



**Public Financing of Home and Community Services for Children
and Youth with Serious Emotional Disturbances:
Selected State Strategies**

June 2006

Office of the Assistant Secretary for Planning and Evaluation

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Selected State Strategies**

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EXECUTIVE SUMMARY

Numerous reports have underscored the contradictions and deficiencies in the nation's mental health service system for children with serious emotional disturbances (SED), including a heavy reliance on residential care and out-of-home placements (e.g., Campaign for Mental Health Reform 2005; New Freedom Commission on Mental Health 2003). Recent studies have also reinforced long-standing concerns that some parents have had to relinquish custody of their children solely to obtain treatment for their children's behavioral or emotional problems (Government Accounting Office 2003). Overall, these reports have motivated federal and state legislators to consider new strategies for improving child mental health services and, in particular, enhancing access to effective home and community services.

Youth with SED include children and adolescents with chronic depression, major conduct disorders, substance abuse problems, and other behaviors that are challenging for families and communities. Many youth with SED are first identified in the schools, child welfare or juvenile justice systems, and they often claim a great deal of public attention because of the wide gap between their need for intensive treatment and the availability of appropriate services, including home-based counseling, respite care, family-to-family support, treatment foster care, and school-based mental health care. More and more studies indicate that these services are effective not only in improving mental health outcomes for youth with SED, but also in reducing or preventing stays in residential care and other out-of-home settings (Hawaii Department of Health 2004; Knitzer and Cooper 2006; Sheidow et al. 2004). Given these signs of progress, policymakers have expressed greater interest in making these services more widely available (Waxman 2006). For example, the 2005 Deficit Reduction Act (Public Law 109-171) authorizes demonstration projects for up to ten states to assess the effectiveness of home and community-based alternatives to psychiatric residential treatment facilities (PRTFs).

States and counties currently are pursuing numerous approaches to support home and community services and, more broadly, to initiate and sustain a fundamental transformation of their child mental health service systems. These approaches include enhancing access to Medicaid coverage of these services, re-directing funds from residential services to community care, integrating funds from the numerous agencies that serve children, designating care management entities to oversee services for high-risk populations, and implementing demonstration projects to develop specific financing models.

The purpose of this report is to present the results of a study of selected public financing mechanisms that states have used to pay for intensive home and community

services for children and youth with SED.¹ Although the study covers several key public strategies for funding home and community services for children with SED, it focuses particularly on the Medicaid home and community-based service (HCBS) waiver as a result of recent federal and state interest in this particular financing approach. Policymakers have focused on the HCBS waiver partly because this financing mechanism allows states to provide an expanded set of Medicaid services to a limited number of children. With an HCBS waiver, states have considerable flexibility in addressing the needs of high-risk children by paying for services not included in their standard Medicaid state plans; at the same time, they can maintain some control over costs by sharply limiting the number of children enrolled in the waiver program.

However, the HCBS waiver is only one of several methods for supporting intensive home and community services for youth with SED. States that already have such a waiver also use other financing mechanisms to support comprehensive mental health care for these children and their families. Previous studies have described the financing of model community-based programs (e.g., Bazelon Center 2003; Pires 2002), but there remains a need to examine in greater detail the mechanisms used by states to finance intensive home and community services and the reasons behind states' decisions for choosing some mechanisms over others. Better information on strategies for selecting the best set of financing mechanisms may help states design and implement new initiatives for broadening home and community-based alternatives to psychiatric residential treatment and other out-of-home care.

To develop this information, the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services contracted with Mathematica Policy Research, Inc. to examine how states and communities have financed, or could finance, these services for youth with SED and their families.

Specific policy questions examined in the study include:

- What are the benefits and disadvantages of HCBS waivers and other financing approaches for building home and community services as alternatives to residential care?
- Why do states feel they need waivers and what are the arguments for or against amending the current 1915(c) waiver program to include PRTFs under the rubric of an “institution?”
- How have different financing approaches been combined to support community alternatives to residential care or out-of-home placements?

¹ States and communities can support child mental health services in many different ways. This report addresses several major public mechanisms available to all states, but it is not designed as a comprehensive review of all possible public and private strategies to finance services for youth with SED.

- What financing strategies are likely to contribute to the sustainability of improvements in mental health services for youth with SED?

METHODS

This report is based on discussions with officials in three groups of states, and a review of federal and state reports on financing services for youth with SED and their families. The three groups of states include those that:

- Are implementing broad, statewide reforms in their child mental health service systems (New Jersey and New Mexico);
- Deliver services to youth with SED through HCBS waivers (Indiana, Kansas, New York, Vermont, and Wisconsin);² and
- Received awards in 2003 from CMS to assess the feasibility of developing an HCBS waiver as an alternative to psychiatric residential treatment facilities (Illinois, Maryland, Mississippi, Missouri, and Texas).

As a group, these states are using many different strategies to configure and support mental health services for youth with SED, are at varying stages in the development of statewide systems, and have encountered a diverse set of obstacles and opportunities for improving home and community services. Consequently, discussions with officials in these states covered a wide range of topics, including the legislative and policy background related to services for youth with SED, the reasons for selecting a given financing strategy or strategies, the benefits and challenges associated with HCBS waivers, the extent to which demonstration projects influenced a state's selection of particular financing mechanisms, tactics for promoting coordination among key agencies, the role of residential treatment centers, and general "lessons learned" from recent state efforts to strengthen the financing of these services.

FINDINGS

Discussions with state officials underscore the challenges of paying for the mix of intensive mental health services that are appropriate to each child and family by combining the resources of different agencies or expanding the type of services covered (or both). Many factors influence the way in which states address these challenges, including:

² Kansas and New York began operating their waiver programs in the mid 1990s and had 2,020 and 1,700 children enrolled in their waivers, respectively, as of 2005; Vermont began its waiver program in 1982 and had 140 children enrolled as of 2004. Indiana and Wisconsin began their waiver programs in 2005 and had 20 and 190 children enrolled, respectively, at the end of that year. Michigan obtained approval for an HCBS waiver for youth with SED in October 2005--too late to be included in this study.

- The proportion of children living in rural areas;
- The set of services covered under the existing Medicaid plan and the status of the Medicaid budget;
- Prior experience with demonstration projects involving home and community services for children with SED;
- Leadership on this issue from the governor's office and the extent of support from the state legislature;
- The willingness of residential provider organizations to engage in discussions of new service models;
- The strength of family advocacy and support for change; and
- The history of collaboration among departments of child mental health, child welfare, juvenile justice, and special education.

Because of the many factors involved, state officials have to balance a variety of issues as they decide what financing strategies are most suitable given a state's resources and constraints. Five findings from this study provide insights into this decision-making process.

First, state officials typically seek to combine a variety of mechanisms and funding sources because no one mechanism provides the flexibility and breadth needed to coordinate and pay for a comprehensive set of intensive home and community services. The mechanisms examined closely in this study include:

- The 1915(c) HCBS waiver.
- The Medicaid rehabilitation option.
- The development of case rates for designated care management entities serving high-risk populations (whereby states pay a monthly fee for each child, allowing the child access to a flexible, individualized array of services and supports).
- A provision in the Tax Equity and Fiscal Responsibility Act (TEFRA) known as the Katie Beckett provision.

Determining what combination of these funding mechanisms is appropriate for a particular state means balancing their advantages and disadvantages in light of the state's fiscal, legislative, and agency resources (see Table ES.1). In addition to these resources, officials at the state or county level can blend or braid funds from multiple child-serving systems, which allows states to pay for a broader range of services than any one agency could cover. This approach is often used in conjunction with a case

rate approach. Many states also have implemented Medicaid managed care (1915(b)) and research and demonstration (1115) waivers that allow for flexibility in types of covered services by implementing managed behavioral health systems. A few states and counties have designated sales, property, or income taxes to generate new revenue to enhance public mental health services, including services for youth with SED.

TABLE ES.1: Advantages and Disadvantages of Four Financing Mechanisms for Supporting Intensive Home and Community Services for Youth with SED		
Funding Mechanism	Advantages	Disadvantages
HCBS waiver	<p>Allows states to provide intensive services not covered in state plan</p> <p>Waives parental deeming requirements</p> <p>Waives statewideness requirements</p> <p>Promotes increase in number of providers offering intensive home and community based services</p> <p>Gives states experience in pricing intensive services and individual care plans</p>	<p>Does not support preventive or “step-down” services</p> <p>Substantial administrative effort for a relatively small number of youth</p> <p>Application development and waiver implementation can be challenging</p> <p>Does little to re-align funding across agencies and may introduce disincentives for sharing costs for community services</p> <p>Does little to reduce geographic disparities within states</p>
Expanding Medicaid rehabilitation option	<p>Offers states opportunities to include certain types of intensive home and community-based mental health services into state plan coverage</p> <p>Services available to all Medicaid beneficiaries, not just subgroups</p>	<p>Risks increasing state Medicaid expenditures if rehabilitative services are used heavily and poorly managed</p>
Case rates used by designated care management entities for high risk populations	<p>Allows state and local agencies to negotiate payment rates for specific high risk populations</p> <p>Provides a mechanism for states to combine funding from different agencies to cover integrated, individualized plans of care</p> <p>Permits monitoring of plan performance and quality of care</p>	<p>Requires experience in managed care technologies and financing models</p> <p>Requires a sufficient case load to support a feasible economy of scale and risk management</p>
TEFRA (Katie Beckett) provision	<p>Waives rules requiring application of parental income to determination of Medicaid eligibility for children who meet SSA’s disability definition, meet certain clinical criteria, and need an institutional level of care</p>	<p>A sharply limited number of children with SED qualify for this provision</p> <p>Expands Medicaid eligibility, thus posing potential cost issues</p> <p>Does not expand types of home and community services covered</p>

A second finding involves the importance of legislative and budgetary action at the state level. In several of the states in this study, the passage of state legislation directly focused on services for children has been an important impetus for interagency collaboration around the financing of services for youth with SED. Although state legislation alone is neither necessary nor sufficient for garnering financial support for intensive home and community services for youth with SED, it can move a state in the right direction by establishing expectations and goals, removing barriers to collaboration, and, in some cases, providing new dollars to build the infrastructure necessary to sustain these services. Discussions with state officials suggest that decisions about how to finance intensive community services have to account for a state's history of legislative and political efforts to improve the child mental health service system.

Third, states and counties that carefully manage access to residential treatment services and psychiatric hospitals tend to have more resources for intensive home and community services. In the process of building financial support for intensive home and community services for children with SED, many states began by re-directing expenditures away from psychiatric hospitals and residential treatment services and toward community alternatives. This process, coupled with careful management of access to beds in both residential treatment facilities and in-patient psychiatric hospitals, is important because it has allowed states to conserve dollars and invest their resources in developing the provider capacity and infrastructure necessary for a community-based service system. Careful management of access to residential care is critical not only because such care is expensive but also because there is little evidence of its long-term effectiveness in solving problems to which it is usually applied.

Fourth, within states, certain administrative and budgetary procedures can support the cost-sharing of services among all or most of the agencies that serve children. Problems with interagency coordination and the associated duplication and gaps in services have long been recognized as a serious barrier to comprehensive child mental health care. In addition to instituting strategies for improving interagency coordination at a policy level, states also have established mechanisms for ensuring that funds from different agencies are integrated at the local level to ensure that the child and family can obtain needed services. In some states, for example, individualized plans of care specify which state agency (mental health, child welfare, juvenile justice, or special education) will pay for which services. In other states, dollars are blended to allow for integrated service delivery across child-serving systems. According to some state officials, case rates are an especially useful financing mechanism because: (1) several agencies can contribute dollars to the case rate for an individual child; and (2) agencies have a predictable amount of dollars to pay for a wide range of home and community services tailored to help children with SED achieve specific outcomes.

Fifth, because of the urgent needs of near-poor children with SED who have little or no insurance coverage for mental health care, and for families of these children who exhaust their coverage, financing mechanisms that allow these

children to access intensive services (even if their families are not Medicaid eligible) are critically important. One of the principal advantages of the HCBS waivers is that they allow states to disregard Medicaid's rules for using parental income in determining a child's eligibility for Medicaid. Several state officials emphasized the importance of this particular component of the waiver because it provides states with a means for: (1) covering high-risk and uninsured or inadequately insured children who would not otherwise have access to mental health services; and (2) ensuring that families do not have to relinquish custody of a child with SED solely to obtain intensive mental health services.

IMPLICATIONS

The findings from this study have three major implications for policymakers concerned with improving mental health services to youth with SED and their families. First, sustained improvements in financing intensive home and community services for youth with SED depends on the development of effective partnerships between key agencies at the state and local levels. No simple recipe can create this partnership. In some cases, the key partnership was forged between the state mental health department and the Medicaid agency. Medicaid programs in every state now pay for a considerable portion of mental health services for youth with SED, while mental health agencies have the experience necessary to manage clinical care, certify providers, and assess service quality. The resources of both agencies can be used to support initiatives that provide appropriate and cost-effective services. Child welfare, juvenile justice and education agencies also are key because they often control considerable behavioral health dollars, and they serve the majority of children who need mental health services and supports.

In states that are actively pursuing ways to expand the availability of home and community-based services, agencies that serve children have developed new partnerships with one another. Discussions with state officials provided many examples of initiatives--often mandated by state legislation or budgetary processes--that bring different agencies together on behalf of youth with SED (e.g., mental health, Medicaid, child welfare, juvenile justice and education agencies). From a state perspective, the challenge is to ensure that the process of collaboration does not threaten the budget of any single agency, but instead leads to an equitable distribution of financial responsibility across the agencies. From a federal perspective, the challenge is to ensure that legislation directly affecting one system or one funding source (for example, Medicaid) does not unintentionally create barriers to interagency agreements at the state level.

