EVALUATING THE NEED FOR HOME-BASED SERVICES FOR CHILDREN

Prepared by the Center for Public Representation
December 2005

I. Introduction

Tens of thousands of children across the country are being denied medically necessary, behavioral health treatment that would enable them to receive services and supports at home and in their own communities, instead of in psychiatric hospitals and residential facilities. As a result, they are stuck in these facilities, displaced from their homes, and left without the treatment they need to avoid an endless cycle of institutionalization.

Intensive home-based services, sometimes referred to as wraparound services, constitute a well-established behavioral health intervention for children – an intervention designed to meet children's needs in their birth, foster or adoptive homes, or in the communities where they live.[1] The planning and provision of intensive home and community-based services require a specific, individualized process that focuses on the strengths and needs of the child and the importance of the family in supporting the child. Intensive home-based services incorporate several discrete clinical interventions, including, at a minimum, comprehensive strength-based assessments, crisis services, case management, clinical teams, and individualized supports including behavioral specialists.

Many states, such as Rhode Island, Wisconsin and Pennsylvania, have demonstrated that intensive home-based services effectively addresses the needs of children with serious behavioral health needs. Across the nation, home-based programs have generated significant cost savings as a result of decreased utilization of more restrictive and expensive services, such as inpatient hospitalization, residential treatment programs, out-of-home placement and repeated reliance on emergency services.

Federal agencies have promoted intensive home-based and wraparound programs. Through the Substance Abuse and Mental Health Services Administration (SAMHSA), the federal government is now funding sixty-seven home-based programs in forty-three states. It has commissioned a comprehensive evaluation of these systems of care, which has generated comprehensive and detailed reports on the structure, characteristics,

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[1] For a bibliography of the professional literature on home-based services, including a description of each service and the data on its effectiveness, *see* Appendix A to CPR's September 2005 QA, *Using Medicaid to Obtain Intensive-Home Based Services for Children with Serious Emotional Disturbance,* available on NRDN's website. These articles also describe the children who can benefit from these services and the risk to them of not receiving necessary treatment.

clinical effectiveness, client outcomes, and organizational challenges of these programs. *See* http://www.mentalhealth.samhsa.gov/publicatons/Publications_browse.asp?ID=14&Topic=Children+and+Families; *see also* http:/www.orcmacro.com.

Federal Medicaid legislation entitles children across the Nation to medically necessary mental health treatment. Under Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate, all states must screen children, diagnose physical and mental conditions found through a screen, and furnish appropriate medically necessary treatment to correct or ameliorate illnesses and conditions. 42 U.S.C. §§ 1396d(a), 1396d(r)(5). Home-based services are mandated under EPSDT for children, and are properly described as case management or rehabilitative services within the scope of the Medicaid Act. 42 U.S.C. § 1396d(a)(13).

Demonstrating the critical unmet need for intensive home-based services is a challenging undertaking. But it is the factual foundation for enforcing, either through litigation, legislation, or public policy advocacy, children's entitlement to medically necessary treatment. This Fact Sheet explores several strategies and investigation techniques for establishing this foundation, drawing upon experience in Massachusetts and other states that have conducted comprehensive analyzes of the unmet need for intensive home-based services.

II. The Children's Mental Health Crisis

An estimated 6,000,000 children suffer from emotional disabilities or serious emotional disturbance. *See* Mental Health: A Report of the Surgeon General, Rockville MD: U.S. Department of Health and Human Services (1999)[Surgeon General's Report]. Approximately 286,000 of these children are detained in psychiatric facilities, 66,000 in congregate care settings, and hundreds of thousands more living at home with inadequate services.[2] At any given time, tens of thousands of children are needlessly "stuck" in hospitals and other facilities – children who are clinically stable and ready to move to less restrictive settings, but are forced to remain institutionalized due to a lack of available community and home-based programs.[3]

