A Report on Home-Based Services for Children in Massachusetts with Serious Emotional Disturbance

Prepared by the Center for Public Representation October 2005

Executive Summary

Children across the Commonwealth are being denied comprehensive and medically necessary behavioral health treatment that would enable them to receive services and supports at home and in their own communities instead of 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. Massachusetts must act now, for to delay even a few more years will waste another child's life.

This report documents the findings and conclusions of nationally renowned experts who conducted studies that provided an analysis of the need for home-based services for children with psychiatric disabilities in Massachusetts. The studies included an assessment of existing home-based services, an evaluation of a sample of children with behavioral health needs, and a financial calculation of the cost of providing home-based services with half the cost being paid for by the federal government through the Medicaid program. Their findings are significant:

- More than 95 percent of the children with psychiatric disorders who were surveyed needed intensive home-based services in the past.
- More than 70 percent of the children need home-based services now to either remain at home or to facilitate their placement with a family.
- Massachusetts could shift up to \$66,000,000 a year from institutional placements to home-based services.
- By reallocating existing resources, Massachusetts could serve more than 1,000 children with comprehensive home-based services.
- The current behavioral health system for children and adolescents is fragmented and disjointed.
- Children with serious emotional disturbance throughout the state suffer harm because Massachusetts does not provide comprehensive and medically necessary home-based services.

An estimated 10,000 children in Massachusetts have emotional disabilities. Approximately 3000 are confined inappropriately in psychiatric facilities or congregate care settings, or totally denied access to services. During any given month, about 100 children are needlessly "stuck" in hospitals or facilities – children who are clinically stable and ready to move to less restrictive settings, but remain institutionalized due to a lack of community and home-based programs. Hundreds more are stuck in residential facilities, while thousands wait endlessly for services at home.

Federal Medicaid legislation entitles children in Massachusetts and 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)) 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.

Home and community-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. 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 and community-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 the full array of integrated 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.

Massachusetts' officials acknowledge the effectiveness of home and community-based programs. In fact, the state offers two models of organized service systems that provide home and community-based services. However, these pilot programs serve a total of 320 children in only 10 of the state's 351 cities and towns. Officials have not made these services uniformly available to children through the Medicaid program or through EPSDT benefits on a statewide basis.

The experts cited in this document are listed in the Introduction. Each of them filed an individual report in the fall of 2004. This document is a synthesis of their findings. But it is more than a summary of expert opinions, professional consensus, cost-saving proposals, a national trend: It is a call to action to save our kids, preserve our families, and maintain our communities. It is our best hope for effectively addressing the problem of stuck kids and for affording many of the neediest children in the Commonwealth a chance. We cannot deny them this chance.

Introduction

Thousands of Medicaid-eligible children in Massachusetts with serious emotional, behavioral or psychiatric disabilities are being denied medically necessary home-based mental health services. Children – some as young as six – are confined inappropriately in psychiatric facilities and residential programs. If they received intensive home-based behavioral services, many of them could remain in their homes, attend their local schools and grow up in their own communities.

An estimated 10,000 children in Massachusetts suffer from emotional disabilities. Approximately 3,000 of these children inappropriately are detained in psychiatric facilities, congregate care settings, or totally denied access to services. At any given time, up to 100 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.

At age 13, Julie's outlook was grim: "She expects life to be distressing with few rewards and considerable anguish," said her psychologist. Abused by her birth parents and abandoned by her adoptive parents, Julie (not her real name) suffered multiple hospitalizations and inappropriate foster placements. Despite significant losses and trauma, she received grossly inadequate mental health services that failed to address her clinical needs, including depression, post-traumatic stress disorder and reactive attachment disorder. By the time Julie was 15, her psychologist expressed concerns she had a borderline personality disorder, marked by emotional instability and hostility, and stated, "She fears abandonment although she often pushes others away." Added her school counselor, "She craves the intimacy of a family, but she is residentialized."

The failure to provide comprehensive and medically necessary home and community-based treatment and support services to children in Massachusetts 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.

Five years ago, the Center for Public Representation began developing an initiative to address this crisis in children's mental health. Staff met with behavioral health clinicians, program administrators, medical directors, mental health professionals, children's advocates, health care consultants and budget analysts in the Commonwealth and throughout the country. Staff reviewed federal and state laws and regulations governing health care, and investigated systems of care for children's behavioral health. They explored creative programs that have successfully addressed the emotional and

psychiatric needs of children in community – not institutional – settings. These included The Kaleidoscope Program in Chicago, Wraparound Milwaukee, and the Mental Health Services Program for Youth (MHSPY), a multi-state pilot with a program in Massachusetts, (MA-MHSPY).