The second implication involves the impact of prior demonstration projects funded under the original federal Child and Adolescent Service System Program, the current federal Comprehensive Community Mental Health Services for Children and Their Families Program, or other foundation-sponsored initiatives. These efforts spawned community level demonstration projects in virtually every state, and many officials with

whom we spoke noted that the roots of current initiatives often lay in the experience gained during the implementation and operation of these projects. This finding underscores the strong potential for positive long-term outcomes of the demonstration projects authorized under the Deficit Reduction Act of 2005.

Finally, the study findings indicate that state officials value HCBS waivers because they can provide states with an additional mechanism for financing home and community services and support other efforts to manage access to residential treatment. Moreover, states would be interested in applying for an HCBS waiver for youth with SED if the criteria for documenting budget neutrality could be linked to psychiatric residential treatment facilities rather than to psychiatric hospitalization alone. In most states, very few children now enter psychiatric hospitals, and even fewer stay for long periods of time. Because most states are spending comparatively little on psychiatric hospitalization for children, they will not save many dollars, if any, by substituting intensive home or community services for treatment in these hospitals. However, as inpatient utilization has decreased, use of residential treatment has increased; this trend has placed corresponding demands on Medicaid dollars because Medicaid covers psychiatric residential care for children in most states. By replacing this residential care with more effective home and community services, states should be saving both federal and state Medicaid dollars, which could be available to enhance home and community services for youth with SED.

I. INTRODUCTION

Numerous reports have underscored major deficiencies in the response of the nation's mental health, juvenile justice, and child welfare systems to children with serious emotional disturbances (SED) and their families, including a heavy reliance on residential care and out-of-home placements (Campaign for Mental Health Reform 2005; New Freedom Commission on Mental Health 2003; U.S. Department of Health and Human Services 1999). In addition, recent studies (for example, General Accounting Office 2003) have reinforced long-standing concerns that some parents have had to relinquish custody of their children solely to obtain treatment for their children's behavioral or emotional problems. Prompted by these findings, many federal and state legislators and program administrators have begun to consider new mechanisms for improving child mental health services.

Youth with SED include children and adolescents with chronic depression, major conduct disorders, substance abuse problems, and other behaviors that are challenging for families and communities. These children and adolescents have claimed a great deal of attention because of the gap between their need for intensive treatment and the availability of appropriate home and community services, which include a range of nontraditional treatments from home-based family counseling, respite care, and family-to-family support to independent skills training, crisis intervention, and treatment foster care. More and more studies indicate that these services are effective not only in improving mental health outcomes for youth with SED, but also in reducing or preventing stays in residential care and other out-of-home settings (Burns 2002; Hawaii Department of Health 2004; Knitzer and Cooper 2006; Sheidow et al. 2004). Given these signs of progress, policymakers have begun to express greater interest in making these services more widely available (Waxman 2006).

The purpose of this report is to present the results of a study of the mechanisms that states use to pay for intensive home and community services for children and youth with SED and their parents. Although the study covers the major public strategies for funding home and community services for children with SED, it focuses on the Medicaid home and community-based service (HCBS) waiver, also known as the 1915(c) waivers, because of the substantial legislative interest in this particular financing approach. It is not intended to be a review of all possible public and private mechanisms for funding mental health services for this group of children.

At the beginning of the study, five states were operating HCBS waivers for youth with SED: Indiana, Kansas, New York, Vermont and Wisconsin.¹ However, the 2005 Deficit Reduction Act (Public Law 109-171) authorizes demonstration projects for up to

¹ Kansas and New York began operating their waiver programs in the mid 1990s, and had 2,020 and 1,700 children enrolled in their waivers, respectively, as of 2005; Vermont began its waiver program in 1982, and had 140 children enrolled as of 2004. Indiana and Wisconsin began their waiver programs in 2005, and had 20 and 190 children enrolled, respectively, at the end of that year. Michigan obtained approval for an HCBS waiver for youth with SED in October 2005--too late to be included in this study.

ten states to assess the effectiveness of home and community-based alternatives to psychiatric residential treatment. As states pursue these demonstration projects and more generally seek to improve their mental health service system for children, they will need information on how different public financing mechanisms can be applied. This report is designed to provide background information to policymakers and program administrators in federal and state departments of mental health, child welfare, juvenile justice, and education who are working to improve care for children and youth with SED.

HCBS waivers allow states to provide an expanded set of Medicaid services to a limited number of children identified as having SED through various clinical criteria. These waivers enable states to provide high-risk children with a set of intensive services not included in the standard Medicaid plan while maintaining some control over costs. However, the HCBS waiver is only one of several methods for supporting intensive home and community services for youth with SED. States and counties are combining many approaches to finance these services and, more broadly, to initiate and sustain a fundamental transformation of their child mental health service systems. These approaches include the various Medicaid coverage options, integrated funds from the numerous agencies that serve children, designated care management entities (CMEs) for high-risk populations, time-limited demonstration projects funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), and other Medicaid waivers (such as the 1115 waivers).

Although case studies have been used in previous studies to describe the financing of model community-based programs (e.g., Bazelon Center 2003; Pires 2002; Stroul 2003), there remains a need to examine in greater detail the mechanisms used by states to finance intensive home and community services, and the reasons behind the states' decisions for choosing one mechanism over another. To explore these questions, the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services contracted with Mathematica Policy Research, Inc. to examine how states and communities have financed, or could finance, these services for youth with SED and their families. In particular, the study examines states' use of HCBS waivers and other financing approaches in order to provide a context for understanding what can be accomplished with and without waivers.

A. RESEARCH QUESTIONS AND METHODS

The study addressed the following research questions:

- What are the benefits and disadvantages of HCBS waivers, as well as other financing methods for building home and community alternatives to residential care?
- Why do states feel they need HCBS waivers, and what are the arguments for or against amending this waiver program to allow for alternatives to psychiatric residential treatment facilities (PRTFs), as well as to hospital level care?

- How and why have different financing approaches been combined to support alternatives to residential care or out-of-home placements?
- What financing strategies are likely to contribute to the sustainability of improvements in mental health services for youth with SED?
- What role do different financing mechanisms play in promoting collaboration among mental health, child welfare, juvenile justice, and special education agencies?
- To what extent have demonstration projects provided the experience that states can use to develop effective financing strategies for home and community services?
- What financial arrangements should be avoided because they work against long-term improvements in the overall system-of-care?

To collect the data required to address these questions, officials in three groups of states were contacted:

- States that are implementing comprehensive statewide reforms in their child mental health service systems, but are not using HCBS waivers as part of this effort: New Jersey and New Mexico.
- States that have HCBS waivers for youth with SED: Indiana, Kansas, New York, Vermont, and Wisconsin.
- States that received grants from the Centers for Medicare and Medicaid Services (CMS) in 2003 to assess the feasibility of developing an application for an HCBS waiver: Illinois, Maryland, Mississippi, Missouri, and Texas.²

Discussions with officials in these states covered a wide range of topics, including the legislative and policy background related to services for youth with SED, the reasons for selecting a given financing strategy or strategies, the benefits and challenges associated with HCBS waivers, the extent to which demonstration projects influenced a state's selection of particular financing mechanisms, tactics for promoting coordination among key agencies, the role of residential treatment centers (RTCs), and general "lessons learned" from recent state efforts to strengthen the financing of these services. Discussions were held during visits to two states (Kansas and New York) and through telephone conference calls with officials in the other states.

² CMS awarded these grants on a competitive basis in 2003 to six states for the purpose of assisting states to develop comprehensive, community-based mental health service delivery systems, through Medicaid, for children with SED who would otherwise require care in a psychiatric residential treatment facility.

These discussions and a review of relevant state and federal reports were used to develop a summary of each state's experience in supporting intensive home and community services for youth with SED. Each summary covered the policy context that shaped the services provided to youth with SED; key features of the HCBS waiver, the feasibility study, or the statewide reform plan (depending on which strategy a state had followed); the role of RTCs in each state's mental health service system for children; and the lessons we might learn from each state's experience. Officials from each state reviewed the summary for their state, and their comments were incorporated to the extent possible.³ The summaries are included in Appendix A, Appendix B, and Appendix C.

B. OVERVIEW OF REPORT

Strengthening the financing of intensive home and community services for youth with SED involves a complex set of policy issues, regulatory constraints, and payment mechanisms. Chapter II presents critical background information on these topics. It describes important system-of-care principles that have shaped the services for youth with SED, the role of the various agencies that serve these children, and the financing mechanisms used by many states.

Chapter III and Chapter IV present the study findings. The former identifies the general financing themes that emerged in our discussions with officials in each of the three groups of states. The latter covers the strengths and weaknesses of four major financing mechanisms: HCBS waivers, the Medicaid rehabilitation option, case-rates for high-risk populations, and provisions in the Tax Equity and Fiscal Responsibility Act (TEFRA), also known as the Katie Beckett provision. The final chapter presents a synthesis of findings with respect to the research questions, and discusses what the findings may imply for current legislative and policy efforts to strengthen the financing of intensive home and community services for youth with SED and their families.

³ Although the summaries are based on information from state officials and related reports, the authors assume responsibility for the accuracy of the summaries and for the conclusions drawn in the "lessons learned" sections. The summaries are not and should not be viewed as officially sanctioned policy statements or program descriptions.

II. MECHANISMS FOR FINANCING SERVICES FOR YOUTH WITH SED AND THEIR FAMILIES: CRITICAL BACKGROUND ISSUES

At least 10 percent of the children in the United States--more than six million young people--have an SED, defined as any diagnosable mental disorder that severely disrupts social, academic, and emotional functioning (U.S. Department of Health and Human Services 1999). An estimated 70-80 percent of these children do not get the treatment they need (Campaign for Mental Health Reform 2005; Koppelman 2004). As a result, many become involved with juvenile justice systems, drop out of high school, and are poorly prepared for adult life (Duchnowski et al. 2002).

Most children and youth with SED are first identified *not* in mental health clinics but in child welfare agencies, detention centers, juvenile courts, schools, primary care practices, and childcare programs. These agencies and institutions play a critical role in providing services for these children, albeit only for a short time or for certain problems (New Freedom Commission on Mental Health 2003). To complicate the issue, the various agencies that serve youth with SED and their families differ in terms of their legislative mandates, treatment philosophies, funding sources, and reporting requirements. In many states, these differences make for a rigid, poorly coordinated delivery system with financing "silos" that are difficult to integrate. For example, if a child with SED comes to the attention of one agency, he or she may have access to community services; if he or she comes to the attention of another agency, residential treatment may be the only option available.

Problems with interagency coordination and the associated duplication and gaps in services have long been recognized as a serious barrier to comprehensive child mental health care. In 1986, for example, the National Institute of Mental Health developed the Child and Adolescent Service System Program (CASSP) as a means to strengthen mental health services for children by improving interagency coordination and developing a cohesive system-of-care, defined by Stroul and Friedman (1986) as "a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families." Ideally, such systems of care should also be community-based and culturally competent (see Appendix D for the ideal attributes of a system-of-care for youth with SED, as defined by Stroul and Friedman 1986).

CASSP provided both an important conceptual framework and financial support for states that wanted to strengthen their systems of care for children with SED and their families by promoting more flexible funding and interagency approaches (Potter and Mulkern 2004). CASSP funding ended in the early 1990s, but Congress passed a new program to support efforts in local communities: the Comprehensive Community Mental Health Services for Children and Their Families Program. This program, administered

by the Center for Mental Health Services (CMHS), provides six-year grants to selected communities, states, or tribal organizations for the purpose of creating, through a demonstration program, sustainable changes in infrastructure and service delivery systems for children with emotional and behavioral problems who require services from several agencies. Grantees are required to match federal dollars with local, state, or other funds in the early years of their programs and must assume an increasingly larger share of program expenses over time. In October 2005, SAMHSA announced 25 new grantees, totaling \$184.5 million over the next six years (Mental Help Net 2005), bringing to over 120 the total number of grantee sites funded to date. As of March 2006, programs were operating in 56 sites.

In addition to federal funds for demonstration projects, several private foundations have sponsored local initiatives to enhance access to community services for youth with SED (see, for example, Saxe and Cross (1998) for an overview of the Mental Health Services Program for Youth (MHSPY), funded by the Robert Wood Johnson Foundation).

Despite more than two decades of experience in the application of system-of-care principles and flexible funding through demonstration programs (see Potter and Mulkern 2004 for a partial review), few states have adopted a comprehensive approach to re-engineering their interagency agreements in support of a statewide financing system for child mental health services (Knitzer and Cooper 2006). Instead, most states have taken an incremental approach to reform, making circumscribed policy changes or implementing demonstration programs under one agency or another. Although these changes have improved access to intensive home and community services for certain populations of at-risk children, the policy and procedural differences still remaining between the various child-serving agencies continue to stifle the emergence in most states of a coordinated, statewide system of financing services for youth with SED (Institute of Medicine 2005).

Nonetheless, many states persist in the search for a better way to pay for services for children with SED and their families (see Armstrong et al. 2006 for a state planning guide). They do so because home and community services offer an opportunity to provide services that are less expensive and more effective than residential care. In fact, a growing number of methodologically sophisticated studies, many based on a randomized design, have demonstrated the positive impact of home and community services such as multisystemic therapy, multidimensional treatment foster care, functional family therapy, various cognitive behavioral therapies, and “wraparound” interventions, among others (see, for example, Burns 2002; Glied and Cuellar 2003; Sheidow et al. 2004). Based on this evidence, states are beginning to recognize the value of these services as essential to any comprehensive child mental health service system (see, for example, Hawaii Department of Health 2004). In contrast to the growing empirical support for these services, there is marked absence of evidence for the long-term effectiveness of traditional residential care (Frensch and Cameron 2002; Joshi and Rosenberg 1997; Weiner et al. 2001).