The children's mental health crisis is a national problem that has drawn the attention of parents, clinical professionals, school districts and public officials in almost every state. Federal officials report that one in five American children has a mental disorder, and that five to ten percent of them have a serious emotional disturbance that impairs their functioning in everyday life. *See* Surgeon General's Report. Despite these alarming statistics, up to 80 percent of children with behavioral disorders do not receive needed treatment. *Id.* As The New York Times has reported, "there are yawning gaps in

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[2] *See* Annie E. Casey Foundation, "Latest Findings in Children's Mental Health (2003),

[3] In Massachusetts alone, there are well over a thousand children stuck in hospitals and residential facilities.

the treatment of mental illness among the nation's children." *See* "Children Trapped by Mental Illness," New York Times, July 9, 2001 at A-1.

Federal and state officials have long acknowledged that there is a children's mental health crisis. Administrators recognize that youths who no longer need acute treatment are held for extensive periods of time in facilities because there are no less restrictive community-based programs. Conversely, children in crisis are "boarded" in hospital emergency rooms and pediatric wards because limited psychiatric hospital beds are full. Not only are there no open beds for children in crisis, but there often are no home-based programs to address crisis situations before hospitalization is the only recourse.

Researchers, clinical personnel, mental health professionals and advocates continue to document the need and the demand for expanded mental health services for children and adolescents. *See* Surgeon General's Report; Appendix A to CPR's September 2005 QA. Newspapers across the country have reported on the "stuck" children and adolescents in psychiatric crisis who are hospitalized, stabilized, and then trapped in the facility due to the lack of home-based treatment programs.

It is estimated that hundreds of thousands of Medicaid-eligible children with serious emotional, behavioral or psychiatric disabilities need, but are not provided, intensive home-based mental health services.[4] *See* Surgeon General's Report; President's New Freedom Commission on Mental Health, <u>Achieving the Promise: Transforming Mental Health Care in America, Report of the Subcommittee on Children.</u> As a result, children – some as young as four – are confined inappropriately in psychiatric facilities and residential programs. If they had access to intensive home-based services, many of them could remain in their homes, attend their local schools and grow up in their own communities.

Many children with serious emotional disturbance often have been traumatized by pre-natal problems, abuse, exposure to violence, separation from their families, and/or multiple placements. *See* articles listed in Appendix A to CPR's September QA. Experts and advocates maintain that children do better in families when those families are provided with home-based services, including enhanced care coordination and often, daily individual care for the child and guidance for caregivers. *See* September QA, pp. 2-5. Residential care and out-of-home placement can be avoided when a multi-disciplinary, family-inclusive team implements integrated and intensive services at home and in the community. *Id.*

These children and their families require specialized intensive services of long duration, designed specifically to help them recover from trauma and/or debilitating emotional disorders and to assist their caretakers in managing their trauma-related aggression and depression. These are known to be some of the highest risk Medicaid-eligible children, both because their symptoms usually increase when they change

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[4] In Massachusetts, state officials estimate that this number could be as high as 15,000.

placement and the skills of their families and foster parents are taxed by their challenging behaviors.

The failure to provide comprehensive and medically necessary intensive home-based treatment and support services to children with serious emotional disturbance exacts a great cost to both the affected youth and society at large. While some children are inappropriately detained in hospitals, others are shuttled to residential centers instead of more beneficial – and less costly – community programs. Still others are left at home without adequate supports, all but assuring eventual hospitalization.

There is no strong evidence that their complex needs are met in residential treatment. On the contrary, their behaviors tend to worsen when they live in groups and are harmed by: (a) separation from people to whom they are attached; (b) not living in a family and participating in the normalizing experience of a community school; and (c) the uncertainty of having no permanent home.

III. The National Response to the Children's Mental Health Crisis

During the last quarter century, the federal government has begun to encourage development of more community-based alternatives, and in particular, interventions for children with serious emotional disorders. These children and their families require specialized intensive services of long duration designed to help them recover from trauma and/or debilitating emotional disorders, and to assist their caretakers in managing their trauma-related aggression and depression.

Seminal events and certain federal initiatives, dating back more than three decades, prompted many states to shift from a primary reliance on institutional and residential services to home-based services for children with serious emotional disturbance.