The Center engaged nationally renowned experts who initiated three separate studies that, together, provide a comprehensive analysis of the need for intensive home-based services for children with psychiatric disabilities, and a strategy to address that need. These studies included an assessment of existing home-based services, an evaluation of a sample of children with behavioral health needs, and a financial calculation of the cost of a model for providing intensive home-based services as part of the state's Medicaid budget.

Federal Medicaid legislation entitles children in Massachusetts and across the country to medically necessary treatment, including mental health treatment. Children who are eligible for Medicaid are entitled to any federally authorized Medicaid service. Under Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate, all states must screen eligible children, diagnose conditions found through a screen, and furnish appropriate medically necessary treatment to correct or ameliorate defects and physical and mental illness and conditions discovered by the screening service (42 U.S.C. §1396d(a)).

The experts conducted extensive reviews of child and adolescent behavioral health services and programs throughout the Commonwealth, met face-to-face with a sample of children with behavioral needs in their homes, residential programs and hospitals, and interviewed their parents, guardians, and providers. They analyzed data and financial models. The experts found that the current behavioral health system for children and adolescents is fragmented and disjointed. Comprehensive and medically necessary home-based services are not being provided uniformly to children with serious emotional disturbance in Massachusetts. The experts recommended that Massachusetts adopt a statewide initiative that provides a comprehensive array of behavioral health supports, including intensive home-based services, through a program that is financed with Medicaid funds under EPSDT.

Home and community-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. 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 and community-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.

The experts, who included clinicians, community mental health professionals, a Medicaid fiscal analyst, a healthcare statistician, professors, and a child psychiatrist, filed extensive reports in the fall of 2004. This document is a synthesis of their findings. It is a clarion call to policy makers and public officials in Massachusetts to expand children's mental health services through a comprehensive array of intensive home-based services designed to treat and support the estimated 3000 children across the Commonwealth who desperately need services in their own home and communities.

In late 2001, attorneys from Wilmer Cutler Pickering Hale and Dorr, LLP, and the Mental Health Legal Advisors Committee joined the Center for Public Representation in filing a class action lawsuit charging Massachusetts officials with violating federal law by failing to provide intensive home and community-based services to Medicaid-eligible children with serious emotional disturbance. The case was tried in U.S. District Court in Springfield in the spring of 2005; a decision is expected in the fall of 2005.

The experts' findings, which are incorporated in this report, were introduced as evidence in connection with the class action lawsuit. Children – including the named plaintiffs – cited in the experts' reports and in the lawsuit, are covered under a protective order, and their names may not be published. In this document, pseudonyms replace children's names.

The experts whose individual reports are referenced throughout this document are:

- Marty Beyer, Ph.D., national child welfare and mental health consultant and licensed clinical psychologist;
- Barbara Burns, Ph.D., professor of medical psychology and director of the Services Effectiveness Research Program at the Department of Psychiatry and Behavioral Sciences at Duke University School of Medicine;
- James Greer, M.D., adult, adolescent and child psychiatrist at The Providence Center, Providence, R.I.;
- Bruce Kamradt, MSW, director of Wraparound Milwaukee and Safety Services for Milwaukee County, Wisconsin;
- David Nace, M.D., senior vice president, corporate medical director and chief clinical officer at United Health Group of United Behavioral Health;
- Carl Valentine, M.A., president of F.C. Valentine and Associates, a consulting firm with expertise in the design and financing of child and family services; and
- Marci White, MSW, former vice president for early childhood services at the Methodist Home for Children in Raleigh, N.C., and former Chief of the <u>Willie M.</u> Section of the North Carolina Department of Human Resources, Division of Mental Health, Developmental Disabilities and Substance Abuse Services.

The Children's Mental Health Crisis

The children's mental health crisis is not restricted to Massachusetts. It 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. Despite these alarming statistics, up to 80 percent of children with behavioral disorders do not receive needed treatment. As The New York Times has reported, "there are yawning gaps in the treatment of mental illness among the nation's children."

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. 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 community-based treatment programs. Children in crisis are "boarded" in hospital emergency rooms or pediatric wards, waiting for an open psychiatric bed, while "waitlisted" children remain at home, waiting for needed services.

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.

Contributors to the following section on the national response to the crisis are Dr. Barbara Burns, Dr. James Greer, Dr. David Nace and Bruce Kamradt. Mr. Kamradt and Dr. Marty Beyer contributed to the subsequent section on Massachusetts' response to the crisis.