This chapter provides the foundation for our analysis of strategies that states have used or could use to pay for intensive home or community services as part of a broader system for financing effective treatment for youth with SED. Specifically, we:

- Present estimates of the number of youth with SED in residential care and the costs associated with care in these facilities;
- Describe the incentives that shape the financing decisions made by different agencies;
- Outline mechanisms for financing home and community services; and
- Discuss financial incentives that shape the policy decisions of state agencies.

A limited number of states and counties (for example, Proposition 63 in California, Spokane County in Washington State and Jackson County in Kansas) have designated sales, property, or income taxes to enhance public mental health services, including services for youth with SED. Because so few localities have designated tax revenues specifically for mental health services, the report does not address this issue further. However, tax initiatives are an important potential source of new revenue for child mental health services and are attracting interest from an increasing number of states and localities.

A. NUMBER OF YOUTH WITH SED IN RESIDENTIAL CARE AND COSTS ASSOCIATED WITH THEIR CARE

When intensive home or community services are unavailable or ineffective, parents and other authorities typically turn to psychiatric in-patient units, residential settings, or other out-of-home placements to treat children with SED. Residential settings include psychiatric residential treatment facilities (PRTFs), residential treatment centers (RTCs), therapeutic group homes, and therapeutic foster care residences. These facilities are owned by a wide variety of public and private entities and are operated under the jurisdiction of various state agencies, including departments of mental health, child welfare, and juvenile justice (Ireys et al. 2006; Goldstrom et al. 2001; Pottick et al. 2004). According to analyses of data from SAMHSA's 1997 Client/Patient Sample Survey, social service agencies, including child welfare units, were responsible for referring about 37 percent of all youth in residential care in 1997, and juvenile justice agencies were responsible for referring another 28 percent.

The number of children in residential settings has increased during the past two decades partly in response to the closing of long-term psychiatric hospitals and in-patient institutions (Manderscheid et al. 2004). As states have focused on closing hospital beds and Medicaid managed care has worked to reduce in-patient admissions and lengths of stay, the number of children placed in residential treatment has increased.

Overall, the number of residential beds in a state is shaped by several factors, including:

- Coverage of residential care for youth with mental illness in the state's Medicaid plan.
- The extent to which juvenile justice, child welfare, special education, and mental health agencies place children in residential care without considering other alternatives.
- Financial incentives that favor placement in residential treatment over provision of home and community care (such as a Medicaid state plan that includes coverage for residential treatment but not in-home counseling).
- The availability of home and community services that could prevent or shorten placement in residential care (a particular problem in the rural areas of many states).
- State agency, juvenile court, provider and family awareness of and willingness to use intensive home and community services as an alternative to residential settings.
- Reluctance on the part of many communities to care for children who are perceived to be very dangerous or uncontrollable.

The total number of beds in RTCs or other out-of-home settings operated or funded by all state agencies combined is an important element in a financing analysis because care in these facilities is expensive. For example, analyses of Medicaid administrative and claims data from New Jersey indicate that annual costs in 1999 for all Medicaid services averaged \$25,759 for a child with an emotional or behavioral disorder who spent 30 days or less in an institution for mental diseases (IMD) and \$73,884 for children who spent more than 30 days in an IMD (Ireys and Cherlow 2004). In 2002, the Colorado state auditor estimated that the average annual cost in fiscal year 2001 for a child in a PRTF was \$56,064 for children committed by the state Department of Youth Corrections (DYC), and \$52,990 for children placed by their county child welfare or mental health agency (Colorado Office of the State Auditor 2002). The cost of care in PRTFs with on-grounds schools was higher, averaging \$68,313 annually for children placed by DYC, and \$65,901 for children placed by a county agency.

In contrast, costs for children who receive home and community services through an HCBS waiver range between \$12,813 and \$28,058 per child per year (excluding Kansas), depending on the particular state and year of waiver operation (see Table II.1). These figures are substantially lower than the estimates of the institutional level of care costs that would have been incurred had these children not been enrolled in the waiver, ranging from \$22,736 to \$113,572 per child per year, again depending on the particular

state and year of waiver operation (Table II.1). Given that total treatment dollars for youth with SED are limited, the more that states spend on residential and other out-of-home care, the less they have for intensive home and community services. Faced with this dilemma, policymakers in many states see their ability to enhance community services for youth with SED as depending, at least in part, on their ability to reduce the number of residential beds and average lengths of stay in residential settings. The monies saved by diverting children from residential care into community treatment are often referred to as “diversion dollars” or “re-investment funds,” and some states allocate all or a portion of these funds to child-serving agencies with the specific goal of enhancing intensive home and community services.

TABLE II.1: Estimates of Expenditures for Home and Community Services and Hospital Level Care for Youth with SED			
State	Year	Estimated Annual Average Per Capita Medicaid Cost For	
		Home and Community Services	Hospital, Nursing Facility or ICF/MR Services^a
Indiana	2004	\$12,813	\$54,513
Kansas	2005	\$607 ^b	\$28,918
New York	2004	\$18,028	\$113,572
Vermont	2003-4	\$28,058	\$40,365
Wisconsin	2003	\$16,129	\$22,736

SOURCE: Applications for an HCBS waiver submitted by states to CMS.

a. These are estimated Medicaid costs that would be incurred for individuals served in the waiver were the waiver not granted.

b. Kansas' per capita cost is substantially less than the other states because of the state's lower reimbursement rates for specific services (see Appendix E), and its larger number of unduplicated recipients (relative to other states with an HCBS waiver).

B. SOURCES OF FEDERAL FUNDING FOR CHILD MENTAL HEALTH SERVICES

In addition to the demonstration projects funded by SAMHSA under the Comprehensive Community Mental Health Services for Children and Their Families Program, states draw from several federal sources to pay for mental health services for children, including Medicaid, Title IV-E and Title IV-B of the Social Security Act, special education, and community mental health block grants, among others. They also draw considerably on state and local general funds.

Medicaid is today's largest payer of mental health services in the nation (New Freedom Commission on Mental Health 2003). Consequently, the program plays a significant role in financing mental health services for youth with SED. About 20 percent of all children with mental illness are publicly insured, mostly through Medicaid, which in 1998 covered 24 percent of all children's mental health expenditures (Koppleman 2005).

States use Medicaid to finance a wide range of mental health services including, in most states, treatment in psychiatric in-patient and residential facilities. Various waivers

(such as the HCBS waiver), if approved by CMS, allow states to waive compliance with certain portions of the Medicaid statute, such as the amount, duration, and scope of Medicaid services they provide. As a result, a state may pay for specialized services not otherwise covered under its Medicaid plan in lieu of placing children in hospital in-patient settings but not, currently, in lieu of placing children in PRTFs.

For children involved in the child welfare system, Title IV-E provides states with matching federal funds to pay for the cost of room and board for eligible children in residential settings, including foster homes and other types of out-of-home care under a court order or voluntary placement. Title IV-E does not pay for mental health services provided outside of residential facilities, although it does cover certain types of administrative services, such as case management. (Medicaid typically pays for mental health services for Medicaid eligible children in foster care.)

Under the Individuals with Disabilities Education Improvement Act (IDEA), children who require special education services because of a disability, including SED, are entitled to receive such services, which will enable them to make progress in school and prepare for employment and independent living. IDEA requires public schools to evaluate children who are referred for special education services and, if it is determined that services are required, these schools must develop an individualized education program (IEP) that documents the type and intensity of services that will be provided (General Accounting Office 2003). Public schools are obligated to ensure that services specified in IEPs are provided, including paying for services if necessary, including mental health services and tuition at private schools designed for children with particular types of problems. Many school systems are reluctant to include intensive home or community services in IEPs because of their cost, although many school systems are paying for the cost of services in residential facilities.

The Community Mental Health Services Block Grant program supports the delivery of a broad range of community-based systems of care for individuals with serious mental illnesses, including children with SED, as an alternative to hospitalization. All states and territories are eligible for the grant program, which is administered by CMHS within SAMHSA. The grants are based on a state's demographic and economic factors. They offer flexible funding that states can use not only to support mental health services not covered by other sources but also to pay for mental health treatment for uninsured individuals. Overall, these funds are quite limited, representing about 3 percent of all mental health costs in most states.

Changes in Medicaid payment strategies to support states' use of intensive home and community services are essential. However, significant improvement in treating youth with SED depends on aligning the incentives and funding priorities of *all* key agencies, not just those that rely on Medicaid funding.

C. FINANCING MECHANISMS

Broadly speaking, there are two policy options through which states can reform the way they finance intensive home and community services for youth with SED:

- They can make comprehensive statewide reforms intended to address the entire service delivery and financing system through procedural changes in all participating agencies at the same time over a period of several years; or
- They can make incremental reforms intended to address pieces of the service delivery and financing system through procedural changes in one agency or one department at a time or in a limited number of counties at a time.

As a practical matter, the latter option is typically more feasible than the former, but the large variety of mechanisms that states can actually use to effect change is the same under either approach. This report focuses on the following four mechanisms (see Table II.2):

1. Medicaid 1915(c) HCBS;
2. The Medicaid rehabilitation option;
3. TEFRA provisions; and
4. Case-rates used by designated CMEs for high-risk populations, using blended or braided funding.

Each is briefly described below, together with other mechanisms that can be important components in developing a comprehensive financing system for children's mental health services.

1. Medicaid 1915(c) Home and Community-Based Services Waivers

Through HCBS waivers, states can expand coverage of mental health services to intensive HCBS for a designated number of children with SED as an alternative to institutional care (defined as hospital level not residential treatment) that would otherwise be covered by Medicaid. States also can use HCBS waivers to expand coverage to populations not otherwise eligible for Medicaid, creating access, for example, to uninsured families and those who exhaust their private insurance because they have a child with SED. These are the families who otherwise may have to relinquish custody of their children to access services.

The waivers are attractive because they allow states to provide selected services to a limited number of children, thereby reducing their risks for a rapid escalation in expenditures. Children are determined to be eligible based on specific clinical criteria and, in some states, on whether the waiver is operational in their county. The expanded package can include a wide range of intensive services that many children with SED and their families need, and that can be combined into individualized plans of care tailored to the needs of the child and family.

TABLE II.2: Mechanisms for Financing Intensive Home and Community Services for Youth with SED	
Mechanism	Description
1915(c) HCBS Waivers	<p>Eligible children must require care in a psychiatric hospital (RTCs in most states do not qualify as psychiatric hospitals)</p> <p>HCBS waivers allow states to waive:</p> <ul style="list-style-type: none"> • Limits on the amount, duration and scope of Medicaid services, thereby enabling the state to offer specialized intensive HCBS not available through mandatory or optional Medicaid services or through other state or county programs • Parental deeming requirements, thereby providing access to intensive mental health services for youth who might not otherwise be financially eligible for Medicaid • Statewideness requirements, allowing the state to implement the waiver in particular geographic areas
Rehabilitation option	<p>A rehabilitation service is defined as “any medical or remedial services (provided in a facility, a home or other setting) recommended by a physician or other licensed practitioner...for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level” (42 CFR 440.130(d))</p> <p>Range of specific covered rehabilitation services defined differently by different states</p>
TEFRA (also known as the Katie Beckett provision)	<p>Gives states the option to waive the deeming of parental income and resources for children with disabilities under 18 years old who are living at home but would otherwise be eligible for Medicaid-funded institutional care</p> <p>Qualifying children eligible to receive all services provided under the state’s Medicaid plan</p> <p>Requires states to determine that:</p> <ul style="list-style-type: none"> • The child has a disability as defined by the Social Security Administration (SSA) disability definition • The child requires the level of care provided in an institution • Providing care inside of the home is appropriate • The cost of care at home is no more than the cost of institutional care
Case-rates for designated CMEs serving high-risk populations	<p>Fee for each child received per month in return for providing a flexible, individualized array of services and supports designed to achieve specific outcomes</p> <p>Different state and local agencies may contribute to case-rates through mechanisms that blend or braid funds</p> <p>Separate case-rates negotiated for different groups</p>

2. The Medicaid Rehabilitation Option

The Medicaid rehabilitation option can include a wide range of psychiatric rehabilitation services, which are defined as “medical or remedial services for maximum reduction of mental disabilities and restoration of maximum functioning” (Table II.2).

Such services include: (1) restoration and maintenance of daily living skills (grooming, personal hygiene, cooking, nutrition, health and mental health education, medication management, money management, and maintenance of the living environment); (2) training in the social skills appropriate to the use of community services; (3) development of appropriate personal support networks; (4) recreational services that are therapeutic in nature; and (5) telephone counseling services (Bazelon Center for Mental Health Law 2001; Smith et al. 2000, p. 84). States vary widely in the rehabilitation services they offer depending on the various political and administrative factors that influenced the states' decision to include this option. Some provide psychological assessment; crisis intervention; individual, group, and family therapy; and day treatment. Others offer home-based services, behavioral management skills training, therapeutic foster care, family preservation services, care coordination, or help in medication compliance (Smith et al. 2000, pp. 75-76). Once a state has adopted the rehabilitation option as part of the state plan, it must make the covered services available to all Medicaid beneficiaries.

3. Tax Equity and Fiscal Responsibility Act of 1982

TEFRA added the "Katie Beckett provision" to the Medicaid program as a state option. This provision allows states to waive the requirement for considering parental income in the process of determining Medicaid eligibility for children with disabilities under 18 years old who are living at home but would otherwise be eligible for Medicaid-funded institutional care. As of 2002, 20 states include this provision in their Medicaid plan, but in only ten do children with mental and emotional disorders qualify (Bazelon Center for Mental Health Law 2002). Children who qualify under the provision are eligible only for the services provided under the state's Medicaid plan. That is, TEFRA did not authorize a specialized package of intensive services for children covered under this provision. (TEFRA included many other provisions not related to children.)

