

# An Advocate's Guide to Overcoming State Barriers and Obtaining a Home- and Community-Based Waiver for Children with Mental Health Needs

A report on interviews in Kansas, New York and Vermont

JANUARY 2003



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The guide was written by staff attorney Mary Giliberti and senior policy analyst Rafael Semansky in consultation with policy director Chris Koyanagi and with assistance by intern Ellen Lupinsky, and was edited and designed by communications director Lee Carty. We gratefully acknowledge the support of the William T. Grant Foundation for development and production of the guide and the general-program support by the John D. and Catherine T. MacArthur Foundation, which enabled us to conduct the preliminary research.

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# An Advocate's Guide to Overcoming State Barriers and Obtaining a Home- and Community-Based Waiver for Children with Mental Health Needs

## INTRODUCTION

Medicaid is a means-tested program that finances health and mental health services for children and adults who meet certain eligibility criteria. Although a broad array of mental health services can be covered by Medicaid, some services needed by families of children with serious mental or emotional disorders can only be covered through a waiver for home- and community-based services.

This waiver, which must be approved by the federal Centers on Medicare and Medicaid Services, can both expand the range of services for Medicaid -eligible children and families and can also be used—at the state's option—to expand Medicaid eligibility to those whose incomes exceed standard Medicaid eligibility requirements in the state. To be eligible, children must have disorders so severe that they would otherwise need hospital-level care.

A home- and community-based care waiver of Medicaid rules can also address the issue of families who lack private insurance or whose insurance fails to cover needed services. Although children in these families may not normally qualify for Medicaid due to their family's income, the waiver can be used to expand eligibility so children can access services available through Medicaid. Without adequate insurance or the waiver, families sometimes turn to the child welfare system, relinquishing custody of their child to access needed mental health services.

However, some states have been reluctant to implement the waiver. Bazelon Center staff surveyed officials from 17 states that are not currently utilizing a home- and community-based waiver for children with serious emotional disturbance and asked them to identify the barriers to applying for such a waiver. We then conducted an extensive interview with state-level officials from New York, Vermont and Kansas, the three states that are currently implementing a waiver for this population, to discover how they overcame these barriers.

Overall, these interviews revealed the ingenuity and dedication of the state

officials responsible for designing and implementing the waiver and the need to take advantage of funding opportunities . When faced with barriers, these individuals found ways to surmount them. They devised program initiatives that started out small and have built upon their successes. Sometimes drawing on their state's experience with developmental disability waivers, they were able to advance the waiver application and implementation processes without a large investment of staff or resources.

State officials found that overcoming barriers to applying for the waiver did not complete their work. They have had to work actively to eliminate additional roadblocks to ensure that the waiver actually leads to adequate community-based services for all children with severe mental health needs. Based on our conversations with officials in states that have not applied for waivers and the experiences of state officials and families in states with the waiver, we have analyzed the principal barriers and developed a set of recommendations. As the three states with the waiver have demonstrated, expanded medicaid coverage can make a tremendous difference for families and children with severe mental healthcare needs and drastically reduce the incidence of custody relinquishment to get care.

## **BARRIERS**

State officials referenced an array of factors they saw as impediments to securing a home-and-community-based waiver for children with mental healthcare needs :

### **1. Lack of state match funds for the Medicaid waiver**

The most common barrier cited by state officials was a lack of state funds to match federal payments under the waiver. Of the states surveyed that did not have the waiver, 11 of 17 (65%) reported that the lack of funds prevented the state from making a waiver application. Following different paths, each of the three states with the waiver did not find the state match to be a barrier. The experiences of these states demonstrate the range of options that can be used to overcome arguments against pursuing waiver applications based on the perception that state matching funds are lacking. By starting small, taking advantage of opportunities, showing successful outcomes from wraparound demonstration projects and working with advocates, states were able to get the matching funds needed for the waiver.

In New York, key policymakers recognized the critical need for intensive mental health services and authorized expansion of residential treatment beds. The state mental health agency then made the argument that the authorized funds should instead be redirected to a community-based waiver because those services would be more effective and appropriate. The Office of Mental Health and the Children's Bureau had followed the successes of wraparound models in

other areas of the country and the chairpersons of the relevant committees in the Assembly were supportive of increasing the availability of community-based services. The New York waiver has been expanded over time and the advocacy community, particularly some parent groups, have had an important role in making the case to the legislature that more slots are needed and that the services are effective.

In Vermont, state match was not an obstacle because the program was small and did not require a lot of funding. Moreover, the state offices of social services, juvenile justice and education now all contribute match funding after recognizing that state dollars already being directed to serve children with mental health needs could be used to draw additional federal medicaid funds to expand resources for this population. The configuration of match funding is calculated on a child-by-child basis. A treatment plan is developed and then a determination is made as to whether the waiver should be used to provide funding for the services in the plan and, if so, which agencies should contribute to the match.