In 1969, the Joint Commission on Mental Health of Children concluded that services for children were seriously inadequate. Only a fraction of those in need were being served. Treatment consisted of office-based psychotherapy or play therapy and residential placement when that failed.

The Children's Defense Fund in 1982 published Jane Knitzer's ground-breaking policy report, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of the Mental Health Services*, which cited children's limited access to care and ineffective care in restrictive settings, and reported that fewer than half of the states assigned a staff member to direct children's mental health services.

The Child and Adolescent Services System Program (CASSP) was formed at the National Institute of Mental Health in 1983 to build integrated systems of care. Grants

were awarded to states that were willing to reorganize their service delivery systems and facilitate the development of interagency and community collaboration.

A few years later, the Robert Wood Johnson Foundation initiated Mental Health Services Program for Youth (MHSPY) to extend CASSP in supported states. MHSPY infused clinical services into system development. MHSPY sites increased understanding about provisions of clinical care in the community in the context of wraparound. MHSPY programs, such as Wraparound Milwaukee, the Dawn Project in Indiana, and the Massachusetts MHSPY program have become national models of integrated care.

In 1992, Congress authorized the Comprehensive Community Mental Health Services for Children and Their Families Program, which remains the largest federal program to date. It supports 90 home and community-based programs. The CASSP philosophy and values (i.e., family-centered individualized care, less restrictive settings, and culturally competent services) thrive in these home and community-based and integrated service systems. A more recent feature requires new sites to implement selected evidence-based interventions. In addition, specific evidence-based treatments for youth with SED are being tested experimentally in a number of sites.

The Surgeon General's Report on Mental Health, issued by the U.S. Department of Health and Human Services in 1999, communicated a hopeful message to the field: It is possible to address the clinical needs of youth with SED. There is strong evidence for diagnosis-specific treatment, including psychosocial, psychopharmacological, and comprehensive home-based interventions for this population.

In 2003, the President's New Freedom Commission on Mental Health Subcommittee on Children and Family outlined nine standards for children's mental health, with home and community-based care heading the list:

- HOME AND COMMUNITY-BASED CARE – Children belong in their homes and in their communities and every effort should be made to keep them there and to return them from institutional to home and community settings.
- FAMILY PARTNERSHIPS – The family is the most important and life long resource in a child's life, as well as being legally and morally responsible for a child.
- COMPREHENSIVE SERVICES AND SUPPORTS – A broad array of services and supports should be available to children and their families, responding to issues that are biological, neurological, psychological, and social.
- CULTURAL COMPETENCE – Services and systems should be responsive to the cultural perspectives and racial, ethnic, cultural and linguistic characteristics of the diverse populations served.
- INDIVIDUALIZED CARE – Services should be individualized to each child and family, guided by a comprehensive, single plan of care for each child and family, that addresses strengths, as well as problems and needs.

- EVIDENCE-BASED PRACTICES – When state-of-the-art, evidence-based interventions are available, families should be informed of them, and these interventions should be made available to children and families.
- COORDINATION – Services and systems should be coordinated at the service delivery level, and the agencies and programs that serve children should be linked with those serving adults.
- EARLY IDENTIFICATION AND INTERVENTION – Services and supports should emphasize early identification and intervention, as well as prevention of mental health problems, to maximize the likelihood of positive outcomes.
- ACCOUNTABILITY – There should be a clear point of responsibility and accountability for children's mental health care at all levels.

The nine standards are critical to the effectiveness, coherency, and accessibility of intensive home-based programs. The Subcommittee, however, acknowledged a need to realign current spending to achieve such standards. In this vein, the Subcommittee proffered the following recommendation: "Develop a plan for Medicaid to support home and community-based services and supports and individualized care."

A few states currently offer the full array of integrated home-based services and have demonstrated that these systems effectively addresses the needs of SED children. These services consistently have reduced institutional placements for children and adolescents and established effective community supports upon discharge. A brief description of four of these model programs is the subject of a separate QA (December 2005), that is available on NDRN's website.