4. Case-Rates for High-Risk Populations

More and more states and counties are contracting with designated CMEs to provide a flexible, individualized array of services and supports for defined populations of youth and pay these CMEs on a case-rate basis in return for meeting specified outcomes. For example, in Oneida County, New York, the Department of Social Services pays a nonprofit CME (Kids Oneida) \$2,550 per month for each youth with SED to provide an individualized plan of care (IPC), including such services and supports as care coordination, family support, crisis response, skill building, intensive in-home counseling services, and respite care (see Appendix B for additional details).

In some other states, several state and local agencies that serve children contribute to the case-rate amount. Wraparound Milwaukee, for example, uses pooled dollars from child welfare, juvenile justice, Medicaid, and mental health (see Appendix B for additional details). This program accepts full risk for enrolled children but is able to purchase a broad, flexible array of services and supports. When necessary, the

program pays RTCs for care (generally very short-term) on the basis of negotiated fee-for-service arrangements, as it does for all other types of services and supports.

Overall, CMEs such as Kids Oneida or Wraparound Milwaukee can provide a wider range of services tailored to the needs of the individual child and family than would be possible for any single agency. Moreover, because the state contracts with these entities, the state can include provisions specifically designed to enhance quality of care, such as specifying that evidence-based mental health treatments will be used to the extent possible.

5. Other Important Medicaid Financing Mechanisms

a. Early and Periodic Screening, Diagnosis, and Treatment Program

States use other Medicaid provisions to pay for mental health services for children, including the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, the optional clinic benefit, 1915(b) waivers, and 1115 waivers. Under EPSDT, all Medicaid-eligible children under the age of 21 are entitled to be screened regularly for physical and mental health conditions. States are required to provide screened children with any medically necessary, federally authorized Medicaid service regardless of whether the service is included in the state's Medicaid plan. Ideally, states would use EPSDT to enhance access to mental health treatment services for children with SED by ensuring that: (1) primary care physicians and clinics use standard screening tools to identify children with or at high risk for SED; (2) identified children are referred for further evaluation and treatment; and (3) identified children have access to a broad range of treatments, including intensive home and community services.

Most states, however, have neither fully put the EPSDT program into practice nor implemented the standard screening tools statewide that can reliably identify children and adolescents at risk for mental health problems (Bazelon Center for Mental Health Law 1999; Koppelman 2004). Consequently, lawsuits have been filed in numerous states alleging shortcomings in the provision of EPSDT services. Some of these lawsuits have focused on a state's failure to provide intensive community-based mental health services to youth with SED and their families that would enable the youth to reside at home or in the community (GAO 2001; Perkins and Strickland 2004). For example, in June 1999, as a result of a class action lawsuit (*Emily Q v. Bontá*), Medi-Cal, the California Medicaid Program, was required to: (1) offer therapeutic behavioral services (TBS) so that children with SED could receive treatment in their communities instead of being institutionalized; (2) assess children in institutions to determine if they qualify for TBS; (3) develop and distribute a request and referral form for providers to request TBS services; (4) revise the EPSDT brochure to inform beneficiaries and applicants about TBS and other developmental services; and (5) provide compensatory benefits to class members wrongfully denied TBS services (Perkins and Strickland 2004). The most recent decision in a class action suit (*Rosie D. v. Romney*) occurred on January 26, 2006 when a judge ruled that Massachusetts violated EPSDT by failing to provide various intensive community-based mental health services, including

comprehensive assessments, case management and clinical oversight, and in-home behavioral health services necessary to maintain a child at home or in the community. (Rosie D. v. Romney, No. 01-30199-MAP, January 26, 2006).

b. *Clinic Option*

Through the Medicaid clinic option, states can provide nonhospital-based community services, but only in community clinics and by or under the direction of a physician. Mental health services supported under this option typically include traditional counseling, psychotherapy, and medication management. The intensive home and community services required by youth with SED and their families are not generally covered under the clinic option.

c. *Managed Care Waivers and Demonstrations*

Through 1915(b) waivers, states can implement managed care delivery systems or "carve out" delivery systems for specialty care (e.g., behavioral health) that limit an individual's choice of provider under Medicaid. These waivers must be budget neutral but do not have to be operated statewide. Although the 1915(b) waiver can be used only for individuals who are already Medicaid eligible, the managed care system can utilize funding streams beyond Medicaid, thereby providing a vehicle for using diverse funding sources to implement a coordinated service delivery system for both Medicaid and non-Medicaid eligible children. CMS approves 1915(b) waivers for two years and states have the option to renew for successive two-year periods.

Medicaid 1115 waivers permit states to conduct demonstration projects that are likely to promote the objectives of the Medicaid program. For example, some states use 1115 waivers to expand eligibility to individuals not otherwise eligible under the Medicaid program, to provide services to Medicaid beneficiaries that are not typically covered, or to test innovative service delivery systems. States must show that the demonstrations will be budget neutral. CMS approves 1115 waivers for five years, after which states can submit renewal applications.

Because they offer states substantial flexibility in developing service packages and extending coverage to particular subgroups of beneficiaries, both 1915(b) and 1115 waivers can be important vehicles for funding intensive home and community services for youth with SED.

6. *Financing Mechanisms in the Study States*

The states in the study are at different points in the process of transforming their mental health services for youth with SED, and have used or are using different combinations of financing mechanisms to do so (Table II.3). The HCBS waiver states tend to use a greater number of mechanisms compared with the states that are exploring the feasibility of an HCBS waiver application. New Jersey and New Mexico

have taken yet a different approach in their effort to implement comprehensive statewide reforms.

TABLE II.3: Use of Selected Mechanisms for Financing Intensive Home and Community Services						
State	Medicaid Program			Other Sources of Funds		
	HCBS Waivers for Youth with SED	Rehabilitation Option^a	Katie Beckett Provision	Case-Rates for High-Risk Populations^b	SAMHSA Grants^c	Other Funds^d
Comprehensive Statewide Reform States						
New Jersey		✓			✓	✓
New Mexico		✓		✓	✓	
HCBS Waiver States						
Indiana	✓	✓		✓	✓	
Kansas	✓	✓			✓	✓
New York	✓			✓	✓	✓
Wisconsin	✓	✓	✓	✓	✓	✓
Vermont	✓	✓	✓		✓	
CMS Feasibility Study States						
Illinois		✓			✓	
Maryland		✓		✓ ^e	✓	✓
Mississippi			✓		✓	
Missouri		✓			✓	
Texas		✓			✓	
<p>a. Only states that use the Medicaid rehabilitation services option to pay for intensive HCBS for youth with SED and their families are indicated by a “✓.” Mississippi has elected the Medicaid rehabilitation services option, but does not use it to pay for intensive home and community services for youth with SED. New York has elected the Medicaid rehabilitation option for some mental health services for children, but the state has not used it to support intensive community services for children with SED.</p> <p>b. Includes states where CMEs have negotiated case-rates with state or local child-serving agencies to provide flexible, individualized services and supports for defined populations of youth and to meet specified outcomes. Service packages typically include a broad array of home and community services and may also include residential care. The entire case-rate may be paid by a single agency (e.g., Medicaid) or by multiple agencies (e.g., Medicaid, mental health, and child welfare). Additional details are provided in Chapter III.</p> <p>c. Includes states that have been awarded grants under the SAMHSA-administered Comprehensive Community Mental Health Services for Children and Their Families Program since its authorization in 1992. Under the previous CASSP program, all 50 states had received support by 1989 (Potter and Mulkern 2004).</p> <p>d. Includes diversion funds, re-investment dollars, and monies from tobacco settlements specifically earmarked for home and community services for youth with SED.</p> <p>e. In development.</p>						

D. FINANCIAL INCENTIVES FOR STATE AGENCIES

Although state departments of mental health, child welfare, juvenile justice, and special education all provide treatment services to youth with SED, the services may vary according to differences in the agencies’ financial and programmatic incentives.

- Child welfare agencies focus on ensuring that children are safe from harm and living under appropriate custody arrangements; the primary sources of federal funding include Title IV-E (for foster care services, including room and board in residential facilities) and Title IV-B (for child welfare services, including family

preservation services) of the Social Security Act. Title IV-E dollars are entitlement dollars (i.e., essentially uncapped) that are designated primarily for the maintenance costs associated with out-of-home placements, including foster care and residential services, but Title IV-B dollars, which can be used to pay for intensive community or home mental health services, are capped. As a result, most youth with SED involved in the child welfare system who need intensive treatment are steered toward some type of residential care.⁴

- With funding from state and federal special education appropriations, special education departments focus on providing services that will promote a child's ability to learn. In most cases, special education officials do not view home or community services as related to education, and hence tend not to include them in a child's IEP. School-based mental health counseling may be included, but usually for strictly defined time periods. It is difficult for parents to argue successfully that intensive mental health services of any kind should be included in the child's IEP; when they are included, they typically entail out-of-school day or residential placements.
- Departments of mental health focus on providing preventive, diagnostic, and treatment services for children who have or are at high risk for mental illness or substance abuse, and receive much of their funding for these services through Medicaid, mental health block grants, and general state and local revenues. Treatment dollars typically move through state and county mental health agencies to local community mental health centers (CMHCs) and hence state and county policies (as well as the state Medicaid plan) shape the incentives for CMHCs to provide home and community services. In a number of states, CMHCs function as quasi-independent agencies under contract with the state and accept risk for mental health services provided to children in their area; as a result, they have strong incentives to replace expensive services (i.e., residential care) with less expensive and more effective alternatives (i.e., intensive home or community treatment.) In most states, however, CMHCs do not bear this risk and are limited to providing services for which Medicaid or the state will reimburse them.

E. THE ROLE OF RESIDENTIAL TREATMENT FACILITIES

In addition to state agencies, PRTFs and RTCs also play pivotal roles in treating youth with SED and, like state agencies, their decisions are shaped by financial incentives. These facilities or centers are owned and operated by various entities, including private nonprofit firms, for profit companies, and to a lesser extent state agencies, and are operated or funded under the auspices of various state agencies,

⁴ Recent Title IV-E waiver demonstration programs involving flexible funding models have led selected states to examine alternative methods for reducing the number of children entering out-of-home placements (Children Bureau 2005). Some of these methods involved payment for in-home parenting services and other community services for families of youth in the child welfare system, including youth with SED.

including departments of mental health, child welfare, and social services (Ireys et al. 2006). In 2000, state mental health agencies alone operated 474 RTCs for emotionally disturbed children with SED with a total of 33,421 beds (Manderscheid et al. 2004). This figure does not include beds operated or purchased by other child-serving systems, and hence is a substantial undercount of the total number of beds for children in residential treatment settings (see Ireys et al. 2006).

In some states, the leadership of RTCs is well organized and may actively resist the development and implementation of financing reforms for children with SED because such reforms typically shift dollars away from residential settings. On the other hand, a limited number of residential centers have begun to re-engineer their services by re-training staff to provide intensive home and community services. They also are taking a broader view of their mission, focusing not only on providing residential treatment but also on a continuum of services that vary in intensity and delivery site. For instance, some centers are beginning to explore methods for providing crisis intervention, stabilization, and treatment services in the home, school, detention centers, or other community settings (Kamradt and Connolly 2003).

III. STATE APPROACHES TO FINANCING HOME AND COMMUNITY-BASED SERVICES FOR YOUTH WITH SED AND THEIR FAMILIES

Developing better mechanisms for financing home and community services for youth with SED is a work-in-progress for most states, and an integral part of their ongoing efforts to improve the child mental health service system. By necessity, discussions with state officials focused on their policy and program environments at one point in time (late 2004 to mid 2005), but these environments can change quickly in response to new legislation or lessons learned from ongoing program implementation. For example, during this period, two states had recently initiated HCBS waivers and were still in the early phases of implementation. In addition, several of the states that had received CMS grants to study the feasibility of developing an HCBS waiver were moving forward to implement study recommendations.

Although the summaries are snapshots of the policies and programs in selected states at one point in time, they illustrate the large constellation of mechanisms available to all states interested in financing intensive home and community services for youth with SED and their families. In particular, they show how the states are combining different financing methods to support these services and why the states made the choices they did. This chapter: (1) describes findings from two states (New Jersey and New Mexico) that have implemented broad statewide financing reforms; (2) presents findings on incremental reforms implemented by the states with HCBS waivers; and (3) discusses the key issues that emerged as states conducted their CMS-supported feasibility studies.

A. COMPREHENSIVE STATEWIDE REFORMS

In light of funding constraints and the many other policy issues competing for legislative attention, few states are likely to have the combination of sustained political leadership, financial resources, and technical capacity required to reform their entire public mental health system for children over a period of several years. Nonetheless, two states in this study--New Jersey and New Mexico--have pursued this goal. (See the New Jersey exhibit and New Mexico exhibit and the states' summaries in Appendix A for more details.)

In 2004, New Jersey began using a statewide administrative service organization (ASO) to manage the financing and monitoring of child mental health services across several child-serving systems. The ASO uses a standard tool to assess children and refers those at risk for out-of-home placement to local care management organizations (CMOs). The CMOs develop individualized service plans (ISPs), provide care

management, and contract with family support organizations (FSOs) for family-to-family services. To help pay for these intensive home and community services, New Jersey implemented the rehabilitation services option under Medicaid and expanded coverage to include such services as mobile response and stabilization, in-home services, and intensive care management.

