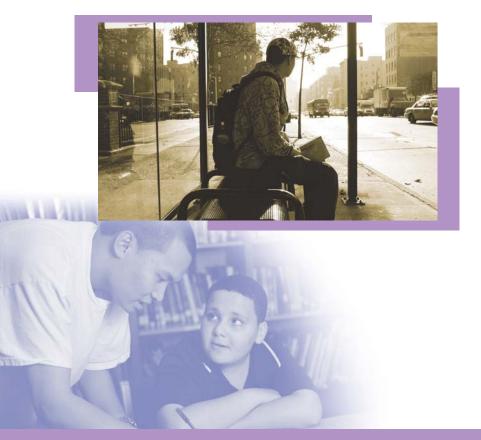
### A FAMILY GUIDE

einvesting in the Community:
A Family Guide to Expanding Home
and Community-Based Mental Health
Services and Supports







Reinvesting in the Community: A Family Guide to Expanding Home and Community-Based Mental Health Services and Supports
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The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has over 1,100 affiliates in communities across the country who engage in advocacy, research, support, and education. Members of NAMI are families, friends, and people living with mental illness such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

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### Acknowledgments

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### Methodology

In developing this guide, NAMI sought early input from a number of stakeholder groups. NAMI held a meeting that included the following organizations: the Bazelon Center for Mental Health Law, the Child and Adolescent Bipolar Foundation (CABF), Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), Mental Health America (MHA), National Association for Children's Behavioral Health (NACBH), and National Federation of Families for Children's Mental Health (FFCMH).

Representatives from several of these organizations reviewed a draft of the guide and provided additional input. A draft of the guide was also shared with families from multiple states. Input from these stakeholders was incorporated into this final version. The input NAMI received was extremely useful in helping to ensure that the guide meets the information needs of families and numerous stakeholders. NAMI also consulted with a number of national experts who help states and communities build a broader array of effective home and community-based services and supports.

### Purpose of Guide

This guide is designed to inform families about effective home and community-based services and supports for children and youth with mental health treatment needs and their families. It is also designed to share information about several states and communities that have engaged in systems reform to increase the availability of these services. The information provided in this guide may in turn help families engage in systems reform activities in their own states and communities.

#### Introduction

Every child deserves to grow up in a home closely connected with family and friends. For a variety of reasons, this does not always happen. For thousands of children with serious mental health treatment needs in America, it fails to happen because they are removed from their homes and communities and placed in residential and other out-of-home settings. While some of these children are removed from their homes for safety reasons, many are removed because alternative intensive services and supports are not available. Many children who are placed in out-of-home settings would achieve better outcomes by receiving services and supports in their homes and communities. For children requiring residential treatment or other out-of-home services, their length of stay may be reduced if intensive home and community-based services were readily available.

Some children and youth benefit from residential treatment. However, it often happens that children with serious mental health treatment needs end up in more restrictive care settings because a broad array of home and community-based services are either not available, not accessible, or not immediately available to address an impending crisis.

About 10 percent of children and youth in the United States have serious mental health treatment needs that cause significant functional impairment in their day-to-day lives at home, in school, and with peers. Half of all lifetime cases of mental illness begin by age 14, and despite effective treatments, there are long delays, sometimes decades, between the first onset of symptoms and when services are provided. About two-thirds of

children and youth with mental health treatment needs—many of whom are children of color—fail to receive the services they need.<sup>3</sup>

Research has advanced our understanding of the services and supports that work well for children and youth with mental health treatment needs and their families, including youth with the most serious needs. Increasingly, research has shown that positive outcomes can be achieved when services and supports are delivered in homes and communities. There is certainly a place for residential and inpatient treatment along the service continuum; however, this level of service should be limited to cases in which it is deemed therapeutically necessary.

Removing children from their homes and communities can be extremely disruptive to young lives. They may lose connection with their home life, community, and school. The difficulty lies not just in leaving their familiar settings, but also in transitioning back. Some children are sent out of state and far from their homes, making it harder to remain connected to their families and communities. Upon discharge, children may not receive adequate transition and family support services, which can create further disruption.

The Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA) has focused for more than 20 years on the development of community-based systems of care for children and youth with mental health treatment needs and their families. A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges of children and youth with serious mental health needs and their families. Since 1992, CMHS has administered *The Comprehensive Community Mental Health Services for Children and Their Families Program* (CCMHS). The CCMHS provides cooperative agreements to communities to transform child-serving systems to improve and expand the services and supports provided to youth and their families. These cooperative agreements recognize the importance of building home and community-based services to help keep children and youth close to home, in school, and thriving in their communities.

The focus on expanding community-based services and cross-systems collaboration through the cooperative agreement has produced the following positive outcomes:<sup>4</sup>

- Increased school attendance with 81 percent of youth regularly attending school after six months of services;
- 20 percent reduction in school absences;
- 44 percent reduction in the percentage of youth suspended or expelled from school;
- 31 percent of youth improved their school grades;
- Youth arrests dropped by more than half;
- Youth showed improved behavior and improved mental and emotional health;
- · Youth became less depressed and anxious; and
- Suicide attempts and ideation decreased.

Over the past decade, national leaders have also called for the broader implementation of research and evidence-based practices representing those services and supports that have been shown to produce positive outcomes for children with mental illness and their families. This call has come in multiple reports, including those issued by the U.S. Surgeon General, the President's New Freedom Commission on Mental Health, and the Institute of Medicine, among others.<sup>5</sup>

By focusing on research-based services, a number of states and communities are more closely examining the current array of services and supports available to children and their families. Public officials increasingly acknowledge their responsibility to be accountable for delivering effective services with public funds, ensuring that services provided to youth and their families are actively helping young people and families.