The federal Medicaid program covers most home-based services. According to an actuarial analysis by Mercer, Inc., approximately 80 percent of the behavioral health home-based services provided by MHSPY are covered by Medicaid and eligible for Federal Financial Participation (FFP). The "uncovered" services primarily involve respite, summer camp and other non-therapeutic recreational activities, room and board in residential placement, and incidental non-medical costs paid to ensure the stability of the family home and environment, such as rent.

Case management and care coordination are central elements of home-based services. Most home-based services are state plan services mandated under EPSDT for children, and are properly described as case management or rehabilitative services within the scope of 42 U.S.C. § 1396d(a)(13) or (19). Specific home-based services – including assessment, case management, mobile crisis services, clinical coordination and treatment, and behavioral specialists – are all covered by Medicaid as part of the EPSDT benefit. 42 U.S.C. §`1396d(a)(13), (19); *see* September QA, pp. 5-6.

Although Medicaid has funded home and community-based services for many years, many states have not uniformly made these services available in their Medicaid programs or through EPSDT benefits. These states do not provide home and community-based services statewide to Medicaid-eligible children, consistent with the nine standards

in the President's Commission's Report. *See* Bazelon Center for Mental Health Law, Making the Most of Medicaid (1999).

IV. Evaluating the Need for Intensive Home-based Services

A few states have conducted comprehensive analyzes of the need for intensive home-based services and developed plans to develop a system of care, with intensive home-based services at the core of that system, on a statewide level. *See* New Jersey's System of Care Initiative; Delivering and Financing Children's Behavioral Health Services in Connecticut: A Report to the Connecticut General Assembly by the Department of Social Services (February 2000).[5] But the vast majority of the states have either failed to take any steps to implement these services, or limited them to local pilot programs. *See* http://www.mentalhealth.samhsa.gov/publicatons/Publications_ browse. asp?ID=14&Topic =Children+and+Families; *see also* http:/www.orcmacro.com. P&As, in collaboration with children and family advocacy organizations[6] as well as professional and provider associations, can play a critical role in documenting the need for intensive home-based services and the substantial gaps in covered services in their states.

While these needs assessments and service system gaps can take many forms, there are three components that should be considered: (1) an assessment of what services currently exist, and whether these services satisfy the nine standards for coherent home-based programs; (2) an assessment of the treatment histories and clinical needs of children; and (3) an analysis of current expenditures on children's mental health services. Through careful planning and coordination, these three components can justify a dramatic expansion of intensive home-based services.

In Massachusetts, as part of the discovery process in a class action lawsuit (*Rosie D. v. Romney)* that sought to compel the Commonwealth to develop a statewide program of intensive home-based services, staff from the Center for Public Representation and a team of children's mental health experts conducted these assessments and generated extensive reports.[7] These reports describe what exists, what is missing, what it costs, and the consequences to children from these gaps. The remainder of this Fact Sheet reviews each of these studies, and suggests strategies for conducting similar assessments in your state.

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[5] A copy of the report is available from CPR or David Parrella, DSS. Contact pris.dawidowicz @po.state.ct.us.

[6] Many states have local chapters of the Federation for Children with Special Needs and the Parent Advocacy League (PAL), which are ready partners for this endeavor.

[7] The reports are available from the Center for Public Representation, info@cpr-ma.org.

A. Survey of Existing Mental Health Programs

Perhaps the most straightforward component of the evaluation is documenting the children's mental health services that currently exist and then determining which of these qualify as intensive home-based services. A starting point is the state's mental health plan, annually submitted to the Center for Mental Health Services (CMHS), a division of SAMHSA. These plans usually document the number of children served by the state mental health authority, the number and type of services available, as well as any innovative or pilot programs. In addition, the mental health and child welfare agencies' annual budget requests, managed care contracts, other reports to the legislature and state advisory councils, and public information about service utilization and expenditures are useful sources of information about available programs for children with SED.[8]

These documents provide the blueprint of what exists, but offer little guidance as to whether the existing programs provide intensive home-based services. This assessment usually requires interviews with key providers, clinicians, family advocacy groups, and university researchers familiar with the children's mental health service system in your state. A careful plan that samples these sources, based upon types of services offered (inpatient, crisis, outpatient, community support, and case management), geographical distribution, and the range of children's mental health needs, should provide ample information to determine how many children actually have access to intensive home-based services in your state.