The National Response to the Children's Mental Health Crisis

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. 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. 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.

Seminal events and initiatives, dating back more than three decades, prompted many states across the nation to shift from a primary reliance on institutional and residential services to home and community-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 Cambridge-based MA-MHSPY (which started in 1998), 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 and community-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 home and community-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."

Many states throughout the country have demonstrated that the full array of integrated home-based services 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 a few of these states' programs is included in Appendix A.

The federal Medicaid insurance program covers most home-based services. 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.

Although Medicaid has funded home and community-based services for many years, some states, including Massachusetts, have not uniformly made these services available in their Medicaid programs or through EPSDT benefits. Massachusetts does not provide home and community-based services statewide to Medicaid-eligible children, consistent with the nine standards in the President's Commission's Report.

The Massachusetts Response to the Children's Mental Health Crisis

A. Background

Lacking necessary, comprehensive home-based services, Massachusetts has relied inappropriately on residential services, thereby reinforcing the incorrect assumption that SED children cannot be effectively treated in their birth, foster or adoptive homes.

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

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.

But instead of developing intensive, long-term, home and community-based services, the state in recent years has focused on the "stuck kids" – children who are clinically stable but remain in psychiatric facilities due to the lack of community alternatives. They are included on the CARD list, a roster maintained by the state of children whose stay on inpatient units is no longer medically necessary. CARD is an acronym for "Cases Awaiting Resolution or Disposition." It is important to underscore that the CARD list includes only children stuck in private psychiatric hospitals and related acute levels of care. On any given day, up to 100 other children are "stuck" in many other kinds of treatment facilities – such as residential programs and public hospitals which are not appropriate for their needs.

By focusing on the high cost of stuck kids in psychiatric hospitals, the state ignored the harm to children who were not living in family homes and to the much larger number of children inappropriately placed in residential programs for long periods of time, or left in birth, foster, or adoptive homes without adequate treatment.

B. Promising services

Due to this reliance on residential services, Massachusetts has not uniformly provided Medicaid-eligible children the full array of integrated home and community-based services demonstrated as effective and provided under EPSDT in many states across the county.

Instead, the state supports multiple agencies at considerable cost to provide certain components of community-based mental health services, such as Family Stabilization Teams (FST), Community Support Programs (CSP), and Emergency Services Programs (ESP). A brief description of these Medicaid programs, as well as certain programs provided exclusively with state funding through other state agencies, is included in Appendix B.

The state also offers two models of organized service systems that provide home and community-based services, but these pilot programs have significant limitations. The state's newly unveiled initiative, Coordinated Family Focused Care (CFFC), presently is designed to serve only 50 children in each of five cities: Springfield, New Bedford, Brockton, Lawrence and Worcester. MA-MHSPY, which was initiated in 1998, serves only 70 children in five communities that ring Boston: Cambridge, Somerville, Medford, Malden and Everett. These programs are more fully described below.

CFFC provides home-based services, with some significant constraints, to children in five selected cities. It focuses on the children potentially going into residential treatment or acute in-patient care in hospitals. CFFC employs an individualized service process that is strength-based and involves the family in the planning of service delivery. It offers components of strength-based assessments, crisis services, and intensive case management, with the availability of "flexible dollars." But access to clinical services is

not integrated into CFFC. Most clinical supports and treatments are not directly provided and must be obtained through the same restricted and cumbersome process as elsewhere in the Medicaid system. In fact, the state's behavioral health carve-out, the Massachusetts Behavioral Health Partnership, will not permit CFFC to access FST, even when such short-term clinical therapy and treatment could be critical in stabilizing the SED child.

Unlike CFFC, MA-MHPSY has no time limit and direct access to clinical services, such as therapy and behavioral specialists. Through a blended funding model, it can arrange for non-clinical supports. But MHSPY serves only 70 children in five cities.

MA-MHSPY is the best example of home-based services in the state. It integrates behavioral and physical care for children with serious emotional disturbance. It targets children at risk of out-of-home placement or those in an out-of-home placement determined to be ready for return to the community or a transitional type placement. Length of stay can exceed a year or more depending on need. Case managers have direct access to all behavioral health services for children. This means any child in MHSPY gets the full coverage of their medical services, including medication, hospitalization and all the standard Medicaid benefits. In addition, they get all the standard mental health and substance abuse coverage.