Within the last few years, there has also been a growing recognition that best practices not having come from academic research may also play an important role in the diverse service array for communities of color. SAMHSA, through the CMHS Child, Adolescent, and Family Branch, has funded initiatives to explore the role of *practice-based evidence*<sup>6</sup> and *community-defined evidence*<sup>7</sup> to enhance the array of effective practices in cultural communities.

This guide is designed to inform families about the importance of expanding the array of home and community-based services and supports available to children and youth with mental illness and their families. It is essential that these children be identified early and provided with effective services and supports.

# Children and their Families Need a Broad Array of Effective Home and Community-Based Services and Supports

Our vision embraces a comprehensive array of home and community-based services and supports to provide treatment and to support the functioning of children with emotional disorders and their families at home, school, work, and in the community. 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.

President's New Freedom Commission on Mental Health, Subcommittee on Children and Family, 2003.8

The needs of children, youth, and their families should drive the array of services and supports that are available in communities. Families and youth should drive the development of an individualized treatment plan with access to those services and supports necessary to achieve the outcomes identified in the plan. Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation. The outcomes that youth and families wish to see should guide decisions about what services and supports are provided.

Families often cite some combination of the following outcomes as important in their child's treatment:

- Improved school attendance and performance;
- Improved family and peer interaction and relationships;
- · Improved ability and skills to manage and control behavior;
- Decreased involvement with law enforcement and the juvenile justice system;

- Decreased rates of substance use and abuse;
- · Reduction in self-harm and suicide related behaviors; and
- Decreased hospital admissions, institutional care, and other out-of-home placements.

There is no single definition for *home and community-based services*. A group of national experts on children's mental health services developed the following definition for intensive home-based services in response to a lawsuit recently decided in Massachusetts that requires an expansion of home-based services:

Home and community-based services are well-established behavioral health interventions for children designed to meet the child's needs in his/her home and community. They may be provided in the child's natural or foster home, or in the community where the child lives. The planning and provision of 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. 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. These services must be provided in a flexible manner with sufficient duration, intensity, and frequency to address the child's needs.<sup>9</sup>

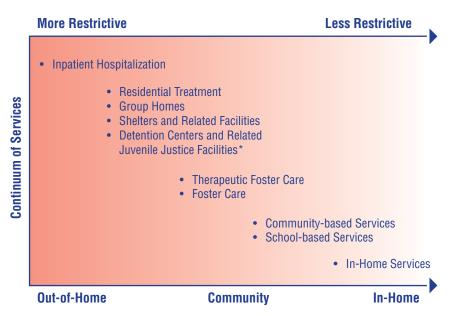
There is no "one size fits all" approach when it comes to providing mental health services and supports. It is therefore essential that a diverse array of services exist to meet the unique needs of each child and family and allow a child and family team to develop an individualized treatment plan. That team should consist of the child's family (and often the child or youth), relevant service providers, and others deemed necessary such as teachers, coaches, neighbors, and extended family members. Coordination of services should be provided by a case manager.

All services and supports that are developed must also reflect and respect a family's cultural heritage and preferred language. The delivery of quali-

ty services and supports should include culturally appropriate outreach, service location, family and youth engagement, assessment, and culturally appropriate interventions. Services and supports should take into consideration the demographics, diversity, and values of the community. The mental health workforce should include providers from diverse cultural backgrounds, who are fluent in the preferred community language(s), and who reflect the cultural diversity in the community.<sup>10</sup>

The following chart depicts the array of mental health services and supports, and the settings in which they are delivered, as a continuum that runs from out-of-home to in-home services.

### A Continuum of Settings and Interventions for Children and Youth with Mental Health Treatment Needs



<sup>\*</sup>Approximately 70 percent of youth in the juvenile justice system have one or more psychiatric disorders, 20 percent have serious mental illness. <sup>11</sup>

The most restrictive services serve the fewest children and are typically the most costly. As a result, most child-serving systems spend a high percentage of their budget on a small percentage of children. In addition,

research shows that for many children, the most effective mental health services and supports are those delivered in their home and community. Also, outcomes improve for many children when therapeutic interventions focus on the child *and* family, which is harder to do when a child is receiving out-of-home services.

As communities focus on expanding home and community-based services, and families work with community leaders on systems reform, it is important to know the services and supports that have been shown through research to produce positive outcomes for children, youth, and their families. All services and supports should be measured on their effectiveness and cultural appropriateness.

The following are some of the essential home and community-based services that can be used to help keep children at home and in their communities:

Early Identification and Intervention – early mental health screening, assessment, and evaluation that are culturally and linguistically appropriate must be part of a comprehensive health care system. Primary care providers, school professionals, and all professionals serving young children should be trained on the emerging signs of mental health related concerns. These professionals should either provide screening, evaluations and assessments, or provide links to mental health and other healthcare professionals in the community who can provide these services. When mental illness is identified early in the course of the illness, it is easier to treat and early intervention leads to better long-term outcomes.

Intensive case management – professional case managers work closely with the child, family, and other professionals to develop an individualized comprehensive service plan. The case manager assesses and coordinates the services and supports necessary to help keep the child at home, in the community, and receiving the most effective services. Case managers work to ensure that children and youth receive family-driven care and when appropriate, youth-guided care.

Wraparound - a definable planning process that actively involves the child and family and that results in a unique set of culturally appropriate community services and natural supports individualized for the child and family and designed to achieve positive outcomes. The services typically used in a treatment plan developed by wraparound teams include mental health evaluations, behavioral support and behavioral aide services, crisis planning and intervention services, parent training and education, medication monitoring, intensive in-home therapy, and related services. To learn more about wraparound, visit the National Wraparound Initiative at www.rtc.pdx.edu/nwi.

Therapeutic Foster Care (TFC) - a placement outside of the family home for youth with serious mental health treatment needs. Therapeutically trained foster parents work with youth in their home to provide a structured and therapeutic environment while enabling the youth to live in a family setting. The trained foster parents work closely with the biological or adoptive family, whenever possible, and receive close supervision and support to help ensure that therapeutic interventions lead to positive results.