1. Evaluation of existing services in Massachusetts

The *Rosie D.* review of existing services in Massachusetts had a three-prong focus: to determine the availability of, and access limitations on, home-based services in Massachusetts; to assess the impact of access limitations on providers such as hospitals, emergency services and residential programs where children get "stuck" due to the scarcity of home-based programs; and to understand the impact of access limitations on children and their families.

After meeting with executive directors, program administrators, and clinicians in providers across the state, Center staff and children's mental health experts concluded that home-based services for Medicaid-eligible children in Massachusetts are insufficient to meet their needs in several significant ways: limited geographical coverage, limited duration, limited intensity, limited capacity, lack of comprehensiveness, and omission of necessary services. For example, the survey of existing programs documented the following deficiencies:

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[8] All of these documents are public records and should be readily available from the relevant agencies or legislative committees. If necessary, P&As can make a freedom of information request to the agency, pursuant to state law.

a. Limited geographical coverage

The few intensive home-based services that do exist in Massachusetts are severely limited geographically. The five pilot programs that were created by the State in response to the *Rosie D.* lawsuit, and in the hope of avoiding a trial, are only available to children in five targeted cities. MHSPY is only available to children in five cities. If a SED child lives anywhere else in Massachusetts, home-based services of sufficient intensity are not available.

b. Limited duration

Typically, the one statewide, Medicaid-funded program (Family Stabilization Team [FST]) is limited to an average of six weeks. FST is considered completed when the child has stabilized and the family has community supports, even if the child and family still require home-based services.

c. Lack of intensity

Many children discharged from residential programs and psychiatric hospitals, and children for whom home-based services could prevent residential and psychiatric hospital placement and disruption in foster homes, require daily in-home support. Their families require daily guidance. FST is typically limited to 8-10 hours a week and other programs are even less intensive.

d. Limited capacity

The five pilot programs only serve a total of 250 children. MHSPY only can serve 70 children. All of these intensive home-based programs have formal waitlists of 10-20 children per program, but informal waitlists of several hundred children who need, but cannot access, these services.

e. Lack of comprehensiveness of services

The comprehensiveness necessary to meet the complex needs of SED children requires both: (a) integrating services so that they operate with the same plan developed with the family; and (b) the capacity to provide services tailored to meet the child's needs and build on the family's strengths, regardless of whether needed services are regularly available in the community.

MHSPY is the only comprehensive program in the state that meets these two criteria. MHSPY has integrated services and can provide services directly that are missing in the community. MHSPY provides clinical services, including in-home individual and family therapy and behavioral specialists. MHSPY can arrange for other non-clinical services and supports as well as clinical services. MHSPY has no limit on duration of services, direct access to all medical and behavioral health services, no

limitation on flexible funds, and broader eligibility criteria than the new pilot programs. The vast majority of MHSPY's services and costs are covered by Medicaid.

f. Failure to provide necessary components of home-based services

Massachusetts fails altogether to include behavior specialists and behavior aides as covered services in its Medicaid program or through its MCOs, even though many SED children have challenging behaviors that require this support. Other states have created Medicaid-funded, intensive home-based services with carefully selected, trained and supervised paraprofessionals providing 1:1 coaching and behavior training for the child, which makes it possible for the child to participate in regular educational, recreational, and other constructive activities.

g. Reliance on residential services

In Massachusetts, the stuck kids problem has been framed in such a narrow way that many children are in residential programs who could be more effectively served with intensive home-based services, including support to help families and foster families manage traumatized SED children. Lacking comprehensive home-based services, Massachusetts relies on residential services that are based on the incorrect assumption that SED children cannot be effectively served in birth, foster or adoptive homes.