The MHSPY program employs a wraparound, individualized, needs-based planning process that is fundamental to providing home-based services. It can arrange and pay for non-traditional services and supports, such as respite care for families, a tutor, a parent aide, transportation, a mentor, etc. It has great flexibility due to the blended funding in the model. It is co-funded by multiple state departments (the Office of Medicaid and the Departments of Education, Mental Health, Social Services and Youth Services), as well as by local school districts. However, as a result of a recent cap rate review by the state Medicaid office and the federal government, the vast majority of its services and costs is covered by Medicaid.

The average cost for enrollees between October 27, 1999 and September 31, 2001 of \$3,300 per person per month was about one-third of what the average child living out-of-home in Massachusetts cost for placement alone. A recent fiscal analysis of current costs indicated that when all medical and behavioral services, including medication, hospitalization, and all other necessary treatment are combined together, the total cost is approximately \$4,500 per person per month, most of which (\$4,200 per month) was for Medicaid-covered services.

C. Evaluation of Existing Services in Massachusetts

In the spring of 2004, two nationally renowned experts in children's behavioral health services visited programs in Massachusetts to evaluate the home and community-based programs currently available to children with serious emotional disturbance. Their review 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 leaders, clinicians and social workers in programs across the state, the 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.

1. Limited Geographical Coverage

Home-based services are severely limited geographically in Massachusetts. The five CFFC programs 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 through Medicaid. These geographical limitations to home-based services in Massachusetts affect children and families across the state. A large number of SED children who could remain in their birth, adoptive or foster homes and attend local schools if they and their families had intensive home-based services. They cannot access CFFC or MHSPY because they do not live in the cities those programs serve. Even if CFFC were to expand, many of these children live in areas without adequate outpatient services that are necessary for CFFC.

2. Limited Duration

Typically, FST is limited to an average of six weeks, Family Based Service (FBS) is generally limited to six months, and flexible support programs and CFFC last one year. In individual cases, the time frames may be extended by special authorization. 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. Many children being discharged from residential and psychiatric hospitals, as well as children for whom home-based services are essential to prevent residential and psychiatric hospital placement and disrupted foster placements, require intensive support for months or years because they have chronic mental health problems.

The limited duration of FST and CFFC services in Massachusetts affects children and families across the state. A large number of children with chronic mental health problems could remain in their birth, adoptive or foster homes and attend community schools if they and their families had home-based services that lasted for months or years.

3. 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.

One provider said that if a child needs more than FST can offer, it has no choice but to recommend residential placement or inpatient hospitalization. The lack of intensity of community-based programs impacts discharges from residential programs. Staff at an acute residential treatment program complained that it is often weeks before children who no longer require acute care can be placed in the community due to inadequate services in the community, and even upon discharge, finds the available services are often insufficient to meet the complex needs of the child.

4. Limited Capacity

CFFC programs already have waitlists, and FST programs sometimes shorten the duration of their services to accommodate more families. Emergency Services Program (ESP) staff said that due to the limited capacity of FST, they have to send children home with an outpatient referral. Staff in ESP programs indicated some children would not have to be hospitalized if they had received adequate and timely home-based services.

5. 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 seamless, integrated services and can provide services directly that are missing in the community. Unlike CFFC, 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 CFFC. The vast majority of MHSPY's services and costs are covered by Medicaid.

6. 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

7. 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. All across the state, home-based services must offer a range of interventions that are individualized to fit the child and family/foster family. 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.

Impact on Children

Four children's mental health clinicians, assisted by a child psychiatrist in a consultant role, conducted an analysis in 2004 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 2002 and 2003. The youth, who ranged in age from 6 to 20, consented through their parents and/or guardians to participate in the sample.

The clinical review was directed by Marci White, MSW. The other clinicians were Dr. Marty Beyer; Narell Joyner, regional program manager overseeing compliance efforts in the *Willie M*. class action lawsuit and mental health consultant in Raleigh, N.C.; and Beth Whitaker, M.A., children's mental health expert on the local entity management team within the North Carolina Department of Health and Human Services. Dr. James Greer, of The Providence Center, served as a consultant to the four reviewers. Ms. White and Dr. Beyer contributed to this section. Dr. Greer contributed to the subsequent section pertaining to behavioral health services available in Rhode Island.

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 of September 2004), as well as any other past 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.

Over the course of ten days in September 2004, the experts conducted on-site reviews. They met with the children, their parents or guardians, and key individual providers for each individual child (e.g., individual and/or family therapist, psychiatrist, school personnel, case manager, behavior specialist, family support worker, social worker, or front-line staff in a child's residential program). In many cases, they contacted additional care providers to gather more information about the children.