NEW JERSEY
<p>Policy Context and Program Characteristics</p> <ul style="list-style-type: none"> • Development of fundamental structural and financing reform of the state's system of mental health care for children began in 1999 and led to the Children's Initiative, a community-based system-of-care that brought together once disparate child welfare, juvenile justice, mental health and Medicaid agencies. • The state implemented the Medicaid rehabilitation option and expanded service coverage and contracted with ValueOptions to provide a single point of entry and standard assessments of children. • This organization refers children who are at risk of out-of-home placement to CMOs, which are local, private, nonprofit entities developed specifically under the new program to serve children with complex, multisystem needs; operating in all of the state's 15 service areas, CMOs serve over 3,000 children. • Each CMO receives about \$500,000 per year to support individualized service planning, provide intensive care management services, and must contract with FSOs, which are new, locally-based family-run organizations funded by the state and play a key role in the reform.
<p>Financing Issues</p> <ul style="list-style-type: none"> • In the first year of reform, New Jersey financed its share of Medicaid costs by combining \$167 million in existing state dollars for children with SED from the child welfare and mental health divisions (including \$117 million previously spent by the department of child welfare on residential care) with \$39 million in new funds authorized for children with SED in the governor's 2001 budget. • To build infrastructure for intensive home and community services, the state used dollars saved by drawing down federal Medicaid dollars for services covered under its expanded rehabilitation option and by claiming federal matching dollars for services that it had previously supported solely with state funds. • Partly because more children are receiving community services than in earlier years, growth in spending for community care has outpaced growth in spending for residential care, which now constitutes a smaller fraction (60 percent instead of 90 percent) of the overall budget for children's mental health than it did before system reform, and the goal is to reduce this ratio further.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • Support from the New Jersey legislature, the governor, and commissioner of key agencies was essential to implement major structural reforms in the state's child mental health system. • By pooling state and federal dollars, New Jersey has been able to provide more appropriate and timely services (including intensive and nontraditional community-based services in addition to residential treatment) in more settings to more children and their families, regardless of illness severity or insurance status. • New Jersey opted to reform its children's mental health system using the Medicaid rehabilitation option because it allowed the state to develop a continuum of services that would be commensurate with a range of mental health needs statewide; the HCBS waiver was perceived as being too administratively burdensome and inconsistent with the goal of serving all children in need, in all areas of the state.

New Mexico also is using an ASO-like statewide agency to administer mental health and substance abuse programs for both adults and children. Funds from several agencies are being pooled to support intensive home and rehabilitation services,

including out-patient services, case management, respite care, in-home treatment services, and wraparound services. The state is in the early stages of implementing its reforms, having officially started on July 1, 2005, after two years of intensive interagency planning and development.

NEW MEXICO
<p>Policy Context and Program Characteristics</p> <ul style="list-style-type: none"> • In response to substantial dissatisfaction with the Medicaid managed care plan, begun in the mid 1990s, that integrated financing for physical and behavioral health, Governor Richardson initiated a major reform effort in 2003, instructing key agencies to develop a behavioral health carve out to be overseen by a single purchasing collaborative. • In a report released in April 2004, the Interdepartmental Behavioral Health Purchasing Collaborative (IBHPC), a cabinet level workgroup, recommended a fundamental restructuring of the state's behavioral health system by establishing a single statewide entity to administer the state's mental health and substance abuse programs. • In the spring of 2005 a contract was awarded to ValueOptions, and the first phase of structural reforms began in July 2005. • As part of the plan, local collaboratives are responsible for identifying unmet needs in particular areas, developing plans and programs to address these needs, and evaluating the quality of services provided through the programs.
<p>Financing Issues</p> <ul style="list-style-type: none"> • Funds for the single behavioral health service delivery system will be braided from the various state agencies that now purchase behavioral health services. First-year funds are to top out at approximately \$350 million in state and federal dollars. In the second year, additional funding streams from the various agencies will be added to significantly increase the total fund. • ValueOptions will manage the entire behavioral health system on a risk basis through capitation, fee-for-service, and other strategies. The IBHPC will work with ValueOptions to make the individual funding streams as flexible as possible within federal or state constraints. • Monies from the following agencies will be braided for child services: the Human Services Department, the Department of Health, and the Children, Youth and Families Department (which includes children's mental health, child welfare, and juvenile justice). • The behavioral health service package will include services previously covered under New Mexico's Medicaid plan (e.g., out-patient services, case management, residential treatment, and in-patient care) and the enhanced services offered under the state's Medicaid managed care program (e.g., behavioral health respite, intensive out-patient services, multisystemic therapy, functional family therapy, and wraparound services).
<p>Lessons Learned</p> <ul style="list-style-type: none"> • New Mexico's statewide behavioral health care system was created by the twin forces of visionary political leadership and the widespread perception of an inadequate public mental health service system. • New Mexico did not implement a HCBS for two reasons: The state did not think it could show budget neutrality, and its overall goal was to re-design the entire behavioral health system rather than to implement incremental changes that would affect a limited number of individuals.

Discussions with officials in these two states also indicated the following:

- The statewide reform efforts were spurred, at least in part, by emerging crises in the mental health system in each state: New Jersey's system was heavily dependent on in-patient and residential treatment beds, with high costs and poor outcomes. In New Mexico, there was widespread dissatisfaction with, and

evidence of deterioration in, the public mental health system with implication of behavioral health Medicaid managed care.

- Reform efforts were initiated and then supported by top levels of government (either the governor's office or the legislature or both).
- Political support for system re-design, including support from family members, led directly to expanding financial resources for home and community services and the infrastructure necessary for major changes to occur.
- Extensive collaboration among key agencies was necessary for the research, planning, and development efforts required to ensure that funds from key child-serving agencies could be: (1) combined or otherwise coordinated to give care managers flexibility in developing ISPs; and (2) managed in a way that would support a continuum of care in which intensive home and community services could be used to improve outcomes.
- Both states planned and instituted reforms to restructure their entire mental health system for children in order to provide a continuum of care for all children with mental health needs--not just those with the most severe conditions in specific areas of the state.

B. INCREMENTAL REFORMS

When comprehensive statewide reform was not politically or financially feasible, other states addressed the problem of a less-than-adequate child mental health system incrementally, implementing specific aspects of a larger program over time. Most of the states with HCBS waivers took this approach. Each has several programs that aim to support intensive home or community services for youth with SED, resulting in wide variation in the services available across different counties or different groups of children within a state. The summaries in Appendix B illustrate this pattern. This section describes the incremental approaches taken by three states: New York, Indiana, and Vermont. Appendix B includes additional information on Kansas and Wisconsin.

New York. New York (see New York exhibit and Appendix B) has had a Medicaid HCBS waiver for about ten years that now serves approximately 1,700 children with SED in 40 of the state's 57 counties and the five boroughs of New York City. Even with the waiver, however, funding strategies in the state vary widely at the county level:

- In some counties, for instance, the waiver is the only vehicle through which some youth with SED can become eligible for Medicaid and gain access to intensive HCBS because counties do not have the resources for providing intensive service through other sources.

- In other counties, children with SED have access to intensive services either through the waiver or through other community-based programs and supports funded by: (1) state re-investment dollars; (2) resources pooled from the Office of Mental Health (OMH), Medicaid, and the local Department of Social Services; and (3) a SAMHSA grant. In these counties, the HCBS waiver supplements, rather than defines, the intensive services available to children with SED.

NEW YORK
<p>Policy Context</p> <ul style="list-style-type: none"> • County departments of mental health and social service play a key role in service delivery because counties provide half of the nonfederal Medicaid match and are required by state law to develop plans for mental health services. • In the mid-1990s, the state instituted the Coordinated Children's Services Initiative (an interagency coordination effort that functions at the state, county, and local levels) to support localities in creating systems of care to ensure that children at risk for residential placement remain in the home and community. • The Medicaid rehabilitation and clinic options provide some out-patient mental health services but not intensive community-based services for children with SED.
<p>Characteristics of the HCBS Waiver</p> <ul style="list-style-type: none"> • A Medicaid HCBS waiver was implemented in 1996, allowing the state to: (1) finance an expanded array of intensive community-based services; (2) lift requirements for applying parental income to otherwise eligible children (known as "deeming"); (3) waive statewideness requirements; and (4) control exposure to rapid increases in Medicaid expenditures by limiting the number of waiver-enrolled children. • In 2003, New York spent \$25.6 million on services (including medical care) for waiver-enrolled children, and in 2005 expects to serve approximately 1,700 children in 40 counties and the boroughs of New York City. • Waiver services are organized and, in some cases, provided by Individualized Care Coordination agencies, which are paid either on a fee-for-service basis or through a case-rate for bundled packages of services.
<p>A County Level Program</p> <ul style="list-style-type: none"> • Kids Oneida, a designated CME for a high-risk population of youth, serves about 200 children. <ul style="list-style-type: none"> – Developed in part through a MHSPY grant from the Robert Wood Johnson Foundation, Kids Oneida offers services similar to those available through the HCBS waiver. – Oneida County pays Kids Oneida \$2,550 per child per month via a blend of state (65 percent) and local (35 percent) funds and Medicaid pays a monthly case-rate of \$1,225 for each Medicaid eligible enrollee.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • Given the different mechanisms used by the state's counties, New York State reflects the diversity of approaches found in the nation as a whole. • Legislation promoting individualized service planning and interagency collaboration has enhanced the effectiveness of HCBS waivers and other efforts to finance intensive home and community services. • The ability to waive parental deeming and statewideness requirements was useful for New York State during the initial implementation of the HCBS waiver. • New York continues to face challenges in managing admissions to residential treatment facilities for children with SED because counties must pay some of the costs for intensive community services but none of the costs of residential care; consequently, counties have a strong financial incentive to place youth with SED in residential settings.

- Still other counties have sophisticated systems of financing. For example, rather than enrolling children with SED into the HCBS waiver, Oneida County uses a managed care model that is based on case rates and depends also on fiscal collaboration among county departments of social service and mental health. Kids Oneida is a nonprofit CME that has negotiated with the county to receive a case-rate of \$2,550 per child per month to provide about 200 children with a flexible, individualized set of services similar to those provided under the HCBS waiver. In addition, the state Medicaid program pays Kids Oneida a monthly case-rate of \$1,225 for each Medicaid-eligible enrolled child.
- Some counties have no special financing initiatives for children with SED.

New York's experience illustrates the challenge of aligning county and state financing in a county-structured state. For instance, when youth with SED cannot enroll in the waiver (i.e., when counties do not participate in the HCBS waiver program or when all waiver slots are filled), counties have a strong financial incentive to admit these children to residential care because the state covers the entire portion of the Medicaid match for residential services whereas the counties have to pay a portion of the Medicaid match for community services.

Indiana. Like New York, Indiana has used a variety of mechanisms to fund intensive home and community services for youth with SED (see Indiana exhibit and Appendix B). In addition to an HCBS waiver, the state uses the Medicaid rehabilitation option and state-funded awards grants of about \$50,000 per year for up to two years to 32 single and multicounty sites (covering about half of its 92 counties) specifically to develop system-of-care programs. In state fiscal year 2005, these sites reported serving 993 children. The funds supporting these programs pay for an individualized, wraparound approach to service planning and provide counties with some flexible monies to support specific services. These dollars, however, are not derived from redirecting existing monies currently being spent on residential care, suggesting that the state has provided modest support for new community services but has not implemented a strategy for reducing and re-deploying dollars spent on residential care. In fact, as noted below, the number of the state's residential beds is increasing.

Indiana's experience provides insight into two important financing issues: legal pressures to expand the number of residential beds and the challenges of implementing innovative projects statewide. The first issue is related to a class-action lawsuit that was filed in the late 1990s on behalf of parents who had to relinquish custody of their Medicaid-enrolled children in order to obtain residential treatment services because the state's Medicaid program did not cover services provided to children in PRTFs unless the children were wards of the state. In January 2004, Indiana lost the lawsuit, forcing it to cover, through Medicaid, services provided to children in PRTFs under the auspices of mental health agencies. This change contributed to an increase in the total number of PRTF beds for children in the state. As of early 2005, 11 PRTFs had a total bed capacity of 150, but state staff expect this number to rise as new PRTFs are completed. This increase will add to the existing beds in residential facilities operated under the

auspices of juvenile justice and child welfare. Indiana’s counties pay the full amount of the state match of federal Medicaid dollars for PRTF services, and most use their child welfare dollars to do so.

INDIANA
<p>Policy Context</p> <ul style="list-style-type: none"> • The state has covered mental health services for Medicaid-enrolled children through the Medicaid rehabilitation option since 1994. • Indiana’s 31 private nonprofit CMHCs have authority over admissions to the state’s approximately 90 beds for children and adolescents in six public psychiatric hospitals, but do not manage admission to PRTFs. • Two federally funded projects were launched in 1997, the Dawn Project in Marion County and Circle Around Families in Lake County, but both projects now are sustained by state and local resources. • In 2005, the state awarded system-of-care grants (about \$50,000 per year for up to two years) to 32 single and multicounty sites, covering about half of Indiana’s 92 counties and serving 993 children.
<p>Characteristics of the HCBS Waiver</p> <ul style="list-style-type: none"> • In its first year, Indiana expected to fill 50 slots distributed across ten counties varying in their experience with system-of-care programs, but only 20 children were enrolled in the first 15 months of operation. • According to state officials, enrollment in the waiver program has been slower than expected primarily because of administrative barriers, such as difficulties with a management information system and delays in processing waiver applications at CMHCs.
<p>A County Level Program</p> <ul style="list-style-type: none"> • The Dawn Project in Marion County (which includes Indianapolis) is a case-rate project for high-risk youth managed by a designated CME, serving more than 1,000 youth and families since its inception in 1997. • The Dawn Project contracts with Indiana Behavioral Health Choices (Choices), a nonprofit entity, to manage children’s clinical and financial processes and to monitor outcomes. • For children referred by child welfare or juvenile court who are at risk of entering or who are in residential care, the Dawn Project charges a case-rate of \$4,379 per child per month to provide a wide array of services and supports and a case-rate of \$1,809 for children identified by Indianapolis public schools (which does not include residential services). • For Medicaid-eligible children, the project bills Medicaid directly for services covered through Medicaid. Medicaid does not contribute directly to the case-rate.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • Developing and implementing the HCBS waiver has required a substantial amount of administrative effort. • Court orders led to programmatic decisions that were inconsistent with expanding intensive community services, underscoring the need for statewide consensus on appropriate future directions for the child mental health system. • Adding dollars for additional community-based services without restructuring management of residential treatment may have limited effect in achieving overall system reform.