B. Survey of the Needs of Children

Needs assessments can be undertaken with widely different processes, depending upon the purpose of the review, available resources, and the methodological sophistication required to persuade a particular audience. It can involve as basic a process as anecdotal reports collected from families by an advocacy organization to a full-scale academic research project. Between these polarities, agencies often examine a small sample of clients and determine what services are provided and what supports appear to be needed. This sample approach can involve as few as five and as many as a hundred individuals, depending on the purpose and sampling precision required. However, twenty to forty cases are sufficient for most purposes. For each child, it is useful to review records from current and prior providers, treatment plans, and education plans (IEP), and then conduct a brief interview with the family to determine the adequacy – and usually the inadequacy – of current services. While it is helpful to have children's mental health professionals involved in the review, knowledgeable advocates can do much of the analysis, organize the process, and support the professionals.

1. Evaluation of Children in Massachusetts

Because it was clear that the *Rosie D.* evaluation would be challenged in court, we had to conduct a statistically-reliable sampling process by qualified experts.[9] As a result, we engaged four children's mental health clinicians, assisted by a child psychiatrist, to conduct an analysis of 43 Medicaid-eligible children who live in Massachusetts and have behavioral health needs. The children's names were drawn from a sample of Medicaid-eligible children and adolescents who had received behavioral health services in prior years from the Medicaid behavioral health carve-out entity. The sample focused on the most needy children in the system – those who had been hospitalized, needed emergency services, or residential placement. The youth, who ranged in age from 6 to 20, consented through their parents and/or guardians to participate in the sample.

The purpose of the clinical review was to examine and analyze the history, mental health treatment needs and the services received by the 43 individuals, with a particular focus on their need for intensive home-based services. The experts examined the children's current mental health treatment needs, as well as other significant time period(s) when they had mental health needs. The primary question was to form an opinion, if possible, as to whether the child now needs or has needed intensive home-based treatment services at a significant point in his or her life.

The experts conducted on-site reviews over the course of a week. They met with the children, their parents or guardians, and at least one clinician for each individual child In some cases, they contacted additional care providers to gather more information about the children. Upon completion of all of the individual client assessments, each expert reviewer summarized her findings and opinions about each assigned child. Their findings are contained in individual reports. The reviewers collectively found that: .

1. Most of the children in the sample need home-based services that include comprehensive assessments, case management, flexible crisis services, clinical supports and team coordination, and, often behavioral therapy and aides.

2. More than 95% of the children needed intensive home-based services in the past, and that more than 70% need these services now, either to remain at home or to facilitate their placement with a family.

3. Nearly all of the children in the sample have serious, complex and chronic mental illnesses or disabilities with needs that are not being met now and cannot be met in the future by discrete short-term services from unconnected service providers.

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[9] The following description of the Massachusetts review was dictated by the demands of litigation and should not have to be replicated in other states, where the needs assessment are used to support policy or legislative advocacy.

4. Most children in the sample have multiple diagnoses, including thought disorders, major depression, post traumatic stress disorder, bipolar disorder, psychosis, attention deficit/hyperactivity disorder, severe communication and sensory integration disorder, autism spectrum disorder, mental retardation, and eating disorders.

5. Most of the children have taken multiple psychiatric medications over time. Many have been taking four or more medications at the same time. Such complexity is further evidence of the need for both sophisticated diagnostic services that provide an accurate, comprehensive and consistent understanding of the child, and set forth intensive, long-term treatment services that are driven by that understanding.

6. Most of the services for children in the sample were traditional outpatient services and were not flexible with respect to their frequency, intensity, location or duration. For some children, simply moving the provision of such traditional services into their homes would probably help make the services more responsive to their individual needs.

7. Time-limited individual therapy and/or psychiatric medication are not effective in addressing such severe, long-term and complex conditions and problems. To be effective, services for these children must continue over time, and must be provided with sufficient frequency, duration and intensity to have any real impact on the functioning of these children.