Mentoring/Behavioral Aide – a para-professional with strong child relationship skills who works with children to improve and eliminate problem behaviors and to develop more positive behaviors. The work includes increasing positive social involvement and activities in school and in the community. Behavioral aides help youth to develop and improve skills, including anger management, social skills, and problemsolving skills that help a child to function well at home and in the community.

Crisis Stabilization/Mobile Crisis Services – emergency services that include some combination of a crisis hotline; mobile crisis teams available 24-hours a day and seven days a week for services needed at home, in school, or in the community; emergency shelters; and connection with acute care hospitalization and emergency room services.

**Respite** – family support that provides a relief from child care by bringing a caregiver into the home or placing a child in another setting for a

brief period of time. Respite care allows families with a child with serious needs, including mental illness, a break from the responsibilities of caring for their child and can help to reduce extreme family stress and the need for out-of-home placement.

Family Support and Education – Family support and education programs can be led by family members, clinicians, or paraprofessionals. Through relationship building, education, collaboration, and problem solving, these programs help youth and families learn about mental illness and effective treatment options; provide hope, support, and encouragement; and teach caregivers to reduce stress and to take care of themselves. These programs also help families understand how to manage the symptoms of their child's mental illness.

Clinical Interventions and Supports – effective and research-based psychosocial interventions provided in the home, in school, or in other community settings that are provided to the child, to the child and parents separately, or to the whole family in the form of family therapy. These interventions may include multi-systemic therapy (MST), functional family therapy (FFT), cognitive behavioral therapy (CBT), parent management training (PMT), interpersonal therapy (IPT), and more. <sup>12</sup> These interventions may also include medication, which requires close clinical monitoring.

Not having enough home and community-based services and supports has caused significant challenges for families. In some cases, this has led to families being forced to relinquish custody of their child to either the child welfare or juvenile justice system to access critically-needed mental health services. This happens most often because families exhaust their private insurance coverage, do not qualify for Medicaid, and turn to the public system for help when their child is experiencing a psychiatric crisis. Much has been written about this national problem with many calls for reform, including an expansion of home and community-based services for youth with intensive service needs.<sup>13</sup>

The good news is that a national consensus is building around the need to realign services, to focus on early identification and intervention, and to implement a broader array of effective home and community-based services.

# Making the Case for Expanding Home and Community-Based Services and Supports

The number of communities, tribes, territories, and states that have made a commitment to increase the availability of effective home and community-based services and supports for children with mental illness and their families is growing.

This is happening for a number of reasons. In some cases, community leaders recognize the importance of achieving better treatment outcomes and controlling rising costs. In others, communities are working to expand Medicaid coverage for mental health services and are using other creative financing options for these services. Statewide expansion of home and community-based services has also occurred in response to litigation. Strong leadership and a commitment to community-based services have also led to reform.

This guide highlights just a few examples of states and communities working to realign their service systems to provide a broader array of services and to produce better outcomes for children and their families.

Much can be learned about strategies to expand home and communitybased mental health services by looking more closely at states and com-



munities that are engaged in ongoing reform. Although every community is different, the step-by-step planning process used by states, the funding strategies used by communities, and the leadership exhibited in communities featured below—are all instructive on approaches to reform. There are also other effective approaches, including legislative initiatives that have led to positive results.

#### Medicaid and Funding Options

The Waiver has been a pivotal service in achieving the goal of keeping children with SED [serious emotional disturbance] with their families, in their homes, and communities thereby decreasing the need for psychiatric hospitalization or residential placement.

New York State Office of Mental Health<sup>14</sup>

The HCBS-SED [home and community-based service – serious emotional disturbance] waiver has assisted with transitioning Kansas from an Institutional model of mental health care to a home and community-based model of health care.

Kansas State Officials<sup>15</sup>

States and communities have used a number of innovative financing approaches to expand the availability of home and community-based services. These approaches have included using Medicaid waivers, combining funds from the budgets of multiple child-serving systems, and participating in federally sponsored grant and demonstration projects. Communities have also received funding for systems reform from private foundations, most often when they have shown effective planning and the political will for change.

Medicaid Home and Community-Based Waivers. The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized under section 1915(c) of the federal Social Security Act. Hence, the HCBS waiver is often referred to as a 1915(c) waiver. The waiver program allows states to apply to the Center for Medicare and Medicaid Services (CMS) for approval to expand the array of home and community-based services available to children and youth with mental

illness. States must show that they can serve children that require a hospital level of care with intensive services at home and in the community at a cost equal to or less than a hospital level of care.

The HCBS waiver has been used extensively by states to increase home and community-based services for children with developmental disabilities, but far less often for children with serious mental health treatment needs.

The HCBS waiver serves children who, if not for the waiver, would be admitted to institutional levels of care, including long-term residential treatment facilities and psychiatric hospitals. It allows states to waive the Medicaid law requirement that all services be provided across the state and allows services to be provided in limited geographic areas. This gives states the flexibility to create small demonstration projects in a limited number of communities to roll-out new home and community-based services, while also controlling costs.

Perhaps one of the most important aspects of the HCBS waiver is that it allows children to be enrolled in the HCBS waiver regardless of their family's income and resources and looks to the child's income as a *family of one* in qualifying the child for Medicaid. Eligibility for Medicaid services under the waiver is dependent on the child's need for services at a hospital level of care.

To make it more attractive for states to use in expanding home and community-based services, the following factors are waived from the federal Medicaid statute for the HCBS waiver:

- Requirement that services be provided statewide, giving states the opportunity to roll-out services in a limited number of communities;
- Requirement on the amount, duration, and scope of services that must be provided to allow states to offer new services in a limited number of communities; and
- For children enrolling in waiver services, their parent's income and resources are not considered when determining the child's Medicaid eligibility, the child is considered a *family of one* and is eligible for waiver services, as long as the child requires a hospital level of care.