The historical absence of Medicaid coverage for treatment services in PRTFs also meant that Medicaid expenditures for residential care were minimal in the 1990s and early 2000s. As a result, there was no financial incentive within Medicaid to develop community services because these services would not reduce Medicaid expenditures

on residential care. In short, there was no “business case” to be made for diverting Medicaid dollars from residential care to community services, as there is now.

The second financing issue--developing a county-based financing program and attempting to apply it statewide--is exemplified by the Dawn Project, a designated CME operating in Marion County (Indianapolis), similar in design to Kids Oneida and Wraparound Milwaukee. The project negotiated case-rates with child welfare, juvenile justice, and special education that cover intensive home and community services for children with SED and their families. Although the project has been a good learning experience for state and county level mental health authorities, several factors have limited the state’s ability to expand this model statewide:

1. Mental health services are planned and organized largely at the county level; as a result, county level factors (such as leadership, population density, and service accessibility) play important roles in shaping mental health services.
2. Most counties have little experience in managed behavioral health care technologies, such as utilization management and risk-based financing, and as a result do not have the experiential foundation necessary to replicate the Dawn Project.
3. In theory, because counties are at risk for the Medicaid match for placements in residential facilities, they should have an incentive to develop Dawn-like projects and participate in the waiver program. However, according to state officials, officials in some counties believe that the number of youth with SED in their county who are at risk for placement in residential care is not sufficient to justify the costs of establishing a Dawn-like system-of-care.
4. The viability of an integrated services program depends on sustained coordination among key county agencies, which can be difficult to achieve because of the agencies’ different missions and funding streams.

Vermont. Vermont is a third state that has taken the route of incremental reform. In Vermont’s case, however, the incremental reforms have added up to a comprehensive statewide system-of-care, in part because the number of children with SED is low compared with many other states and in part because state officials have been working aggressively on reforms for almost a quarter of a century (see Vermont exhibit and Appendix B). In contrast to New Jersey and New Mexico, which have initiated comprehensive reforms statewide in a relatively short period, Vermont has achieved the same end by using a variety of financing strategies over a long period.

VERMONT
<p>Policy Context</p> <ul style="list-style-type: none"> • Vermont has built a comprehensive system-of-care for children with SED, using a variety of financing mechanisms including: <ul style="list-style-type: none"> – A Medicaid HCBS waiver. – TEFRA provisions. – An expanded Medicaid rehabilitation option. – State legislation mandating interagency collaboration. – Active management of access to residential settings. • Vermont has been working actively to enhance services for youth with SED since 1982, when it received its HCBS waiver.
<p>Characteristics of the HCBS Waiver</p> <ul style="list-style-type: none"> • Approximately 140 children were enrolled in Vermont’s HCBS waiver in 2004, with an average enrollment duration of 14 months. • Total Medicaid funding for services provided to waiver-enrolled children was capped at \$3,212,100 in 2003. • To ensure that services are coordinated for any child with an SED, CMHCs develop IPCs in collaboration with the parent, schools, pediatricians, and other key stakeholders, as mandated under state legislation. • Each IPC specifies a budget for treatment (typically \$100-\$200 per day depending on the needs of the child, with an average of \$156 in 2004) and identifies the fiscal responsibilities of key agencies: mental health, special education, and child welfare. <ul style="list-style-type: none"> – If a child under the custody of the child welfare system is placed on the HCBS waiver, child welfare will pay for designated services, billing Medicaid for the portion of services covered under the waiver provisions. – In recent years the Department of Education has substantially reduced its financial support for mental health services by discouraging the inclusion of mental health services in IEPs. • The state uses the dollars contributed by child welfare and other agencies as part of the state Medicaid match.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • Although the state uses numerous funding mechanisms to pay for intensive home and community services, state officials view the HCBS waiver as an essential component of the overall financing system. • The IPC process, and the fact that final authority over placement decisions resides with the Department of Mental Health, ensures that access to residential and in-patient care is closely monitored.

In 1982, Vermont applied for and received a Medicaid HCBS waiver. This small, but important, component of the state’s mental health system for children with SED allows it to provide these children with intensive services beyond those available in the standard Medicaid benefit package. In doing so, the waiver allows Vermont to manage the costs of care for high-need children by helping it to avoid costly institutional level placements. The waiver also allows the state to serve children who would not otherwise be Medicaid eligible because parental income is usually applied to children for purposes of determining eligibility (a process known as “deeming”). Other key financing strategies in Vermont include the following:

1. By passing Act 264 in 1988--which mandated interagency collaboration and parental involvement at all levels of decision-making--Vermont enhanced support for the coordination and planning of community-based services. The goal of this

effort was to ensure that families of children with SED would be provided with an IPC that was developed and coordinated by teams of mental health, special education, and child welfare staff and family members and that specified which agencies would pay for which services in the IPC.

2. By expanding the Medicaid rehabilitation option in the mid 1990s, the state made other services available, such as targeted case management.
3. By using the Katie Beckett provision in the TEFRA, the state was able to provide services for some children with SED whose families had incomes above the Medicaid criteria and who did not meet clinical criteria for the waiver.
4. By increasing eligibility for Medicaid to 300 percent of the federal poverty level, the state ensured that all but a very few children had health coverage.

The product of Vermont's multifaceted and aggressive use of financing alternatives is a comprehensive, flexible mental health care system for children with SED.

C. CONTEMPLATING FUTURE REFORMS

The feasibility studies conducted by Illinois, Maryland, Mississippi, Missouri, and Texas indicate that these states are seriously contemplating an HCBS waiver to finance reforms to their mental health system for children. Each of the states used its grant dollars for somewhat different purposes, but collectively, their efforts tell a great deal about how change begins and where it leads in the ever-evolving landscape of the child mental health system. For instance, discussions with officials in the five states that received grants from CMS to study the feasibility of developing an application for an HCBS waiver provide fresh insight into the key financing issues that emerge as states work to improve the financing of intensive home and community services.

In most states, assessing the feasibility of an HCBS waiver application entailed an examination of a state's overall system-of-care for youth with SED. Some states saw the act of developing an application for an HCBS waiver for youth with SED not only as a contribution to their ongoing efforts to enhance the child mental health service system but also as a vehicle to encourage collaboration among child-serving agencies, thus making the somewhat disparate missions and funding streams of these agencies more congruent with one another. Many grantees used their funds to build on work already underway through interagency committees or as a result of state laws requiring them to improve their systems of care for youth with SED. In addition, most grantees used the funds to support studies of the factors that must be considered in the service expansion process, including defining provider case-rates, determining the number of children with mental health service needs, and identifying needed services.

Maryland, for example, actually applied for an HCBS waiver in the 1990s and was denied because the state used residential facility expenditures rather than expenditures

for care in psychiatric hospitals in its cost-neutrality calculations. In its continuing efforts to build support for intensive home and community services, the state is using its CMS feasibility grant dollars to develop actuarially sound case-rates and build support for a pilot wraparound program that it plans to launch in two locations (see Maryland exhibit and Appendix C), which would re-direct Medicaid dollars now spent on residential treatment to local CMEs to provide individualized, intensive home and community services and supports. A committee is working on convincing child welfare and juvenile justice agencies that a wraparound program could reduce their direct costs by reducing stays in residential facilities, detention centers, and foster care. These agencies, however, have little incentive to support such a program because as long as a Medicaid-enrolled child is in a residential facility, they are not obligated to cover the cost of care, which is paid for by the state mental health department or Medicaid.

Missouri passed legislation in 2003 and 2004 to address the problem posed by a policy that forces parents to relinquish custody of their children in order to gain access to mental health treatment. The bill paved the way for the state to both increase interagency collaboration and obtain a CMS grant for a feasibility study. The study addressed the question of how to expand access to mental health services and supports so that parents would not have to turn to the child welfare system for help (see the Missouri exhibit and Appendix C). Through the study, the state found that in 2003, about 600 children were in state custody for no reason other than that was the only means through which their parents could secure mental health care for them, and that the total annual cost in 2002 for such children was about \$43,000 per child. The study presented a series of five alternatives to providing these children with mental health services (see Appendix C), including a Medicaid HCBS waiver. The state has submitted an application for an HCBS waiver and is in the process of developing a new data system that should support efforts to implement a comprehensive system-of-care.

Several challenges were common to the states with feasibility studies:

- Determining the unmet need for intensive community services (see the summaries for Illinois and Missouri in Appendix C).
- Gathering the information needed to estimate the costs of certain services, or to calculate case-rates for a given service package or population, or both (see Appendix C, Texas and Maryland).
- Strengthening the interagency support needed to better align funding and services in general and working with juvenile justice agencies and juvenile court judges in particular to increase awareness of community alternatives to residential care (Appendix C, Missouri and Mississippi).
- Finding the most appropriate way to perform the cost-neutrality calculations required for an HCBS waiver application (Appendix C, Maryland and Mississippi).

MARYLAND
<p>Policy Context</p> <ul style="list-style-type: none"> • In 1997, Maryland's Mental Hygiene Administration (MHA) organized an application for an HCBS waiver for youth with SED, but the application was denied because the state had used RTCs rather than psychiatric hospitals or in-patient facilities as the basis for establishing cost neutrality. • The MHA has developed a plan for implementing a wraparound model in which designated entities would be paid a standard case-rate for managing services for selected children, providing a broad range of home and community services as alternatives to residential treatment, and would assume risk for all mental health service costs. <ul style="list-style-type: none"> – The plan will be piloted in Baltimore City and Montgomery County. – The average length of enrollment is expected to range from 16 to 18 months and cost \$4,500-\$5,000 per child per month. • The state has submitted an amendment to its existing 1115 waiver to implement locally-based CMEs supported by a flexible case-rate and is awaiting CMS' decision.
<p>Feasibility Study Goals and Challenges</p> <ul style="list-style-type: none"> • The state used funds from the CMS grant to: <ul style="list-style-type: none"> – Subcontract with a university to conduct actuarial analyses to determine the costs of RTC placements and the number of youth in these settings to inform development of specific case-rates for the pilot program. – Explore how wraparound concepts and case-rate strategies can be applied in two localities by consulting with the directors of other similar programs. – Convene an expert panel to assist leaders of RTCs in gaining the technical expertise and perspectives needed to develop intensive community services as additional product lines. • The state recognizes the challenge of persuading other agencies to participate in the wraparound program and hopes that that social service and juvenile justice agencies will contribute dollars to fund the program because they are responsible for two-thirds of children with SED in residential settings. • The MHA also is beginning discussions with the state Department of Education to investigate whether improvements in community-based care will affect the use of nonpublic day school programs for youth with SED.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • Finding a mechanism acceptable to state and federal Medicaid agencies to support community-based services can be time-consuming even when a detailed plan is available. • Prudent arguments for strengthening home and community services involve re-directing existing funds rather than projecting substantial cost savings. • Braided funding is an effective way to garner financial support for a wraparound program because it allows each agency to retain some control over its dollars.

Based on the results of their feasibility studies, four of the five grantees are actively exploring the next steps needed to submit an application for an HCBS waiver for youth with SED. Like the states that already have these waivers, these states view the waivers as one component in the larger service system and as a conduit to an incremental service expansion in which costs are shared with the Federal Government.

MISSOURI
<p>Policy Context</p> <ul style="list-style-type: none"> • Legislation passed in 2003 and 2004 required the child welfare agency to identify children in state custody solely because of mental health needs, and develop a plan for each child in conjunction with other appropriate agencies and the family. • The individualized plans, indicating which agencies will provide and pay for services, must be approved by a juvenile court, after which children return to their families. • Based on an interagency financing agreement, the department of mental health bills the child welfare agency for the cost of services as specified in the plan. • The legislation also: <ul style="list-style-type: none"> – Waived the state's standard means test for Medicaid eligibility for children in need of mental health services to avoid custody transfers; and – Authorizes the department of mental health, in partnership with key stakeholders, to establish a management team to develop a comprehensive, coordinated children's mental health service system.
<p>Feasibility Study Goals</p> <ul style="list-style-type: none"> • The study's central question was how to expand access to mental health services and supports in order to prevent parents from having to turn to the child welfare system for help. • The grant allowed the state to: <ul style="list-style-type: none"> – Identify characteristics of children with SED in state custody exclusively because they need mental health services; and – Estimate the extent and nature of current Medicaid, mental health, and child welfare expenditures for these children, and determine the cost of providing mental health services for these children in the community.
<p>Selected Findings from Feasibility Study</p> <ul style="list-style-type: none"> • In calendar year 2003, approximately 600 children were in state custody solely for the purpose of accessing mental health services; total annual costs of providing care to these children were approximately \$43,000 per child in 2002. • On the basis of study findings, the contractor identified five options open to Missouri in terms of what it could do to improve its mental health system.
<p>Lessons Learned</p> <ul style="list-style-type: none"> • New state laws to prevent custody relinquishment and coordinate mental health services helped to lay the groundwork for a process of planning for service system reforms. • To finance community services for children with SED who did not qualify for Medicaid, Missouri applied for a Section 1915(c) HCBS waiver because it will allow the state to control Medicaid expenses while providing mental health services to children who, until now, have not been served adequately and whose families have had to relinquish custody to access services.

D. SUMMARY

The findings in this chapter illustrate the diversity of mechanisms that states are using to pay for intensive home and community services for youth with SED. This variation is a function not only of the mosaic of funding sources and financing mechanisms available to them, but also of the many historical, legislative, and experiential factors that are unique to any given state. Despite this variation, four themes are common across the states.

First, legislative or budgetary action has been an important impetus for interagency collaboration around planning, financing, and program development.