Dr. Greer, in his consultant role, met with two children in the sample. He reviewed their records as well as the case files on three other children. He also reviewed summaries, drafted by the clinicians, on the other children in the sample.

Upon completion of all of the individual client assessments, each expert reviewer summarized her findings and opinions about each assigned child. Those findings and opinions are contained in their individual reports. Ms. White reviewed and synthesized their findings.

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. The clinicians found that

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

Beyond Cookie Cutter Services

The complexity of the mental illnesses and conditions of the children in the sample is clear. Most 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. A number of the children also appeared to pose treatment dilemmas for the professionals working with them. 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.

Cookie cutter services will not address the needs of these children. The very nature and complexity of their needs require services that are highly individualized and flexible. 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. But all of these children need more assistance than their families, school, medication and once a week 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. Intensive home-based services, designed and implemented by a talented behavior specialist to fit a youngster's particular needs and situation, have made a tremendous difference for him and his family. 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, set service model or mold are what virtually every child in the sample needs – and what very few of them are getting or have gotten in the past.

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.

Billy (not his real name) is a 12-year-old tragedy at risk of out-of-home placement. He has severe communication and sensory integration disorders that impede his ability to express himself and to understand facial expressions or body language in others. Due to aggressive behaviors, he is heavily medicated. He struggles with his grandmother's death and his parents' separation, as well the recent move from a house trailer to a cramped apartment and the resultant loss of his dog. He has no friends. His longtime therapist cautions, "Removal from home would be a disaster for him." He would benefit from a comprehensive assessment and a complete behavior intervention that includes 1:1 behavioral services in the home daily, including weekends, from a coach who also could provide guidance and support to his mother.

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. Case management must be much more than identifying and helping to link services. Effective case management for children with chronic mental health needs requires a leadership role and advocacy.

Such 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. 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.

It is a given that children are harmed and damaged simply from the disruption of removing them from their homes, even when it is necessary to do so to protect them, and then compounded by moving them from placement to placement. Many of the children in this sample have been through many disruptions of placement, services and relationships. It is evident that they continue to suffer from the combined effects of these losses and of the abuses they have endured. Such harm and damage contributes further to their already serious and chronic mental health problems. The provision of intensive home-based services wherever a child is living helps to mitigate such damage by building on the strengths and capabilities of the child and those caring for him. Addressing the child's needs in this way also helps avoid out-of-home placements and hospitalizations.

Twists of Geography

But for simple geography, the children reviewed in the sample are not receiving home and community-based services. If they lived in Rhode Island, many of them would probably qualify for and receive medically necessary home-based services, funded by Medicaid, according to the child psychiatrist who served as a consultant to the four expert clinicians.

Based on face-to-face meetings and/or complete record reviews of five children in the sample, the psychiatrist determined these youth have a medical necessity for home and community-based services, but are not receiving them. The psychiatrist also reviewed the individual client summaries drafted by the clinicians of the remaining children in the sample, and concluded that most of these children represent a reasonable cross-section of children with serious emotional disturbance and mental health conditions. The conditions and needs of these children are similar to those of children in Rhode Island who are receiving intensive community-based services or home-based therapeutic services. Unfortunately, because they live in Massachusetts, their medical need for home-based services is not being met.

These children would be eligible for Medicaid-funded intensive community and home-based treatment services in Rhode Island, where the availability of such intensive mental health services has significantly reduced the need for out-of-home placements, inpatient psychiatric hospitalizations and high intensity residential treatment programs for this population. These services have not only been cost effective; they have significantly improved the quality of life for those children in Rhode Island. Similarly, many of these home-based services are available to children with behavioral health needs in other New England states, including Maine and Vermont.

Cost Analysis: a Model for Massachusetts

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.

According to Carl Valentine, an expert consultant who has worked in more than forty states developing strategies for the financing of community-based behavioral health services using Medicaid, Massachusetts also could reap such rewards. Mr. Valentine contributed to this section of the report.

During the summer of 2004, the 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; 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 former Division of Medical Assistance, the Massachusetts Behavioral Health Partnership, communications to and from the federal Centers on Medicare and Medicaid, as well as materials describing the established Mental Health Services Program for Youth (MA-MHSPY), the state's recent initiative, Coordinated Family Focused Care, executive and legislative reports, and myriad 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.