The fact that middle income children may qualify for waiver services, helps to reduce the number of families that face placing their child in either the child welfare or juvenile justice system to access mental health services.

States that have used the waiver have added a number of home and community-based services to other medically necessary Medicaid services for children and youth. The following are some examples of the services that states have added under the HCBS waiver. Nearly all of the services have been shown to produce positive outcomes and to be cost effective:

#### Kansas (1997)

- Wraparound facilitation;
- Family support and training;
- Independent living/skills building;
- Respite;
- · Attendant care; and
- Professional resource family care.

### Michigan (2005)

- Respite;
- Family support and training;
- Therapeutic foster care;
- Wraparound facilitation;
- Community living supports;
- Therapeutic camp;
- Skills development;
- Staff assistance;
- Medication management; and
- Transition services.

### New York (1996)

- Individualized care coordination;
- Respite care;
- Skill-building services;
- Intensive in-home services;

- Crisis response services; and
- Family support services.

Much can be learned from the experience of states that have adopted the HCBS waiver for children and youth with mental health treatment needs. In Kansas, the process for gathering support for the waiver began with the collaborative efforts of the State Mental Health Authority, family advocacy organizations, and the Association of Community Mental Health Centers (community mental health providers)—all working together to secure legislative support for the waiver. <sup>16</sup> Once that support was obtained, Kansas applied for and received approval of the waiver from CMS. It is likely that support for the waiver in other states followed a similar path.

Children and youth served by the HCBS waiver have achieved positive outcomes. Kansas reports the following positive outcomes for children and youth receiving waiver services:<sup>17</sup>

- 95 percent of children live in a permanent home setting;
- 79 percent receive grades of A's, B's, or C's;
- 88 percent are attending school regularly;
- 92 percent are without arrests or contact with law enforcement;
- Significant decrease in institutional expenditures, total number of youth served in institutions, total bed days, and in the average length of stay for youth;
- Significant increase in waiver slots, with a significant drop in institutional expenditures; and
- Transformation from an institutional model of mental health care to a home and community-based model.

Similarly, in New York, with a commitment to increasing home and community-based services and supports through the HCBS waiver and other initiatives, there has been a 37,000 bed-day reduction in inpatient settings for children under 12 years old and a drop in referrals to residential treatment facilities. This has translated into a cost savings for the state and more children being served at home and with their families. As an added positive outcome, families in New York whose chil-

dren are receiving waiver services report feeling more confident in supporting the growth and wellness of their children.<sup>19</sup>

The states with HCBS waivers for children with serious mental health treatment needs have provided useful data that shows that the cost of waiver services is less than half of the cost of institutional services:

States with 1915(c) Waivers (year granted)	Number of Waiver Slots	Average Annual per Child Cost for Waiver Services	Average Annual per Child Cost for Institutional Services
Kansas (1997)	Originally - 305 Now - 2,061	\$13,501.00	\$27,563.00
New York (1996)	Originally - 125 Now - 1,506	\$46,550.00	\$113,572.00
Vermont (1982)	Originally - 150 Now - 111*	\$23,344.00	\$52,988.00

<sup>\*</sup>In Vermont the number of slots dropped because the number of children with autism being served under the waiver increased, so the costs increased, and the state responded by reducing the number of waiver slots. Also, the 1915(c) waiver was rolled into another Medicaid waiver in October 2005.

Despite the cost savings and positive treatment outcomes that the states profiled above have achieved with the HCBS waiver, officials in a number of states have shared their concerns about applying for a waiver. According to results from a survey done by the Bazelon Center for Mental Health Law, state officials identified a number of concerns about the waivers, which are listed below, along with responses to those concerns:<sup>20</sup>

• Lack of state match funds for the Medicaid waiver – Medicaid is a program financed jointly by federal and state governments. Although states expressed concern with contributing the state funding portion of Medicaid, one of the main benefits of the waiver is that it allows states to start small with a limited number of waiver slots and minimal costs, demonstrate success with positive outcomes, and then consider waiver expansion;

• Most children are served in RTCs and not hospitals – section 1915(c) of the Medicaid law provides that eligibility criteria for the waiver requires a showing that a child requires a hospital level of care. When states are applying for the waiver they must show "cost neutrality"—which means that the cost of serving children with home and community-based services is not greater than the cost of serving them with a hospital level of care. Many states no longer have children in psychiatric hospitals; instead, they are being served in residential treatment facilities, so states believe that they cannot apply for the waiver because they cannot show cost neutrality.

However, based on information shared by state officials in the Bazelon Center's report, states have satisfied this requirement by using historical cost data that shows the cost of serving children in a psychiatric hospital. Kansas continues to use cost data from their children's psychiatric hospital that has long since closed to show cost neutrality for their waiver. New York showed that despite the fact that their application to CMS included children that received services in a residential treatment facility, those facilities were defined as hospitals under New York state law. Therefore, those children were receiving a hospital level of care as required by the Medicaid law. Clearly, there is a need for clarification and technical assistance from CMS to increase use of the HCBS waiver for children with serious mental health treatment needs. A recent CMS demonstration project may help to bring some clarity to this issue (see information below on the CMS Community Alternatives to Psychiatric Residential Treatment Facilities Demonstration Project).