Although legislation alone is neither necessary nor sufficient for garnering financial support for intensive home and community services for youth with SED, it can certainly move a state in the right direction by establishing expectations and goals, removing barriers to collaboration, and, in some cases, providing new dollars to build the infrastructure necessary to sustain these services. Some of this money has come from diversion dollars, re-investment funds, or tobacco settlement monies.

Second, extremely tight budgets have made states reluctant to add services to their Medicaid plans for fear that they will substantially raise expenditures, and current federal priorities are not favorable for expanding coverage of services for youth with SED. At this point in time, few states appear to be considering seriously an expansion of the Medicaid rehabilitation option to cover intensive services for these children, although many have taken this step in the past.

Third, system-of-care demonstration projects gave states useful experience in the financing of intensive home and community services. Although many of these demonstration projects did not continue after federal funding ended, some states (e.g., Kansas, Indiana, Mississippi, Maryland, Texas, and Wisconsin) indicated that the projects were critical to developing technical experience in: (1) funding and managing community services; and (2) fostering the interagency collaboration that underpins a flexible and comprehensive set of services for youth with SED. In fact, states with these projects typically created coordinated systems-of-care in selected locations, which, in some states, helped build the administrative support for a waiver application.

Fourth, states and counties that carefully manage access to residential treatment services and psychiatric hospitals tend to have more resources for intensive home and community services. Careful management of access to residential care is important for a variety of reasons. The evidence supporting the effectiveness of residential treatment is poor (Frensch and Cameron 2002; Joshi and Rosenberg 1997; Weiner et al. 2001) and managing access to residential placements avoids both the high cost of such care, as well as the problems that occur when children return to their families without appropriate transition and family support services. In fact, much of the initial success of Wraparound Milwaukee resulted from re-directing child welfare, juvenile justice, and Medicaid funds from residential care to intensive home and community services (Kamradt and Connolly 2003).

Discussions with state officials indicated that establishing a statewide gate-keeping system for managing admissions and lengths of stay in residential treatment depends on several factors including:

- The use of standard assessments that are strength-based, culturally competent, and family focused to inform service planning.
- The availability of community services that provide an effective alternative to residential care.

- The extent of collaboration among key agencies, which ensures service continuity and prevents a child from “cycling” from one agency to the next.
- Financial incentives that favor HCBS over residential placement.
- Recognition on the part of juvenile court judges, child welfare case workers, providers and families that intensive home and community services are effective alternatives to residential care.

IV. STRENGTHS AND WEAKNESSES OF SELECTED FINANCING MECHANISMS

In addition to documenting the financing issues specific to each state, the discussions with state officials provided general information on the states' experience with the following four financing mechanisms: HCBS waivers, the Medicaid rehabilitation option, case-rates used by designated CMEs, and the Katie Becket provision of TEFRA. This chapter examines the strengths and weaknesses of each of these mechanisms (Table IV.1). As noted in Chapter II, states also have other Medicaid financing options (for example, the EPSDT program, Section 1115 waivers and Section 1915(b) waivers), but these are not covered again in this chapter.

A. HCBS WAIVERS

According to state officials, HCBS waivers offer five benefits. First, in allowing states to circumvent restrictions on the type, amount, duration, and scope of Medicaid services, the waivers permit states to provide selected individuals and their families with a set of specialized intensive HCBS that would not otherwise be covered by any other financing mechanism. These services include wraparound facilitation, respite care, parent support, daily living skills, and other services (see Table IV.2).

Second, HCBS waivers allow states to lift requirements for applying parental income to children, thereby providing access to medical and mental health services for youth who might not otherwise meet the Medicaid financial eligibility criteria. These services include not only the specialized intensive services covered under the waiver, but also all other services offered in the state's standard Medicaid plan. This feature of the waiver is especially valuable for children in low or moderate-income families in which one or both parents work but whose employer-based insurance has very restrictive mental health benefits or none at all, as well as for parents of children with serious disorders who exhaust their private insurance coverage. Lifting these requirements also allows children with SED who enroll in an HCBS waiver to obtain services without having to be wards of the state, so parents no longer have to relinquish custody of their children to obtain services for them.⁵

Third, HCBS waivers remove the "statewideness" requirement for standard Medicaid services, thereby allowing states to roll out waiver services county by county as resources and experience allow. As a practical matter, most states have designated a certain number of slots that will be open under the waiver and established mechanisms for determining which counties or localities can enroll children in the waiver. For example, New York makes 610 total slots available, and has allotted a

⁵ Having an HCBS waiver, however, does not automatically mean that a state does not also have problems with custody relinquishment because waivers typically serve very small numbers of children, and waiver eligibility criteria does not automatically include children whose need for treatment exceeds parental resources.

certain number of slots to 40 of its 57 counties and to all the boroughs in New York City. Overall, this translates into a total of about 1,700 children served annually because many children are enrolled in the waiver for only part of a year. Other states, such as Vermont, have capped waiver expenditures, allowing IPCs to be developed for as many children as possible, provided that total expenditures for all plans do not exceed the limit.

TABLE IV.1: Advantages and Disadvantages of Four Financing Mechanisms for Supporting Intensive Home and Community Services for Youth with SED		
Funding Mechanism	Advantages	Disadvantages
HCBS waiver	<p>Allows states to provide intensive services not covered in state plan</p> <p>Waives parental deeming requirements</p> <p>Waives statewideness requirements</p> <p>Promotes increase in number of providers offering intensive HCBS</p> <p>Gives states experience in pricing intensive services and individual care plans</p>	<p>Does not support preventive or “step-down” services</p> <p>Substantial administrative effort for a relatively small number of youth</p> <p>Application development and waiver implementation can be challenging</p> <p>Does little to re-align funding across agencies and may introduce disincentives for sharing costs for community services</p> <p>Does little to reduce geographic disparities within states</p>
Expanding Medicaid rehabilitation option	<p>Offers states opportunities to include certain types of intensive home and community-based mental health services into state plan coverage</p> <p>Are available to entire eligible Medicaid population, not just subsets</p>	<p>Risks increasing state Medicaid expenditures if rehabilitative services are used heavily and poorly managed</p>
Case-rates used by designated CMEs for high risk populations	<p>Allows state and local agencies to negotiate payment rates for specific high-risk populations</p> <p>Provides a mechanism for states to combine funding from different agencies to cover integrated, individualized plans of care</p> <p>Permits monitoring of plan performance and quality of care</p>	<p>Requires experience in managed care technologies and financing models</p> <p>Requires a sufficient case load to support a feasible economy of scale and risk management</p>
TEFRA (Katie Beckett provision)	<p>Waives rules requiring application of parental income to determination of Medicaid eligibility for children who meet SSA’s disability definition, meet certain clinical criteria, and need an institutional level of care</p>	<p>A sharply limited number of children with SED qualify for this provision</p> <p>Expands Medicaid eligibility, thus posing potential cost issues</p> <p>Does not expand types of home and community services covered</p>

Waiver Services	Indiana	Kansas	New York	Vermont	Wisconsin
Case management, wraparound facilitation, individualized care coordination	✓	✓	✓		✓
Respite care	✓	✓	✓	✓	✓
Parent/family/home education, support and training, including financial management counseling	✓	✓	✓	✓	✓
Daily living skills, independent skills training	✓	✓	✓		✓
Community and social supports and crisis intervention, response			✓	✓	✓
Environmental modification and specialized transportation				✓	✓
Adaptive equipment				✓	✓
Therapeutic foster care				✓	✓
Day habilitation and supported employment services					✓
Counseling and therapeutic services					✓
Intensive in-home autism treatment					✓
Intensive in-home services			✓		
SOURCE: State applications for a Medicaid 1915(c) HCBS waiver.					

Fourth, in some states, the HCBS waivers have contributed to an increase in the number of organizations that provide intensive home or community services, such as respite care or family-to-family support. For these organizations, predictable access to clients and reimbursements brings economies of scale that can sustain them over time and, in turn, make intensive home and community services more available.

Finally, the states with HCBS waivers have gained considerable experience in pricing intensive home and community services. For example, several states have contracted with family organizations for the delivery of various kinds of family support programs and services. Appendix E provides examples of the cost of these and other services provided through the waivers. An examination of the actuarial implications of these costs was beyond the scope of this study, but additional study of states' collective experience in developing costs estimates for specific home and community services could be a useful resource for states working to expand coverage of these services.

Although HCBS waivers help states to support intensive home and community services for selected youth with SED, they also have several disadvantages. Overall, state officials cited six disadvantages of the HCBS waivers.

First, HCBS waivers for youth with SED are focused on treatment services for high-risk or high-need children, and as a result do not allow states to support services that would prevent children from moving into a high-risk category. Nor does the basic

Medicaid plan in many states cover services for these children. The result is a gap in coverage for children whose problems are not serious enough either to qualify for the waiver or to be addressed through Medicaid.

Second, building the administrative support necessary to develop and implement a waiver requires substantial administrative effort that results in coverage for a relatively small number of children. For example, Indiana (see Chapter III) found that it had to provide substantial guidance to county level personnel in the use of software that enrolls and tracks waiver enrollees. The combination of too few computers and field workers who had relatively little experience with a new software package contributed to lower enrollment rates than anticipated. During the first 15 months of operation, the waiver enrolled only 20 children.

Third, HCBS waivers alone do little to align funding practices and financial incentives in a way that would make home and community services for children with SED more widely available. For instance, although the waivers have brought state Medicaid and mental health agencies together in the effort to strengthen coverage for intensive home and community services for youth with SED who need a hospital level of care, they do not directly affect financing practices in other agencies, such as child welfare, that often cover residential services for the majority of youth with SED, nor do the waivers currently allow for alternatives to residential treatment. If child welfare and juvenile justice agencies are not financially motivated to support home or community services, then the HCBS waiver itself will be a somewhat isolated effort that affects only a small proportion of the target population. Indeed, that has been the case in all of the current waiver states. Discussions with state officials suggest that HCBS waivers have the most impact when states also have passed legislation compelling child-serving agencies to enhance collaboration and align their missions and funding streams to jointly support the financing of intensive home and community services.

Fourth, in states where counties play a major role in financing services for youth with SED, the HCBS waiver can introduce or reinforce a financial disincentive to support home or community services. For example, if counties must contribute to the state Medicaid match for waiver services but not for residential care, they are more likely to place youth with SED in residential settings than to link them with community services because it will be less expensive for the counties to do so even though it will be more expensive for the state. The same rationale holds for counties in which state child welfare agencies pay for the majority of residential care for youth with SED. For these counties, it is likely to be financially advantageous to pay for residential care through Title IV-E funds rather than to contribute a portion of the state Medicaid match for waiver services.

Fifth, the HCBS waivers may do little to reduce a state's geographic disparities in access to mental health services and the fragmentation of the mental health system. For example, not all counties in New York State can enroll children with SED in the waiver even though it has been in existence for about a decade. Although the rationale for waiving statewideness may be reasonable in the early stages of waiver

implementation (i.e., so states can gain experience with the waiver before expanding it more broadly), states may be slow to broaden access to all of its jurisdictions because of cost concerns.

Finally, children who improve enough to disenroll from a waiver are likely to need some continuing treatment services. Unless the state provides an effective continuum of services, most of which would not be covered under an HCBS waiver, maintaining the benefits of waiver services can be challenging. Many program administrators who have implemented an HCBS waiver underscore the importance of viewing the waiver as one part of a larger, continuing effort to strengthen the child mental health service system and improve interagency collaboration overall.

B. MEDICAID REHABILITATION OPTION

Because federal regulations give states wide latitude in defining the type, scope, and delivery site for services covered under this option, the services covered under the Medicaid rehabilitation option vary widely from state to state (see Chapter II, Table II.2). For example, states offer services such as assessment, in-home services, school-based services, behavioral management skills training, and crisis intervention. Depending on the state, services may be covered under this option if they are provided either in the child's residence, school, or other community institution. This flexibility is very useful to states because it allows them to cover a number of intensive home and community services that are particularly important for youth with SED and their families.

Despite the flexibility offered by the rehabilitation option, several officials see the expansion of the option as financially risky. Offering the services is potentially expensive because these services are needed and sought after by families, and because they would be available to all categorically eligible beneficiaries, not just to high-need children; consequently, the rise in utilization could increase state Medicaid expenditures substantially.

C. CASE-RATES USED BY DESIGNATED CARE MANAGEMENT ENTITIES FOR HIGH-RISK POPULATIONS

States, counties and other local jurisdictions in several of the study states have developed approaches that specifically serve youth with SED using managed care technologies and risk-based financing. These approaches provide a case-rate to a designated CME to provide a flexible, individualized array of services and supports and intensive care management for youth with SED and their families, giving the CME wide latitude in individualizing care in return for meeting specified outcomes. These include Wraparound Milwaukee in Wisconsin, the Dawn Project in Indiana, and Kids Oneida in New York. New Jersey's CMOs are also modeled on this approach, but they do not involve risk-based financing currently. Other states like Maryland are exploring similar alternatives. These approaches seek to achieve better cost and quality outcomes by

providing an alternative to placement of youth in residential treatment. Referrals to these programs typically come from juvenile justice, child welfare, and education agencies, which contribute to the case-rate for each child. Thus, comprehensive services for children enrolled in these programs are paid for by multiple child-serving agencies and delivered in a coordinated and efficient manner by designated CMEs. Moreover, CMEs are usually under contract to report specific performance measures to the states as a means for tracking quality of care. Because of these contractual agreements, CMEs typically aim to provide only those services that have demonstrated effectiveness.

The successful application of managed care principles to services for youth with SED has several advantages, including comprehensive service coordination; careful tracking of service utilization, quality, and costs; and accurate monitoring of performance and outcomes. However, this approach also has several disadvantages. First, it requires expertise in financial management, organizational development, clinical supervision, and data systems--a set of skills that can be developed in many state and local agencies only through substantial training and technical support.