Not all of the behavioral health services provided by MHSPY are covered by Medicaid, at least absent a special waiver. The Medicaid state plan-covered services account for about 80 percent of the total per member per month rate. Therefore, the resultant Medicaid-covered behavior health services component of the rate ranges from a lower-bound rate of \$3,733.97 per member per month to a higher-bound rate of \$4,112.68, with a best estimate amount of \$3,920.90 per member per month for Medicaid-covered behavioral health services inclusive of related administration and overhead costs. Using the best estimate per member per month rate for Medicaid supported behavioral health services results in an annual cost of \$47,051 per child.

This estimate is further supported by 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 cost for residential treatment and administrative costs. If, as in MHSPY, 80 percent of the services were 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 at about the 20 percent level 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.

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, 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.

If Massachusetts reinvested the resources that it currently spends on unnecessary hospitalization and residential placement, and used them for Medicaid-covered homebased 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.

Appendix A

Selected Home-based Programs Provided in Other States

Wraparound Milwaukee

The President's New Freedom Commission on Mental Health Subcommittee on Children and Family cited Wraparound Milwaukee as an exemplary program in children's mental health and in the delivery of comprehensive and individualized care to children with serious mental health needs.

Established by the Milwaukee County Health and Human Services Department in 1995 to address the rising number of children being placed in psychiatric hospitals and residential treatment facilities, Wraparound Milwaukee created comprehensive home and community-based alternatives for children with serious emotional disturbance. The program, which served 847 families in 2003 and received over \$30 million in funding from Medicaid, mental health, child welfare, and juvenile justice, has been responsible for reducing residential treatment placements in Milwaukee County from a daily average of 375 placements to approximately 70 placements and for reducing the use of psychiatric inpatient care from several thousand days of care to under 300 per year for SED youth. Although Wraparound Milwaukee benefits from the additional funding and support of non-Medicaid resources, many of the home-based supports it offers and outcomes it achieved, can be and have been replicated in other states through programs developed primarily with Medicaid resources and covered services.

Wraparound Milwaukee is an example of a home-based services program. The program operates on a philosophy that emphasizes individualizing care, building on the strengths of a child, meeting the needs of children and families across life domains, involving families as full and active partners in all treatment decisions. Wraparound Milwaukee utilizes a team-driven process involving the family, child, natural supports, clinical provider agencies and other supports to develop, implement and evaluate the care plan. In fact, the Wisconsin Medicaid agency authorizes this integrated, coordinated team to make decisions related to the medical necessity of services for the enrolled child.

In Wraparound Milwaukee, a care coordinator/case manager facilitates the team process, helps the family identify strengths and needs and helps obtain services the integrated planning team identifies. The team and case management functions are critical to the success of the program, both by ensuring that needed services are provided and by ensuring that all distinct services and providers are integrated into a coordinated service approach. Instead of a single service, Wraparound Milwaukee care coordinators can directly access over 80 different covered services including individual and family therapy, substance abuse, in-home therapy and behavior management specialists, crisis stabilization workers as well as other covered services such as mentors, tutors, job specialists, transportation, and day treatment.

Wraparound Milwaukee also provides a 24-hour mobile crisis team that can intervene at the child's home, at school, or wherever the child resides if he or she has a mental health crisis that threatens the child being removed from a community placement.

Besides significantly reducing the numbers of residential treatment, psychiatric hospital and correctional placements, clinical outcomes of enrolled youth have improved based on nationally accepted evaluation instruments. In addition, the school attendance of enrolled youth has increased. Similarly, there has been a significant decrease in recidivism rates of delinquent youth from prior to enrollment in Wraparound Milwaukee to one and three years following disenrollment (average enrollment period is 18 months).

Community-Based Intensive Services

Home-based behavioral services also have enabled Rhode Island children at risk of out-of-home placement to make progress, improve functioning, and continue to live in their communities with their families or foster families.

Through a program known as Community-Based Intensive Services (CIS), community and home-based services are provided by bachelor's and master's level clinicians, and may be offered up to 20 hours a week based on acuteness and intensity of need, consistent with medical necessity. Children receiving these services typically remain with their families, though these services may also be provided to children in residential care. These services are offered for a period of six months and may be renewed repeatedly based on need. The services are coordinated by a case manager and prescribed, delivered, and monitored by a team that includes the family member, relevant providers and professionals, and the case manager. The specific interventions provided by this program, either directly or in affiliation with another provider, include comprehensive assessments, mobile crisis intervention, case management, behavior therapy or specialists, medication, counseling and other clinical therapies as needed. All of these services are funded by Medicaid.