In Kansas, the tobacco settlement provided an opportunity for state-match dollars for the waiver. Kansas received a large settlement and there was a general commitment to use the money for children. In addition, the Commissioner of Mental Health/Mental Retardation at the time was very supportive of the waiver. He had a background in developmental disabilities and believed that the waiver for that population had been very successful, and it should also be used for children with mental or emotional disorders. Kansas was in the process of closing its state hospital and needed a plan for alternative ways to serve children. Accordingly, the agency and the advocates were able to argue that the waiver met an emerging need. One official described it as “the right people in the right place.”

The Kansas agency also did not ask for a large appropriation and started with \$1 million. They believed it was important to start small and demonstrate success by measuring outcomes. As of March 2002 the program was funded at \$2.5 million in state funds (approximately \$6.5 million from all funds). Advocates have been helpful at the state legislature in arguing for additional match money for the program and have highlighted the stories of the families who have been helped. The waiver now pays 30-40% of the dollars spent on intensive community-based mental health services for children in Kansas’s public mental health system.

## **2. Most children are served in residential treatment facilities, not hospitals.**

Ten of the states without a waiver (59%) reported that most children in their state are served in residential treatment centers, not hospitals. Officials from these states saw the requirement that children meet a hospital level-of-care as precluding their application for a waiver. Again, states that had a home-and-

community-based waiver for these children reported different ways to overcome this barrier.

All state officials interviewed stressed that a state does not have to show that it will be or is operating the same number of hospital beds as the waiver slots requested. There is an understanding that the waiver will divert individuals from hospital level of care. States used ongoing wraparound projects and other data sources to estimate the number of children who would need hospital level of care in the absence of the waiver. Accordingly, even states that are serving children in residential treatment facilities can estimate the number of children in their population who would meet hospital level of care and use that number to help establish a beginning baseline for waiver slots.

In its original application, New York used cost data from children who had received more than 60 days of psychiatric hospitalization in a calendar year, defined to include residential treatment facilities or hospitals. Upon reapplication, the Health Care Financing Administration (now the Centers for Medicaid and Medicare), questioned whether residential treatment facilities met the level-of-care criterion. New York was able to show that these facilities were defined as hospitals under state law.

Vermont does not place many children in psychiatric residential treatment facilities so, unlike New York, the need to demonstrate equivalence with hospital care is not an issue for the state. In fact, Vermont does not use hospitals much at all, and there are no children's psychiatric inpatient units in Vermont. For its application, the state used cost data from its state hospital unit for children prior to its closure. At the time the waiver was being written, the state closed those beds. In its reapplication, the state estimates how many children need a hospital level of care and can be diverted through the waiver program. It does not have to hospitalize any children to qualify them for the waiver.

Kansas also used data from its state psychiatric hospital prior to closing the beds, so it did not have to confront this issue directly. However, it does not currently have nearly as many beds available as waiver slots because the state estimates the number of children meeting the level of care, not those actually residing in the hospital. In addition, children who currently live in a residential treatment facility who also meet the level-of-care criterion could be candidates for the waiver when they return to an appropriate community setting. Like Vermont, the state's mental health system rarely places children in residential treatment. The place of residency is important for remaining eligible for the waiver once implemented (basically, youth must be in a community setting to be on the waiver, but this is less important in determining initial eligibility than whether the child's behaviors and symptoms meet a hospital level of care). Kan-

Officials note that they want to avoid residential and hospital care so children are still given access to waiver services in the community whenever possible. Most youth are at home when they become eligible for the waiver, and 90% are able to continue living at home.

### **3. Concern about the budget-neutrality requirements of the waiver**

Eight states without the waiver (47%) reported that the budget-neutrality requirements discouraged them from applying for one. However, based on the reports of the three states having the waiver, budget neutrality is not an actual impediment. While the waiver might result in higher costs for serving individual children outside of institutional settings, the waiver's budget neutrality can be established on the basis of average costs for all children served through the program.

The three states currently operating a waiver reported no problem with cost neutrality because of lower average costs for community-based services compared to the high cost of institutional care. Each state found that it had an adequate level of funding and that average costs in their waiver program were lower than their institutional costs.

Kansas currently spends on average \$12,000 for mental health services per child per year on the waiver; hospital costs are much higher.

New York used the cost data from children who spent more than 60 days in hospital level of care. That came to an average of \$84,000 per year per child in their original application and \$77,429 in the reapplication. The waiver on average costs approximately \$40,000 per slot for all Medicaid expenses.

