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.

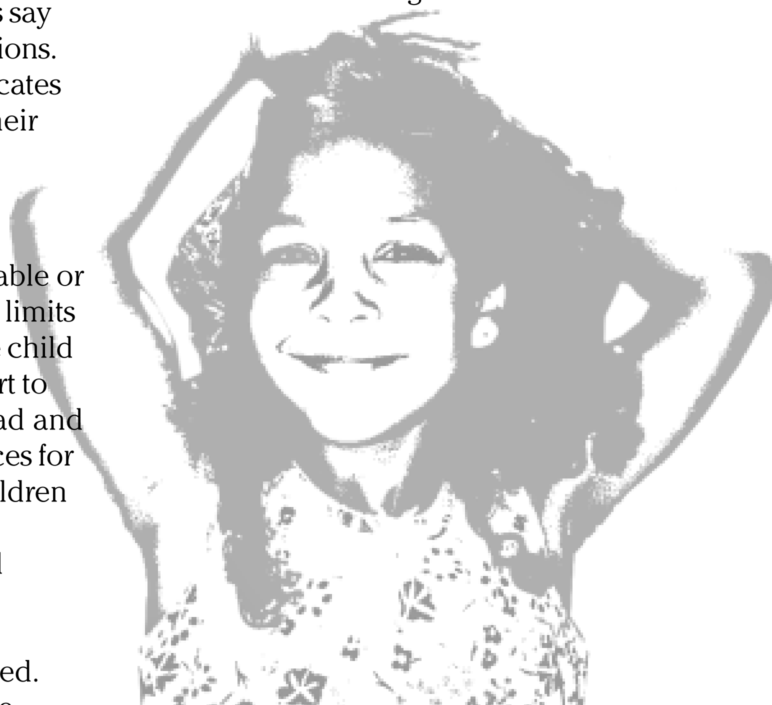
The Problem

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.