- Concern with meeting the budget neutrality requirements for the waiver states must show that the cost of serving children under the waiver with home and community-based services is equal to or less than the cost of serving them at a hospital level of care. A number of states expressed concern that they could not meet the budget neutrality requirement; however, as the table, above, shows, the cost for home and community-based services for states that have used the waiver is far less than the cost for institutional services.
- Lack of data information systems to collect cost data for the waiver application the states that are using the waiver, including New York, Kansas, and Vermont, found that they did not need to

- develop new data information systems for the waiver services; instead they gathered sufficient data from their existing data systems. Also, officials in those states asked providers to help in estimating the cost of community-based services to include in the cost data section of the CMS waiver application.
- Insufficient state mental health infrastructure to apply for and implement the waiver states that have the waiver used existing personnel to apply for the waiver and indicated that they did not find the waiver application to be overly burdensome. All of the states with the waiver saw it as part of their larger strategy to increase access to effective home and community-based services and to produce better service outcomes. A number of states and communities that are expanding access to evidence-based home and community-based services have tapped into foundation and other grant funds to help spearhead their transformation work.

Medicaid rules and regulations are complex, however much can be learned from states that are using Medicaid to expand mental health services. The more that families know about Medicaid and other financing options, the better equipped they will be to raise these options in their communities

CMS Community Alternatives to Psychiatric Residential Treatment Facilities Demonstration Project. In February 2006, the federal Deficit Reduction Act (DRA) was signed into law. The DRA authorized a new Medicaid demonstration project designed to expand the use of the Medicaid HCBS waiver for children with mental illness in ten states. The Community Alternatives to Psychiatric Residential Treatment Facilities (PRTF) Demonstration Project awarded grants to the following ten states: Alaska, Florida, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia. Florida's application is pending because the state legislature has not approved state matching funds for the project.

Before the demonstration project, as stated above, the Medicaid law under the section 1915(c) waiver authority only allowed states to provide alternative services to children that required a hospital level of care.



States and advocates have long hoped to extend the HCBS waiver to include children with mental health treatment needs eligible for a residential treatment level of care and not just a hospital level of care. The demonstration project does just that. It allows up to ten states to test the cost effectiveness of providing coverage for home and community-based service alternatives for children who would otherwise receive care in a residential treatment facility. The demonstration program runs for five years from 2007 to 2012. At the end of the demonstration project, states may continue to provide home and community-based alternative services to participants in the program.

The evaluation of the demonstration project will address the following two primary issues: Does providing home and community-based services to children and youth under the demonstration project (1) maintain or improve their functioning across the life domains of community living, school functioning, juvenile justice involvement, family functioning, alcohol and drug use, mental health status, and program satisfaction; and (2) on average, is the cost of serving youth at home and in the community no more than the anticipated residential treatment costs if the demonstration project did not exist?<sup>21</sup>

This demonstration project makes it easier for these ten states to expand the availability of home and community-based services and to expand the pool of children who are eligible for these services based on their clinical level of need.

The TEFRA Medicaid Option. States can also opt for the TEFRA Medicaid option to pay for home and community-based services and supports. TEFRA, enacted under the Tax Equity and Fiscal Responsibility Act, allows states to provide Medicaid coverage to children who meet the "disabled individual" criteria under the Social Security rules, require a hospital level of care but can be served in their home or community, and who can show that if they were in a hospital they would be eligible for Medicaid coverage. Like the Medicaid home and community-based waiver, states must show that they can serve children that require a hospital level of care in the community at a cost equal to or less than a hospital level of care.

With the TEFRA option, states cannot limit the number of slots that are available to children and their families, unlike the Medicaid home and community-based waiver. Although this does not make it as easy for states to control costs, it offers them another Medicaid coverage option for intensive home and community-based services for children who require an intensive level of care. Also, like the Medicaid HCBS waiver, the TEFRA option ignores family income and allows children to be qualified based on the level of care they need.

In addition to waivers and Medicaid options, states and communities are legally required to provide Medicaid eligible children and youth with comprehensive home and community-based services that are medically necessary to address their mental health treatment needs. The Early, Periodic, Screening, Diagnosis, and Treatment (EPSDT) provision of the Medicaid law is a broad mandate that requires these comprehensive services to be provided for Medicaid eligible children.

Other Creative Funding Approaches to Expand Home and Community-Based Services. In most states and communities, there is often little new funding for home and community-based services and the pool of money shrinks further during difficult fiscal times.

Therefore, in order to fund new home and community-based services, many states and communities must redirect funds from high-cost services and those that are not achieving positive outcomes.<sup>22</sup> Financing should not drive service design and delivery, rather children's clinical needs should drive services. Children should always be served in the least restrictive setting that meets their current level of clinical need.

A number of states and communities have combined funding from multiple child-serving agencies to expand intensive home and community-based services as an alternative to out-of-home placement. In most communities, a broader array of services is funded by combining funds from mental health, Medicaid, federal grants and demonstration projects, child welfare, education, and juvenile justice.

Wraparound Milwaukee is a program that creatively uses pooled funding—funds combined from multiple child-serving agencies—to provide services to youth. This program and its success have attracted much national attention. Wraparound Milwaukee operates with a \$40 million budget, with combined funding from child welfare (\$10 million), juvenile justice (\$10 million), Medicaid (\$13 million), and mental health (\$7 million).

The wraparound program operates through a centralized care management organization for children at immediate risk of out-of-home placement in a residential treatment facility, juvenile correctional facility, or psychiatric hospital. The pooled funding allows flexibility for the program to invest in effective and individualized services and supports for children and their families. The program director reports that blended funds are more easily re-directed from out-of-home to community-based care. <sup>23</sup>

Wraparound Milwaukee has achieved the following impressive outcomes by providing children and youth with an array of home and community-based services:<sup>24</sup>

• Reduction in the number of youth in residential treatment facilities from 375 to 80—residential treatment is used on a very limited basis and for short-term stays;

- Reduction in the use of inpatient psychiatric hospitalization from 5,000 to 175 days per year, representing a major cost savings. The funds saved are reinvested in the program;
- Reduction in the cost of care—the average cost of wraparound services is \$4,000 per youth per month, compared with the monthly cost for residential treatment of \$7,800, resulting in a considerable cost savings;
- Improved clinical functioning with a 20 point average improvement on the Child Behavioral Checklist (CBCL)—an instrument designed to measure the child's functioning;
- · Reduction in re-offending rates for justice-involved youth; and
- Improved school attendance.