8. All of these children need more assistance than their families, school, medication and weekly therapy can provide. The extent and complexity of the children's needs overwhelm them and the people they live with – natural families, foster families or group home staff. The children and their caregivers need access to daily assistance and hands-on guidance and support where they live, go to school, work and play.

9. Many of the children in the sample have serious and persistent behavioral issues that require a behavior plan and an in-home behavioral aide to implement the plan on a consistent basis, to coordinate with other providers to ensure consistency, and to teach the family how to respond to behavior problems. Without such services, many of these children may not be able to remain at home, succeed at school and avoid institutional placement.

10. Every case in the sample demonstrates an absence of the essential element of functional, effective case management that "takes the reins" for needs assessment, service planning, monitoring and advocacy to ensure that the child gets what he or she needs.

11. Case management is the key to another essential element of effective services for children in this sample – "integration" of services across all settings

and domains of the child's life. Integration is especially important because over time, many different adults, service providers and even public agencies are likely to control or be involved in various aspects of the child's life.

12. For all of the children, it is critical to have a team that includes the family, a case manager, and relevant providers to plan, coordinate, integrate, monitor, and ensure delivery of needed services on a long-term basis.

13. Many of the children were harmed from the disruption of removing them from their homes, even when it is necessary to protect them, and then compounded by moving them from placement to placement.

The review concluded that intensive home-based services would make a tremendous difference for him and his family. The provision of intensive home-based services wherever a child is living helps to prevent removal from the home by building on the strengths and capabilities of the child and those caring for him. Such flexible, intensive, individualized services, which are driven by a commitment to shape services to fit the child rather than an attempt to fit the child into a pre-existing service model, are what virtually every child in the sample needs – and what very few of them are getting or have gotten in the past.

C. Evaluation of Children's Mental Health Expenditures

Although home-based programs differ across the Nation, they have demonstrated significant success and generated significant cost savings, as a result of decreased utilization of more restrictive and expensive services such as inpatient hospitalization, residential treatment programs, out-of-home placement and repeated reliance on emergency services.

A fiscal analysis of the state's mental health program expenditures for children's services is a relatively straightforward undertaking that can be done using state agency budget and contract data, plus Medicaid expenditures. While this information may initially seem complicated and even daunting to assess, most of the basic costs for children's mental health services can be found in a few sources. The fiscal officer from a large provider or a former state budget analyst can be of invaluable assistance, and they usually are quite willing to cooperate.

The fiscal analysis first should attempt to identify the state's expenditures on inpatient and residential services for children. The former is usually covered by Medicaid and can be gleaned from Medicaid claims data.[10] The latter is usually funded

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[10] Medicaid claims data is not readily available, but usually can be obtained under state public records statutes. However, because of the enormous volume of this electronic information and the complexity of computer codes, P&As may want to seek expert assistance in requesting and analyzing this data.

by state mental health, child welfare, and sometimes juvenile justice agencies. Financial data on residential expenditures is generally available from state budget requests and agency reports.[11] The total cost of inpatient and residential services represents the amount the state is currently investing in segregated services. Medicaid and program experts generally agree that at least 20% of these costs can be saved if intensive home-based and wraparound programs are available statewide. *See* Report of Carl Valentine in *Rosie D,* available from CPR. Moreover, this is a conservative estimate, based upon the experiences of these programs in several states, and the dramatic reduction in out of home placements generated by intensive home-based services. These savings are then available to finance the development or expansion of home-based services.

1. The Massachusetts fiscal study

In *Rosie D.* a consultant prepared a fiscal analysis of home-based services: (1) to determine an average cost for providing home-based or wrap-around services that are eligible for federal reimbursement under Title XIX (Medicaid) for children requiring behavioral health services;[12] and (2) to describe potential funding strategies for establishing a statewide program in Massachusetts of home-based services using Medicaid.