If it appears that a child warrants more intensive services than traditional outpatient treatment, the assessing clinician completes two rating scales, the Modified Children's Global Assessment Scale (MCGAS) and the Ohio Mental Health Consumer Outcomes System Youth Problem, Functioning, and Satisfaction Scales (OHIO). In addition, within the first month of treatment, a Child and Adolescent Functional Assessment Scale (CAFAS) is completed. This scale also is used as an outcome measure at various times during treatment. The rating scales and reviews result in acuity determinations, which guide the intensity of service. All clients must be at risk of hospitalization or placement out of the home in order to be eligible for CIS services.

Each child's treatment and plan are reviewed at least monthly by a multidisciplinary team comprised of the case manager, a masters level therapist, the child and family member, and the psychiatrist. All cases are subject to periodic Medicaid review by the state agency, the Department of Children, Youth & Families.

CIS services include intensive case management, home and community-based individual and family counseling, including behavior management training of primary caretakers in the home and community. In addition, 24-hour-a-day emergency service backup including a child trained clinician and a psychiatrist on call is available as needed. Acute situations may also be addressed in the context of a partial or "day" hospital setting. Typically, the therapist models appropriate behavior management interventions for the primary caretaker or coaches them during situations as they occur in the home while the worker is present. Child psychiatric services are office-based.

Children and adolescents who require long-term community/home-based services or who require ongoing support for greater than 20 hours per week are referred to other community agencies with home-based treatment services designed to meet these needs. These services include comprehensive assessments, mobile crisis intervention, case management, behavior therapy or specialists, medication, counseling and other clinical therapies as needed, and can offer any or all of these interventions with greater intensity and frequency than our program. All of these services are funded by Medicaid.

Home-Based Therapeutic Services

When CIS level intensity interventions are not adequate or comprehensive enough to meet the needs of clients and families, or the need for intensive services is identified as longer term and chronic, the child is referred for assessment to one of four Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation (CEDARR) centers across the state. The centers provide information for families about available services, perform comprehensive evaluations of children with special needs, make treatment recommendations, coordinate care, and provide ongoing re-assessment and treatment reviews. A CEDARR evaluation may result in referral to a Home-Based Therapeutic Services (HBTS) program. There are approximately 14 HBTS providers in Rhode Island. The only access to HBTS services is through a CEDARR center. This process evolved from Rhode Island's EPSDT program, in which primary care providers could prescribe Medicaid-funded therapeutic services for their patients. The establishment of CEDARR centers and HBTS programs was designed to provide utilization review and standardization in the provision of these services.

HBTS services were designed and initiated by Christine Ferguson, the former commissioner of the Department of Children and Families in Rhode Island and the former public health commissioner in Massachusetts. The services are now widely used by Medicaid-eligible children in Rhode Island and have allowed many children to continue to live in their family settings rather than being acutely hospitalized or placed in residential treatment settings. In the family and community context in which their problems occurred, more effective interventions have met with greater success than residential settings, which disrupt families and decrease learning. Children in substitute care in Rhode Island have been able to return from out-of-state placements to local, less restrictive settings where they were able to reintegrate into their own families and communities. These children experienced a reduction in inpatient psychiatric treatment

days compared with the period preceding the availability of an intensive community-based treatment program.

Behavioral rehabilitative and therapeutic services

Pennsylvania lacked adequate home-based, community-based, and school-based behavioral rehabilitative and therapeutic services to address the behavioral health needs of severely emotionally disturbed children and adolescents prior to a 1991 EPSDT lawsuit (*Larry K. v. Snider*). Despite a clear need for such services to support the severely emotionally disturbed child and family at home, physicians, psychologists, and other behavioral health professionals did not prescribe or recommend them due to the absence of commercial or Medicaid billing codes or reimbursement mechanisms for home-based, community-based, and school-based professional mental health services.

As a result of the settlement stemming from the *Larry K*. lawsuit, Pennsylvania established a process for requesting and receiving reimbursement for home-based, school-based, and community-based behavioral services from Medicaid through a case-by-case application process. While this development was positive, the complexity and difficulty of requesting and creating home-based, community-based, and school-based professional mental health services on a child-by-child basis through the individual application process discouraged many clinicians from recommending them, despite the significant number of children who needed them.

Subsequently, the Pennsylvania Medicaid agency created a fee schedule that allowed for several of the most frequently requested services — mobile therapy, therapeutic staff support, and behavioral specialist consultants. This provided an incentive for some practitioners and agencies to recommend or begin to provide these services. Nonetheless, the administrative paperwork, approval requirements, and inadequate reimbursement rates for these home-based, community-based, and school-based professional mental health services created a barrier to effectively delivering the services in a timely manner to children and adolescents.