Many states and communities have financed the increased availability of home and community-based services through multiple funding strategies, including maximizing mental health coverage under Medicaid and applying for waiver options; combining resources from multiple child-serving agencies and diverse sources; redirecting funds from residential treatment to home and community-based services, whenever possible;



and focusing on paying for those services that produce the best outcomes.<sup>25</sup>

Private Insurance Coverage. Family advocates helped to secure a major federal policy victory in 2008 with the passage of the *Paul Wellstone-Pete Domenici Mental Health Parity and Addiction Equity Act of 2008*. This federal law requires group health plans that cover mental health treatment, to do so on the same terms as all other health conditions. Despite this exciting victory, work remains to be done to ensure that private insurance coverage includes a broad array of home and community-based services. Many private insurance companies limit coverage to those services provided in traditional clinical and medical settings. Family advocacy and leadership will be needed to help ensure that private insurance companies provide coverage for medically necessary home and community-based services and supports that help to keep children and youth with serious mental health treatment needs at home and in their communities.

### Statewide Reform and Community Leadership

In a number of cases, statewide reform in expanding home and community-based services has come in response to legal action. Two states are featured below that have engaged in extensive and detailed planning to expand the array of services available to children, youth, and their families. Although every state is unique and must undergo an individualized planning process to expand services and supports, much can be learned from the planning and service roll-out process undertaken by Massachusetts and Arizona in response to court intervention.

*Massachusetts*. In Massachusetts, a federal class action law suit was filed under Medicaid law claiming that services and supports were being denied that would allow children with mental health treatment needs to remain at home and in their communities rather than receiving services in psychiatric hospitals and residential facilities. The law suit also claimed that many children struggled at home without adequate supports and remained at high risk for repeated out-of-home placements.<sup>26</sup>

In 2006, the Court found that Massachusetts had violated Medicaid law by failing to provide needed and timely services to children. The Court ordered the state to identify children with mental health treatment needs through screening at well-child visits and to develop in-home services, including comprehensive assessments, case management, behavior supports, and mobile crisis services.<sup>27</sup>

In response to the litigation, Massachusetts worked with a broad group of stakeholders in developing the Children's Behavioral Health Initiative (CBHI), which is coordinating reform efforts. The reform calls for the development of a system of coordinated services, including the expansion of home-based services, for all Medicaid eligible children with serious mental health treatment needs in the state. In August 2008, the governor signed into law comprehensive children's mental health legislation.<sup>28</sup>

Stakeholders in Massachusetts have identified the following systems reform principles in their work to expand home and community-based services for children and their families:<sup>29</sup>

- 1. Collaboration between child-serving systems, treating providers, and the child and family;
- 2. The measurement and collection of data on functional outcomes to monitor and ensure that services provided improve the child's functioning;
- 3. Collaboration across child-serving systems and with the family and other individuals important in the child and family's life in developing and implementing an individualized treatment plan, which includes monitoring the child's progress and revising the plan, as needed:
- 4. Access to a comprehensive array of home-based and related services and supports;
- Home-based services are provided by trained and qualified providers and address the complete needs of the child; they are evaluated and monitored to ensure that positive outcomes are continuously being achieved;
- 6. Services are provided in the least restrictive and most appropriate setting for the child's needs;

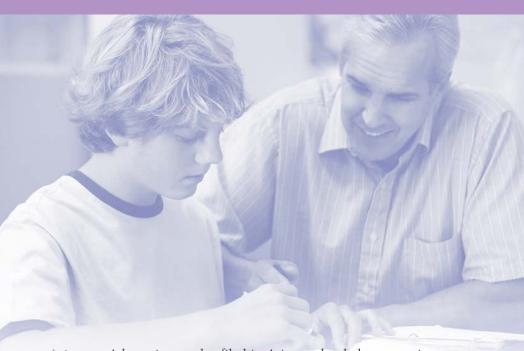
- 7. Children identified as needing home-based services are assessed and served promptly;
- 8. Services are designed for the unique needs of the child and family;
- 9. All steps are taken to ensure stability in the services the child receives, including intensive services to avoid out-of-home placements and to help during periods of transition;
- 10. Home-based services are provided in a manner that respects the child and family's cultural traditions and heritage;
- 11. Home-based services include support and training for parents in meeting the child's needs and to help the child develop the skills needed for self-management and improvement; and
- 12. The treatment plan maintains a connection to the child and family's natural supports.

The Massachusetts reform plan also calls for the following action steps to be taken to improve the systems serving children and their families:<sup>30</sup>

- Screening and Identification all Medicaid-eligible children must be screened by primary care physicians or nurses to identify potential mental health conditions as part of well-child visits, during visits to primary care offices, or at the request of a parent or caregiver. Six screening instruments or questionnaires are available for screening.
- Mental Health Evaluation children identified through the screening as having a potential mental health condition must be referred for a mental health evaluation. Those identified as having a mental health condition are provided with intensive care coordination and an assessment for home-based services.
- Intensive Care Coordination when a child is identified with a serious mental health condition, the child is entitled to intensive care coordination, which includes a comprehensive home-based assessment, a single care coordinator and treatment team, and an individual care plan for all services. Intensive care coordinators are trained in the wraparound planning process that helps to ensure that the child and family receive the services needed for the child to succeed.
- Treatment Planning Process the intensive care coordinator convenes the treatment team. That team works through the wraparound planning process to establish an individualized treatment plan made up of home-based services that build on the children's