The consultant engaged in an extensive review of budget data, reports, materials and documents from the state's Office of Medicaid, the state's Medicaid carve-out provider, communications to and from the federal Centers on Medicare and Medicaid, materials describing the MHSPY program and the state's recent home-based pilot program, executive and legislative reports, and other documents about home-based programs in other states. His analysis focused on services for seriously emotionally disturbed children and adolescents, and relied heavily on a detailed actuary study by the Commonwealth's own capitation rate expert, Mercer Inc.[13]

The fiscal review included a projected cost for providing intensive home-based services, based upon national data on similar programs serving similar needy children. For example, the Wraparound Milwaukee program funds a home-based services program that provides all necessary services at an annual cost in FY 2001 of $52,200 per child. This rate includes community care costs, inpatient psychiatric hospitalization, placement

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[11] State budget expenditures by agency, service type, and client utilization is also maintained in electronic form and usually requires expert assistance to obtain and review.

[12] The data and conclusions of this cost projection for intensive home-based services, and the portion covered by Medicaid, should be generally applicable to most states and need not be recalculated by experts in each state.

[13] Because the consultant's conclusions would be tested at trial, it was important that he conduct an exhaustive review of all relevant state expenditure data. Absent the demands of litigation, the fiscal analysis can be less rigorous than that undertaken in Massachusetts in the *Rosie D* case.

cost for residential treatment and administrative costs. If, as in MHSPY, 80 percent of the services are supported as Medicaid reimbursable behavioral health services, Wraparound Milwaukee's annual Medicaid-supported behavioral health services cost would be $41,760 per child per year, while the remaining 20 percent or $10,440 would not be Medicaid-reimbursable. A similar home-based program called Kids Oneida, operating in Oneida County, New York under a Medicaid 1115 Waiver, has a similar Medicaid-supported annual cost of $41,760 per child per year. This rate is supplemented with federal Title IV-E and Emergency Assistance funding for out-of-home care and with state /local prevention block grant funding for summer camp, community supervision, life coaching, supported independent living, and discretionary funds. New Jersey is developing a similar home-based program that provides all necessary behavioral health services with projected costs falling in a similar range of $50,000 to $60,000 per child per year.

The fiscal review concluded that Massachusetts could provide a comprehensive, intensive, and all-inclusive program of home-based services to needy children at an average annual cost of approximately $59,000 a child. Of this amount, approximately, $47,000 would be for Medicaid-covered services. Given the current rate for federal financial participation (FFP), approximately half of this Medicaid cost, or approximately $23,500, would be reimbursed by the federal government.

Based upon the experience of other states, serving children with home-based services, rather than more expensive and restrictive forms of care such as hospitalization and residential placement, is likely to generate significant cost savings. Based upon Massachusetts' own experience with MHSPY, the review concluded that these savings could well result in an average savings of $2,016 per month ($24,197 per bed/year) for each child currently served in out-of home placements who would be appropriate for home-based services.

Massachusetts is currently spending $22,000,000 just on unnecessary hospitalization in private facilities for a relatively small number of children. This figure does not include the cost of unnecessary hospitalization in public facilities, or unnecessary placement in expensive residential programs. The additional cost of these often unnecessary and potentially avoidable out-of-home placements is over $68,000,000.

Finally, the review found that if Massachusetts reinvested the resources that it currently spends on unnecessary hospitalization and residential placement, and used them for Medicaid-covered home-based services that could be funded in significant part with FFP, it would have more than $75,000,000 to reinvest in more cost efficient behavioral health services. These resources could be used to care for approximately 1,271 children in their homes and home communities with the current level of state funding.

V. Conclusion

Children with serious emotional disturbance clearly need, but in many states are not being offered, intensive home-based services. P&As can play a critical role in advocating for these services and convincing states to provide them. Whether through litigation, policy advocacy, or legislative and budget initiatives, P&As can help make the case for structural reform of the children's mental health services system. These efforts are best undertaken in collaboration with family and child advocacy organizations, as well as other professional partners. These efforts will require a showing of both a pressing unmet need and a realistic strategy for addressing that need. Such a showing can be made through a compelling presentation of the inadequacy of current services, the clinical unmet needs of children, and the money wasted on segregated and harmful out of home placements.