Vermont spends \$24,259 per child per year, which also is significantly less expensive than long-term hospital care.

### **4. Lack of an information system to develop needed financial data**

Some states without the waiver (18%) felt hindered by lack of an information system to develop the needed data. Data systems should not be a barrier to applying for the waiver. With some ingenuity, including surveying providers, states should be able to gather sufficient information from existing MIS systems for the application. Each of the states that have the waiver reported that they used existing data systems and did not find the financial-data requirement burdensome.

New York had an existing data base developed by the Bureau of Financial Planning in its Office of Mental Health. This allowed the state to calculate the costs of children who spent more than 60 days in an inpatient facility. To get waiver-service costs, the state surveyed its providers and asked them to estimate the costs of a wraparound package.

Vermont also was able to use its existing management information system (MIS) system. A state official predicted that any typical MIS system with client service and financial components would be able to provide the necessary data.

Kansas had an existing MIS system that had supported five other state waivers and could be used to gather data for the children's waiver.

##### **5. Insufficient state mental health infrastructure to serve children with SED**

Some states without the waiver (18%) had this concern. Although each of the states with the waiver had to address infrastructure issues, officials reported that the waiver was a helpful source of funding and served as a catalyst for positive change.

In terms of infrastructure at the state agency level, each state used existing personnel to do the waiver application and each state found that the waiver application was not burdensome. In Kansas, a state employee who worked with other waivers in the state, including the developmental disabilities waiver, also assisted with the waiver and the state used a consultant to help finalize the application. According to the state, the consultant was not expensive and the contract was short-term and less than one year.

All of the states viewed the waiver as part of the state's larger strategy for increasing access to effective mental health services for children with serious emotional disturbance. The waiver provided helpful financing and incentives for working very closely with the provider community to better the overall system of care for these children. As a Kansas official stated, "the waiver was a crucial step that has led to more steps to building a community-based system."

In New York, the small size of the original waiver program caused infrastructure problems, particularly with the provision of alternative services such as respite and skill-building services. Because some providers were only serving a small number of children, they could not cost-effectively offer or subcontract for the full array of services. Agencies without the caseloads to warrant [WAS did not have the volume] full-time employees [so they] hired part timers and had scheduling difficulties. As the program has expanded, the agencies have been able to hire more dedicated personnel. The state has also adjusted the rates paid for these services to reflect additional costs. Finally, the state is investigating ways to simplify the program to deal with the volume of paperwork required for billing.

In Vermont, work on infrastructure issues has been an ongoing process. It is critical to have providers who are willing and able to do the work, and the state has had to work on human resource development so that providers use home- and community-based, strengths-based, and wraparound, individualized service planning and delivery. The state has received foundation and government grants to help train providers and direct care workers. State officials felt that the waiver

program would not be a success without this component.

Kansas faced initial reluctance by some providers and a need to improve infrastructure. State officials addressed the reluctance by changing the reimbursement structure for waiver services so the mental health centers would not have to contribute any of the state match that is normally required for non-waiver services. Kansas also included start-up funds for some of the mental health centers and provided training on wraparound services. Kansas built on the experience with some demonstration projects that had successfully implemented wraparound services for children with a high level of need.

#### **6. Expanding Medicaid eligibility is not a priority.**

Only one state without the waiver (6%) reported that expanding Medicaid eligibility was not a state priority. This low number reflects a growing recognition of the need for greater access to mental health services and a new awareness of the tragic consequences of failing to provide such services, including increased custody relinquishment and juvenile justice involvement.

The states with the Medicaid waiver were able to argue that the waiver offered a more effective means of serving children already served by public systems. For children already in psychiatric hospitals or at risk of admission, the costs of the waiver would be minimal. However, even states that do not tend to hospitalize children for psychiatric care found that the efficiencies of the waiver could be supported against costs already incurred by providing services through juvenile justice (state funds only), child welfare (state and Medicaid funds) and education (state and federal funds) systems. With the addition of the waiver, more children would become Medicaid-eligible, but they would also be able to draw federal matching funds for their services.

In New York, the waiver was not originally seen as an expansion, but rather as a way to divert children who were currently inappropriately institutionalized and to convert proposed residential beds to community-based services. Increases in the number of waiver slots have not been seen as expansions, since children admitted to residential beds for 30 days would thereby have qualified for Medicaid anyway. The family advocates have been successful in educating state legislators about the effectiveness of the waiver services for families and the need for additional slots in the program.

In Vermont, the state is committed to providing health coverage to all children in the state and the waiver benefits from that commitment. Over 94% of the children in Vermont have health care coverage, either commercial or Medicaid. In addition, the waiver is sometimes used for short-term placement for children who either have Medicaid or can access the states' Child Health Insurance Program or who are underinsured by their commercial plan because the

waiver provides a richer array of services and is easier to manage and bill.