- strengths, empowers the child's family, integrates the family's culture, and "wraps" appropriate services around the needs of the child and family.
- Covered Services Massachusetts is planning to implement seven new statewide services that are designed to help children succeed at home and avoid unnecessary hospitalization or residential placement, including the following:
  - o Intensive Care Coordination care coordination is the cornerstone of the new system and uses the wraparound planning process to develop and implement an individual care plan based on the strengths and needs of the child and family;
  - o Comprehensive Home-Based Assessments;
  - o Mobile Crisis Intervention therapeutic response to a child's mental health crisis by trained and qualified professionals available in-home and in the community on a 24-hour/7-day a week basis;
  - o Crisis Stabilization Services short-term crisis stabilization bed to prevent or help in a crisis that also supports parents and caregivers and links children with appropriate services;
  - o In-home Behavioral Services including behavior management therapy and behavior management monitoring in settings where children are naturally located;
  - o In-home Therapy Services addressing the child's mental health needs and promoting healthy functioning of the child within the family; and
  - o Therapeutic Mentoring Services therapeutic mentors work with children to address their daily living, social and communication needs in their natural settings.

Much of the expertise on effective mental health services for children that went into and came out of the Massachusetts case has been documented on Web sites that include valuable information for families and other communities working on reform. For more information, visit <a href="https://www.mass.gov/masshealth/childbehavioralhealth">www.mass.gov/masshealth/childbehavioralhealth</a> (developed by the state for the children's behavioral health initiative) or <a href="https://www.rosied.org">www.rosied.org</a> (developed by the Center for Public Representation, which represented the children and families in the Massachusetts case).



*Arizona.* A lawsuit was also filed in Arizona that led to sweeping mental health reforms in the children's mental health system. The settlement in the case was unique because it represented the first statewide overhaul of a mental health system that operated under a Medicaid managed care contract.<sup>31</sup>

Like the Massachusetts case, the Arizona case provides a snapshot into the process of statewide reform to expand the array of services for children. In Arizona the state adopted a set of systems reform principles that are nearly identical to the 12 principles adopted in Massachusetts.

In Arizona, reform leadership existed at the highest level with the Governor endorsing the principles and case outcome by stating, "For too long, the state has failed Arizona's children with mental health needs. This settlement represents my commitment to improving children's behavioral health services in Arizona."<sup>32</sup> Leadership at the highest levels of government helps to encourage reform.

The settlement committed the state to take the following action steps:

- Develop flexible wraparound supports and case management;
- Develop child and family teams for all children;
- Train and coach frontline staff and supervisors in delivering effective services to children and their families;

- Develop a quality assurance program that measures fidelity to the principles; and
- Make specific improvements in the structure of the managed care arrangement to ensure that children receive the mental health services and supports necessary to improve their service outcomes.

The settlement in 2001 called for reform to be implemented over a sixyear period. In 2006, the parties in the case agreed to a three-year extension for implementation of the reforms through 2010.

The Massachusetts and Arizona cases caused the states to place a sharper focus on achieving better outcomes for children and youth with serious mental health treatment needs and their families by providing a broader array of effective services and supports.

Another case that focused on the need to expand community-based services was issued by the U.S. Supreme Court in 1999. In the *Olmstead* case, the Court decided that unjustified isolation and segregation of individuals with disabilities, including mental illness, in institutions constitutes discrimination under the Americans with Disabilities Act (ADA).<sup>33</sup> The ADA is a federal law to protect individuals with disabilities from discrimination. The court recognized that institutional confinement denies individuals the opportunity to participate in important life activities like family relations, social contacts, work, educational advancement, and cultural enrichment. The decision applies to children and the need to provide them with services in the least restrictive setting consistent with their level of clinical need. It has resulted in many states engaging in planning to increase community-based services.<sup>34</sup> Unfortunately, it has not led to widespread action in implementing a broader array of services and supports.

Strong Leadership and a Commitment to Improving Outcomes. In many communities, systems reform has come from strong leaders working with a sustained commitment to systemic change that leads to positive outcomes. Although only one community is included here, many communities have seen positive systems reform with strong leadership.

*Hampton*, *Virginia*. Hampton has had strong leadership for many years in providing children and families with services and supports that promise to keep children at home and in their communities. In the early 1990s, leaders in Hampton took a closer look at how their budgets were being spent. They discovered that a considerable amount of money was spent on sending children and youth to residential treatment centers. The outcomes for these children were not good and the costs were high.<sup>35</sup> The community recognized the fundamental principle that every child deserves a family, and proceeded to build an array of services and supports around the idea of keeping children at home and with their families

The community leaders embraced a number of the CMHS systems of care values, including that all services for children and their families are child-centered, family-driven, community-based, strength-based, and culturally and linguistically competent. They also started with the outcome they wanted to achieve—keeping children and families together and serving children in their communities—and then developed the services and supports that were needed to achieve that result.

Hampton developed the following core values and beliefs as the foundation of their system of care:<sup>37</sup>

- Keeping children and families together is the best possible use of resources;
- Hampton's community policy and management team and family assessment and planning team partner with all who can support the successful outcomes of children and their families;
- Hampton begins with outcomes, not process;
- Families are experts about their families;
- All stakeholder groups are accountable to positive outcomes for children and their families at home, in school, and in the community;
- Child-centered, family-driven, and community-based service delivery is the law and must be turned into action;
- Hampton will do whatever it takes to support the success of children and families; and
- Trying hard is not good enough.

Community leaders recognize that services must be individualized and change as the needs of children and their families change. They remain true to the community's core beliefs and values as they continue to look for innovative services and supports that produce positive outcomes.

Here are a number of the positive systemic and service-related outcomes that Hampton has achieved in their ongoing work on systems reform:<sup>38</sup>

- Hampton seldom uses residential treatment as a service option. 6.9
  percent of all children served by Hampton in 2006 received residential services, with the state average at 25 percent;
- Hampton uses residential services as a last resort. 13.4 percent of service dollars in 2006 were spent on residential services with the state average at 44 percent;
- Hampton had no children placed in residential treatment facilities for a significant part of calendar year 2007;
- Hampton has made a strong commitment to interagency collaboration since 1993 to support children and families remaining together in the community through services including intensive case management, therapeutic foster care, parent training, family reunification, and intensive in-home services; and
- No Hampton children have been placed in out-of-state care for over 10 years.

