⁵ While incontinence underwear ameliorated S.D.’s condition, it could not correct his spinal bifida or bladder incontinence. The treatment’s purpose was to improve his physical and mental well-being and allow him to engage in “age appropriate activities.”³⁶ This case illustrates key distinctions between corrective and ameliorative services, and provides evidence of the importance of maintaining EPSDT’s entitlement to ameliorative treatment.

The importance of “ameliorate” is also evident in *Collins v. Hamilton*. In *Collins*, the federal District Court granted partial summary judgment for a plaintiff class of Medicaid children under 21 who required mental health services, holding that the state of Indiana violated Medicaid requirements by failing to pay for long-term residential psychiatric treatment.³⁷ The state contended that a child’s entitlement to psychiatric services was limited to “active” treatment that was “designed to achieve the

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²⁹ Webster’s Third New International Dictionary Unabridged 67 (Merriam-Webster Inc. 1981).

³⁰ *Id.* at 511.

³¹ *S.D. v. Hood*, at *8.

³² *Id.*

³³ *Id.* at *1, **7-8.

³⁴ *Id.*

³⁵ *Id.* at *1.

³⁶ *Id.* at **7-8.

³⁷ *Collins v. Hamilton*, at 848, 851.



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recipient's discharge from inpatient status at the earliest possible time."³⁸ But the court bridled at the state's position "that these children are 'lost causes' and that it is not feasible to treat these children."³⁹ Rejecting the narrow treatment argument, the court held that,

The Medicaid Act specifically directs the State to "ameliorate" mental illnesses in children. "Ameliorate" is defined as "to make better or more tolerable." ...Required treatment includes anything that is to make a condition, even a long-term condition like mental illness, more tolerable.⁴⁰

Although Indiana's policy may have been struck down on alternative grounds, an expansive definition of "ameliorate" assures that long-term residential psychiatric treatment is available under Medicaid.

In *Pediatric Specialty Care, Inc. v. Arkansas Department of Human Services*, the United States Court of Appeals for the Eighth District held that the Arkansas Department of Human Services must pay for day-care and therapy services under Arkansas' child health management services program (CHMS), if such treatment ameliorates conditions discovered by EPSDT screenings.⁴¹ Emphasizing the importance of the term "ameliorate," the court stated that the early-intervention day treatment required by its decision must be from a "day treatment program [that] help[s] *ameliorate* each child's condition."⁴² Throughout the opinion, the court uses the ameliorate mandate from § 1396d(r)(5) in conjunction with language from § 1396d(a)(13) to assert that day-care and therapy services, "for the maximum reduction of physical or mental disability and restoration

of a individual to the best possible functional level,"⁴³ must be provided.⁴⁴

The court described benefits of these services that are consistent with what would be considered necessary to "ameliorate" a child's condition.⁴⁵ These services can be distinguished from services that "correct" a condition, or, as the dictionary explains, "make or set right," or "remove the errors from," a child's underlying medical condition.⁴⁶ For example, the court points to a "decreased chance of being placed in special education classes"⁴⁷ as a benefit of day treatment services. This type of benefit does not correct a child's developmental disability, but it does ameliorate the effects of that disability. Again, this demonstrates the unique and separate value of the term "ameliorate" in the EPSDT provisions, and its use in defining a broad entitlement to services.

³⁸ *Id.*, at 848, citing 42 C.F.R. § 441-154.

³⁹ *Id.*, at 849.

⁴⁰ *Id.* (Citations omitted).

⁴¹ See *Pediatric Specialty Care, Inc. v. Ark. Dept. of Human Servs.*, 293 F.3d 472, 480 (8th Cir. 2002).

⁴² *Id.* at 481, n. 8 (emphasis added).

⁴³ 42 U.S.C. § 1396d(a)(13).

⁴⁴ See *Pediatric Specialty Care, Inc. v. Ark. Dept. of Human Servs.* at 479-81.

⁴⁵ *Id.* at 478-79.

⁴⁶ *Supra* n. 31.

⁴⁷ *Pediatric Specialty Care, Inc. v. Ark.*

In *Chisholm v. Hood*, the U.S. District Court for the Eastern District of Louisiana held that the state of Louisiana's Medicaid program did not adequately provide community-based behavioral and psychological services to autistic children, who were found to need these services in EPSDT screenings.⁴⁸ The state did not dispute the plaintiff's contention that these services were essential to treating autistic children.⁴⁹ In its holding that these services are necessary "to correct or ameliorate ... the effects of autism," the court offered the un rebutted testimony of Dr. Grant Butterbaugh, a psychologist, who argued that psychological services may improve functioning, and may at least mitigate the effects of autism.⁵⁰ The testimony of Dr. Butterbaugh was aimed at the ameliorative impact of these services. His testimony, as cited by the court, did not demonstrate that behavioral and psychological services would correct the children's autism.

Based on the testimony, the court was persuaded that the services at issue "are necessary to combat and avoid the often tragic effects of autism."⁵¹ The decision emphasized the ameliorative quality of psychological services, but

the court also used terms such as "remedial" and "preventive and rehabilitative" to describe treatment benefits. These more expansive treatment descriptions suggest that the court's decision mandating behavioral and psychological services for autistic youth could be more broadly based than on the EPSDT ameliorate mandate alone. It is clear, however, that the ameliorative services mandate likely improves access to services that do not unambiguously correct a defect or condition.

Ameliorative Services Need Protection

As this article demonstrates, courts have relied on the "ameliorate" mandate in 42 U.S.C. § 1396d(r)(5) to compel states to provide services as varied as long-term residential psychiatric treatment, day-care services, incontinence underwear and community-based psychological services. Medical services that ameliorate a condition, but which may not ultimately correct it, nonetheless encompass a broad array of services, and are part of a high-quality health care system. Access to ameliorative services also are consistent with the legislative goals of the federal laws that expanded the EPSDT entitlement,

which were to make sure that poor children had access to a wide range of appropriate medical services.⁵²

Access to these services could be restricted in California if ameliorate language is removed from the EPSDT mandate. More broadly, children's access to health care will be reduced if a waiver is implemented, because meeting medical necessity requirements would be more difficult—likely in ways we cannot predict. These impacts are significant and would likely grow over time. A Section 1115 waiver that includes a waiver of the ameliorate mandate would not advance the objectives of the Medicaid statute.

California should not seek to gut the state's EPSDT provisions. This waiver could significantly weaken access to health care for California's most vulnerable children.

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California's waiver proposal could mean substantial rollbacks in medical care for needy children.

Dept. of Human Servs. at 479.

⁴⁸ *Chisholm v. Hood*, 133 F. Supp. 2d. 894, 901 (E.D. La. 2001).

⁴⁹ *Id.* at 897.

⁵⁰ *Id.* at 898.

⁵¹ *Id.*

⁵² *Supra* n. 2-3.