Second, even states with experience in the use of case-rates to pay for services for youth with SED in selected counties may find it difficult to expand the arrangement statewide. Again, the financial and experiential resources needed to broadly implement even a well-tested program take time to develop at a local level.

D. THE TEFRA PROVISION

As noted in Chapter II, the Katie Beckett provision in TEFRA allows states to waive the requirement for considering parental income in the process of determining Medicaid eligibility for children with disabilities under 18 years old who are living at home but would otherwise be eligible for Medicaid-funded institutional care. The strength of this provision lies in the fact that it extends Medicaid eligibility to children who would not normally have access to Medicaid services and who are likely to have no or inadequate coverage for mental health services.

However, the provision is restrictive in that it requires states to determine that: (1) the child has a disability as defined by the SSA disability definition; (2) the child requires the level of care provided in an institution; (3) home care is appropriate; and (4) the cost of home care is no more than the cost of institutional care. For children with SED, documentation of a disability that meets SSA standards can be particularly difficult. As of 2002, 20 states had a TEFRA option, but of these, only ten included children with SED (Bazelon Center for Mental Health Law 2002).⁶ In 2001, in nine of these ten states (all except Vermont), the percentage of children with SED was less than 21 percent of all children enrolled in Medicaid through this TEFRA provision, amounting to less than 2,500 children with SED across all ten states (Bazelon Center for Mental Health Law

⁶ Alaska, Arkansas, Delaware, Maine, Minnesota, Mississippi, New Hampshire, Vermont, West Virginia, and Wisconsin.

2002). In addition, TEFRA does not expand coverage of home and community services; rather, it expands eligibility to a state's existing Medicaid benefit package.

V. SYNTHESIS AND IMPLICATIONS

Discussions with state officials indicate that policymakers in many states are committed to finding better ways to finance intensive home and community services for youth with SED and their families because the problem is urgent and legislative interest is high. Also, the evidence for the effectiveness of home and community services for this population is growing. In contrast, sustainable outcomes associated with residential treatment and other out-of-home placements have not been demonstrated and the costs of these interventions are high. The discussions also provide numerous examples of how states finance these services by combining various mechanisms--from cobbling together several Medicaid-based strategies (e.g., the HCBS waivers, the rehabilitation option, and the TEFRA provision) to broad statewide reforms of the child mental health system as a whole.

State officials' decisions regarding a suitable combination of financing mechanisms vary from state to state because of many factors, including differences in demographic variables, political leadership, financial resources, and availability of technical expertise. Discussions with state officials underscore the challenging political environments in most states because financial resources are sharply limited. In addition, developing a long-term commitment to collaboration between and among key state departments, county agencies, private sector providers, family members, and other key stakeholders requires substantial administrative time and, in most instances, sustained leadership from the governor's office or the legislature.

Moreover, each individual financing mechanism has particular strengths and weaknesses, and no single mechanism alone can address the scope of challenges involved in paying for intensive home and community services for youth with SED. Although comprehensive statewide reforms, like the ones being implemented in New Jersey and New Mexico, promise fundamental improvements in child mental health services over a number of years, most states are approaching the task through incremental reforms because they tend to be more politically, financially, and technically feasible.

Overall, state officials have to balance a variety of issues as they decide what financing strategies are most suitable and sustainable given a state's resources and constraints. Discussions with state officials point to the following issues as critical in their decision-making process:

- ***Finding a process for re-directing expenditures away from residential treatment services and toward community alternatives, coupled with careful management of access to beds in both RTCs and in-patient psychiatric hospitals.*** Programs in Wisconsin, New York, and other states illustrate the financial benefits of ensuring that community services are both available to and used by all agencies that serve children in order to avoid unnecessary out-of-home placements and payments for services that have little

evidence of effectiveness. In sites such as Wraparound Milwaukee and Kids Oneida, traditional models of intervention, such as removing a child from the home, are no longer viewed by court judges or most mental health professionals as the treatment of choice for children with SED because other, evidence-based treatment options are available. The key challenge for states is to develop administrative and tracking mechanisms that shift the emphasis from paying for out-of-home placements to supporting a range of home and community services.

- ***Devising an administrative structure that supports equitable sharing of service costs among all or most state and local level agencies that serve children, including Medicaid, mental health, child welfare, juvenile justice, and education.*** Cost-sharing arrangements can be implemented at several levels. For example, at the local level, a designated agency can receive funds from multiple agencies to support services provided to selected children with SED. In some states, such as Vermont, legislation supports the development of individual care plans that specify which agency (mental health, child welfare, juvenile justice, or special education) will pay for which services. In still other states, local agency staff meet regularly to ensure that needed services are covered for designated children; these local teams can be supported by state level counterparts to find ways to pay for specialized services not otherwise covered (for example, the Coordinated Children's Services Initiative in New York).
- ***Developing financing strategies that promote flexibility in supporting IPCs.*** One of the major challenges in financing home and community services for youth with SED is paying for the particular combination of services that each individual requires. Because each funding source covers some needed services but not others, state officials in most states have to find different means for combining funding sources for each child depending on his or her needs. However, discussions with officials in some states (e.g., Indiana, New York, and Wisconsin) suggest that case-rates are especially useful in promoting flexibility in service planning. Case-rates mean that dollars can be used to purchase a wide range of individual, family, and community services to help the child reach specific outcomes.
- ***Establishing procedures that do not remove or dilute local or state responsibility for higher levels of care.*** Ideally, local agencies should arrange for the care of youth with SED who live in their jurisdiction. In many cases, this means that counties contribute to a share of the costs--to the state Medicaid match, for example. But policies that obligate counties to cover a portion of the costs for community or home services but not for residential care bring financial disincentives to improving access to community services. If county governments are asked to share responsibility for community services, it makes sense to ask them to share responsibility for residential care as well, but there is, understandably, often a great deal of political resistance from localities on this point.

- ***Providing children with SED access to intensive services even if their families are not Medicaid eligible.*** One of the principle advantages of the HCBS waivers is that they allow states to waive Medicaid’s deeming rules, as does the Katie Beckett provision in the TEFRA legislation. Several state officials emphasized the importance of this particular component of the waiver because it allows states to: (1) cover high-risk and uninsured or inadequately insured children who would not otherwise have access to mental health services; and (2) ensure that families do not have to relinquish custody of a child with SED solely to obtain intensive mental health services.
- ***Enhancing policy coordination among agencies and institutions that serve children.*** Discussions with state officials suggest that sustainable improvements in the financing of services for children with SED will not occur in the absence of a strong commitment to policy coordination by all key child-serving agencies and institutions. In many states, this commitment began and was sustained through legislation mandating interagency collaboration. In addition, efforts to engage the leadership of RTCs in discussions of new community-based models of care have increased at both the federal and state levels. In particular, officials in several of the states in this study have supported workshops and conferences with directors of residential settings to ensure that their perspectives are taken into account and that they are made aware of the rationale behind reform agendas as new financing strategies are developed and implemented.
- ***Finding providers of nontraditional services in areas where such providers are in short supply.*** Several directors noted a serious “Catch-22” in the development of comprehensive community service systems: States cannot pay for these services because there are no organizations to provide them, and the organizations do not exist because there is no money to support them. Building provider capacity appears to be one of the most difficult challenges facing state officials. Some officials indicated that, in theory, a part of the provider capacity problem could be addressed by re-training staff of RTCs and enlisting the cooperation of residential programs to diversify the type of services they offer, including home and community services. The clinical and administrative leaders of these facilities have considerable experience in treating children with SED; furthermore, in most states that are moving to home and community care, the number and bed capacity of residential facilities are likely to decrease as home and community services expand. The experienced staff who leave their positions as a result of this restructuring can act as a natural labor pool for states that can give these qualified individuals an opportunity to apply their skills in a community setting.

The findings from this study have three major implications for policymakers concerned with improving mental health services to youth with SED.

First, sustained improvements in financing intensive home and community services for youth with SED depend on the development of effective partnerships between key agencies at the state and local levels. The state descriptions in Appendix A, Appendix B, and Appendix C provide substantial evidence that the financing of these services is more effective when agencies work together in new ways.

In some cases, the key partnership was between the state mental health department and the Medicaid agency. Medicaid programs in every state now pay for a considerable portion of mental health services for children, especially for youth with SED, but mental health agencies have the experience necessary to manage clinical care, certify providers, and assess service quality. The resources of both agencies are therefore needed to support initiatives that provide appropriate and cost-effective services. Child welfare, juvenile justice and education agencies also are critical partners, because they control many behavioral health resources and serve the majority of children needing mental health services and supports.

The descriptions of the states in the appendices include numerous examples of initiatives--often mandated by state legislation--that bring these different agencies together on behalf of youth with SED. Because the same children are often served by several agencies, interagency coordination makes fiscal sense; from a state perspective, however, the challenge is to ensure that the process of collaboration does not threaten the budget of any single agency but leads instead to an equitable distribution of financial responsibility across the agencies. From a federal perspective, the challenge is to ensure that legislation that may directly affect one system or one funding source (for example, Medicaid) does not unintentionally create barriers to interagency agreements at the state level.

The second implication involves the impact of prior demonstration projects funded under the original CASSP program, the current Comprehensive Community Mental Health Services for Children and Their Families Program, or other foundation-sponsored initiatives. These efforts spawned demonstration projects in virtually every state, and officials in most of the study states noted that the roots of current initiatives often lay in the experience gained during the implementation and operation of these projects. In many cases, individuals who were involved in early projects moved into leadership roles in subsequent initiatives. This observation suggests that the demonstration projects authorized by the 2005 Deficit Reduction Act (Public Law 109-171) will provide important opportunities not only to strengthen the financing of community services for youth with SED in selected states but also to develop a new generation of leaders whose experience can have enduring effects on the field.

Finally, the study findings suggest that more states would be interested in applying for an HCBS waiver for youth with SED if the criteria for documenting budget neutrality were linked to PRTFs rather than to psychiatric hospitalization alone. In most states, very few children now enter psychiatric hospitals, and even fewer stay for long periods of time. Because most states are spending comparatively little on psychiatric hospitalization for children, they will not save many dollars, if any, by substituting

intensive home or community-based services for treatment in these hospitals. Rather, the savings for state and federal Medicaid agencies will come from decreasing current use of residential treatment facilities by replacing that treatment with effective and less costly home and community care, which could be available to enhance home and community services for youth with SED.

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GLOSSARY

TERM	DEFINITION
Administrative Services Organization (ASO)	An entity that contracts with a state or other purchaser to provide designated administrative services, such as billing or utilization tracking
Blended Funding	The process of integrating funds from different sources (e.g., Medicaid and block grant monies) to enhance flexibility in supporting an individualized set of services for designated patients
Braided Funding	The process of combining funds from different sources to support an individualized set of services so that expenditures from each source can be tracked and applied to specific individuals eligible for that funding
Capitation Rate	A fixed amount of money paid per person for covered services for a specific time; usually expressed in “per member per month” units
Care (Case) Management	Procedures and processes used by trained service providers or a designated entity to assist children and families in accessing and coordinating services
Case-Rate	A fixed amount of money paid per person to allow a provider or designated entity to pay for covered services needed by that person; rates are typically based on diagnoses of persons who present for services and expressed as monthly amounts
Cost (Budget) Neutrality	Refers to the requirement that if a State applies for Medicaid waivers under sections 1115, 1915(b) and/or 1915(c), they must demonstrate that the program does not exceed what the federal government would have spent without approving the waiver; states can do this by showing that the average per capita expenditure estimated by the state in any fiscal year for medical assistance provided with respect to the group affected by the waiver does not exceed 100 percent of the average per capita expenditure that the state reasonably estimates would have been made in that fiscal year for expenditures under the state plan for such individuals if the waiver had not been granted

TERM	DEFINITION
Cost Shifting	The practice of obtaining care for a child at the expense of another party or agency
Level of Care Criteria	Guidelines employed to assist in the determining the appropriate setting and intensity of behavioral health treatment
Psychiatric Rehabilitation Option	An optional Medicaid service that can include (depending on state definitions) community support programs, school-based services, crisis intervention services, and out-patient psychotherapy services
Purchasing Collaborative	A collaborative behavioral health services model that brings all agencies tasked with the delivery, funding or oversight of behavioral healthcare services together to create a single behavioral health service delivery system
Section 1115 Research & Demonstration Projects	This section of Title XIX of the Social Security Act (SSA) provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program
Section 1915(b) Managed Care/Freedom of Choice Waivers	This section of Title XIX of the SSA provides the Secretary authority to grant waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid
Section 1915(c) Home and Community-Based Services Waivers	This section of Title XIX of the SSA provides the Secretary authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings
Title IV-E Demonstration Waiver	This title of the SSA provides states with an opportunity to design and test a wide range of approaches to improve and reform child welfare by waiving certain requirements; general objectives of the waivers include the development of family-focused, strengths-based, community-based service delivery networks that enhance the child-rearing abilities of families to enable them to remain safely together when possible or to move children quickly to permanent settings

NOTE: Definitions are adapted from Armstrong et al. (2006).

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PDF Files Available for This Report

Main Report <http://aspe.hhs.gov/daltcp/reports/2006/youthSED.pdf>

Appendices <http://aspe.hhs.gov/daltcp/reports/2006/youthSED-A.pdf>

APPENDIX A: States with Comprehensive Statewide Reforms

APPENDIX B: States with Home and Community-Based Service Waivers

APPENDIX C: States with a CMS Grant for a Feasibility Study and Development
Project for Community-Based Treatment Alternatives for Children with SED

APPENDIX D: Values and Principles Supporting the Systems of Care Approach

APPENDIX E: Cost of Services Provided Through HCBS Waivers

This full report and links are also available in **HTML** format at:

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