In Kansas, although the waiver did provide for additional services reimbursed by Medicaid, it was not regarded as a major expansion. It was instead considered a step to help implement effective community-based alternatives for children already receiving hospital services or those at risk of hospitalization. Because the state was closing its hospital, the waiver was viewed in the larger picture as part of a strategy of redirection of funds. The state also hoped that the waiver would reduce the state's incidence of families' turning to child welfare and relinquishing custody of their child in order to access mental health services. Family groups and the state report that the practice was reduced by the waiver. Finally, the tobacco-settlement funds were very helpful in allowing the mental health agency to secure the funding for the waiver.

## **RECOMMENDATIONS FOR ADVOCATES AND POLICYMAKERS**

After talking to state officials and family members in the states with the waiver, we have developed a set of recommendations for drafting a waiver designed to promote keeping children in their homes and communities and minimize the incidence of custody relinquishment.

### **1. Form a task force to give input on drafting and implementing a waiver application.**

In Kansas, a task force was formed that included families, advocates, providers, state policymakers and others to work on a series of issues. At first the task force worked on the waiver application, defining what services would be included in the waiver. It continued to operate and give input after implementation. The benefit of forming a task force is that it provides a forum for identifying a meaningful package of services, gaining consensus and building widespread support for the waiver.

### **2. Choose an expansive array of services to add to the state's Medicaid plan for this population.**

Each state that has a home- and community-based waiver has added services to the state's array. It is important to include a broad array of services in order to be able to achieve the waiver's goal of keeping the child in the community.

- Kansas added wraparound facilitation, parent support and training, respite care and independent-living services.
- Vermont added flexible supports, including respite care, home supports, family supports, community-social supports and crisis supports, and transportation, environmental modification and adaptive equipment.

- New York added individualized care coordination, respite care, skill building, intensive in-home services, crisis-response services and family-support services.

**3. Make sure the amount of money allocated for home- and community-based services is adequate.**

Under Medicaid law, services provided under the waiver must be cost-neutral to the Medicaid program. That is, on average it cannot cost more to keep a child in the community than in a psychiatric hospital. But the three states operating the waiver are far below cost-neutrality in their expenses; their waivers cost approximately half as much as hospital costs. As a result, there is lot of leeway and, as long as expenses stay below the cost-neutrality cap states should not shortchange the community system. If the community system does not have enough resources, then children will not get the services they need to stay at home. Some of the states with waivers have experienced difficulty in recruiting and maintaining an adequate number of behavioral health aides and respite workers. If the waiver is underfunded, this becomes more of a problem.

**4. Ensure that children who need help can get access to the waiver.**

States have a great deal of latitude when it comes to developing clinical criteria for when children will meet “a hospital level of care” and thus qualify for the waiver. Advocates and policymakers should ensure that the criteria selected will allow children who are being inappropriately served to qualify for home-and community-based services, particularly children who would otherwise come into custody through child welfare or juvenile justice.

**5. Allow children to access services through the waiver long enough to remain stable.**

Some advocates have been concerned that children whose condition improves while on the waiver risk losing the services because they are no longer deemed to need the hospital level of care. Once the waiver services are removed, the child will have to deteriorate again to get help, leading to an unhealthy and illogical health care system. Accordingly, advocates and states should ensure that

the waiver does not remove children too quickly from the program and that adequate planning and implementation of services takes place when a child is ready to transition.

## CONCLUSION

State officials in Kansas, Vermont and New York illustrate the adage, “where there’s a will, there’s a way.” The reality is that, in most other states, children with mental health needs continue to experience the effects of uncertain political will. All of the barriers identified by these three states were overcome. For example, when New York did not have adequate data on the cost of community services under the new waiver, the state surveyed its providers to get that information. When the community mental health centers in Kansas were hesitant about the waiver, the state agency did not require them to contribute any funds to the state match, carving out an exception to the usual Medicaid arrangement and creating an incentive to participate. The states made use of opportunities, such as tobacco settlement money, closing of state hospital beds and other fortuitous events. Working closely with state legislatures and family advocates was also helpful.

Currently, only three states have a waiver for children with serious emotional

disorders, while all 17 of the states we surveyed had a waiver for individuals (including children) with developmental disabilities. It is time for the mental health community to find the will and thus, the way to offer the rich array of waiver services to children with serious emotional disorders in the community.

### **MORE INFORMATION**

These officials interviewed for this study are willing to provide information and assistance to other states and advocates interested in the waiver. Their names and contact information are:

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