After a second EPSDT lawsuit was filed in 1999 (*Kirk T. v. Houstoun*), Pennsylvania provided detailed program descriptions, simplified administrative billing processes and quality assurance reporting requirements, raised reimbursement rates, and increased specific training and written resources to support providers who wished to provide the services. In addition, a tracking mechanism was put into place to support the timely delivery of these services.

As a result of such changes, an increased number of clinicians and agencies in Pennsylvania began to recommend and deliver these services for a significant number of children who required them. Currently, home-based, school-based, and community-based behavioral services are widely utilized in Pennsylvania, in both fee-for-service and managed Medicaid environments. These services are effective in supporting children with serious emotional disturbances and enabling them to remain in their homes and communities.

Appendix B

Existing Home and Community-Based Mental Health Services in Massachusetts

Family Stabilization Teams provide a very time-limited form of some homebased services. The services of a FST program are designed primarily for delivery during an episode of acute emotional disturbance and secondarily after an out-of-home treatment episode such as inpatient hospitalization. They provide a high level of clinical supports and treatment, but are seriously limited in the areas of capacity and intensity to meet the number of families whose SED children could benefit from the service. It is basically about a six-week program. Services are generally limited in intensity to 10 hours per week. Providers maintain that the six-week average period of time was not sufficient to meet the long-term mental health needs of SED children. FST was also not targeted at some of the children who needed the service the most: dually diagnosed children with a developmental disability or autism and severe emotional disturbance. Additionally, FST is not helping those youth placed in residential treatment programs who could be transitioned home with a longer-term treatment alternative. Finally, FST does not have an integrated team process that utilizes a strength-based approach involving families who identify the needs of the child and take an active role in treatment decisions.

Community Support Programs (CSP) are designed to provide a variety of services to children and their families with a documented history of a behavioral health disorder that has required hospitalization or has resulted in serious impairment to the child at risk of hospitalization. Services include outreach and supportive services such as advocacy, coordination of treatment, outreach, assistance with basic needs, skill building and linking families to community services. CSP is considerably less intense than FST, does not provide clinical interventions, and primarily is a program that assists families with accessing generic supports rather than providing behavioral health treatment. The average period of time a family is served by CSP is about nine weeks for most children and families.

The Emergency Services Program (ESP) is good for short-term, crisis assessments of children potentially needing psychiatric hospitalization and the usual access point for the FST team, but is not otherwise a comprehensive home-based alternative. ESPs are the gatekeepers for inpatient hospitalization. Families with children in psychiatric crisis may contact an ESP provider on a 24/7 basis. ESPs perform crisis screening, medication evaluation, short-term crisis counseling and stabilization. The ESPs seem to serve a vital function to reduce unnecessary hospitalization of children through providing crisis intervention services. Because of the very limited duration of service provided by the ESPs, since they are office or facility-based rather than home-based, and because they do not provide long-term clinical supports or case management in the home, the Emergency Service Program does not provide home-based services or even work as part of a home-based service.

In addition, there are a few programs operated and funded by other state agencies (and not Medicaid) that offer some form of home-based services, but these programs are not available to Medicaid-eligible children unless they meet additional, strict eligibility requirements of those agencies. Even then, these programs are limited in capacity, intensity, comprehensiveness, duration, and services, and most have long waiting lists due to limited funding.

The Individual and Family Flexible Support Program (IFSP), run by Department of Mental Health, can fund community-based, individualized interventions. This program focuses primarily on the coordination of services, such as making telephone contacts and attending planning meetings, case consultation, teaching and modeling appropriate behaviors, arranging for parent aide services, homemaker services, and some use of "vouchers" to purchase items that may support the plan.

Enhanced Therapeutic Foster Care is a program currently funded by DMH and the Department of Social Services for children in DSS custody. The program places children identified as ready for discharge from acute care inpatient facilities and determined to be clinically appropriate, in a highly specialized therapeutic foster homes with a capacity to provide a three-month infusion of community wraparound services. Services include the availability of therapists, mentors, advocates and some respite; not included are case management or behavioral training and support for the family. The program overall has very limited capacity statewide to families, the duration of the program is usually limited to six months and the program does not to help children once they return home.

The Family-Based Services (FBS) system operated by DSS is limited to referrals from DSS; some relinquishment of custody and control is forced on families who seek this alternative for their SED child. While there is no one model, FBS providers offer the following services: in-home treatment, parent aides, parent education, and specialty services for victims of trauma, sexual abuse, substance abuse or domestic violence. It has long waiting lists as a result of capacity restrictions, and limited funds that preclude purchasing or arranging all needed services.