Hampton contributes their success in developing an effective system of care to a number of key factors, including the following:<sup>39</sup>

- Trust and strong working relationships between and among leadership in child-serving agencies;
- Trust and strong working relationships between local elected officials and agency staff;
- Local government officials' belief in the need for innovation and best practices in serving children and their families, and the strong belief that families are the primary natural community resource for their children;
- Firm belief among local leaders, department directors, and program staff that children have better outcomes when served in the community rather than in out-of-home placements;
- Significant and consistent leadership and support from Juvenile and Domestic Relations Court judges;

- Development of a family assessment and planning team dedicated to community services and co-located in the child welfare department;
- Clear focus of purpose from the beginning in creating innovative community-based services and bringing children home from out-ofcommunity residential treatment centers; and
- The commitment from multiple agencies to offer resources to support the development of a robust children's mental health system and related services.

Principles, reform efforts, and action steps developed through litigation provide guidance for families and other key stakeholders working to implement a broader array of effective mental health services for children and their families. Much can also be learned from states and communities redesigning services through Medicaid waivers and other financing options and in communities with strong leadership.

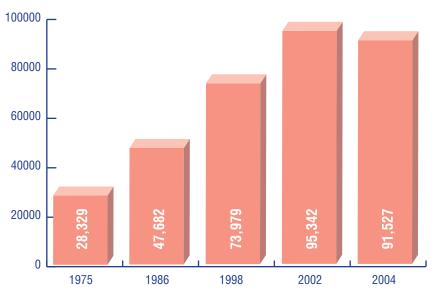
# The Use of Residential Treatment Facilities ~ A National Snapshot

Children with mental illness continue to enter residential facilities, especially children whose families cannot find or do not have the resources to obtain the community services and supports needed to keep their children at home.

SAMHSA Report on State Regulation of Residential Facilities for Children with Mental Illness <sup>40</sup>

The number of children and youth with mental health treatment needs treated in residential treatment centers has increased significantly over the past 30 years. Although the question of why this is happening has not been well-studied, it is likely the result of a reduction in psychiatric hospital beds for children; the lack of an adequate supply of home and community-based services in many communities; and the failure to provide mental health services early when less intensive services would be more appropriate.

## Episodes of Residential Treatment Facility Use for Children with Emotional Disturbance\*



\*Episodes – first-day census plus admissions (Sources: Mental Health U.S., 2004; Milazzo-Sayre, 2008)

Data show that close to 100,000 children and youth were served in licensed residential treatment facilities in 2004, the latest year for which data is available.

The data show a continued and steep increase in the number of children and youth served in residential facilities over the past nearly 30 years. This is happening despite calls from national leaders for an increase in the availability of intensive home and community-based services and a reduction in the level of out-of-home care.

Recently released data from a national household survey show an annual rate of 227,000 youth aged 12 to 17 that received mental health services in residential treatment centers. <sup>41</sup> This number is significantly higher than the number reflected in the graph above because it includes youth served in both licensed and unlicensed facilities, whereas the graph data is limited to youth served in licensed facilities.

Children are referred to residential treatment from a number of sources, including the child welfare system, the juvenile court system, hospitals, community mental health and other providers, family members, schools, and other sources. <sup>12</sup> States and communities should look at the root cause of why children are increasingly being placed in out-of-home care. Inadequate case management and a lack of family support to help manage and keep children at home may be factors. Needed are more case managers who see their end goal as keeping children and families together and who are skilled at structuring services to meet that goal.

The quality, safety, and effectiveness of residential treatment programs vary greatly across the country. The use of the term "residential treatment center" often describes an array of different types of facilities and treatment centers that use different approaches in serving children and youth. Some of these treatment centers are licensed and regulated by states, while others are not. Some use promising and therapeutic approaches in addressing the needs of children and youth. Others use punitive and harsh approaches that have been shown to be harmful. Families need to assess these programs carefully before selecting one for their child.<sup>43</sup>

Many residential treatment providers are developing stronger links with families. Many are also increasingly focused on providing evidence-based and promising interventions within their residential programs recognizing the importance of improving treatment outcomes for children and their families. Others have diversified the services they provide to children and their families beyond residential treatment to include outpatient services, family support services, therapeutic foster homes, and more. Families report that some of these programs have shown promising outcomes for children and youth.

There have been historical tensions between residential and community-based service providers. In light of these tensions, the Child, Adolescent and Family Branch of the Center for Mental Health Services convened a meeting of stakeholders to better link and integrate residential service providers with community-based providers. The meeting included youth and families from across the country. A significant outcome of

that meeting was the development of a Joint Resolution titled *Building Bridges Between Residential and Community Based Service Delivery Providers, Families and Youth.* The resolution includes a set of shared principles, values, and practices.<sup>45</sup>

Families are encouraged to review the *Building Bridges* resolution. It acknowledges the need for stronger links between families and all treatment providers, the need for a broader array of effective services, and the need to increase the availability of home and community-based services and supports.

Although research on the effectiveness of residential treatment is limited, *family-centered residential care* is an emerging best practice. The key components of family-centered residential treatment are consistent with the *Building Bridges* resolution and include the following:<sup>46</sup>

- Maximize regular contact between the child and family (home visits; explanation of any restrictions in contact; review policies to ensure they encourage contact);
- Actively involve and support families with a child in residential treatment (place families on agency boards; create parent advocate positions within treatment centers; include and involve youth and families in all aspects of service planning; share information, training, and knowledge with families; work with youth and families on transitions; use treatment strategies that families can use in their homes; use culturally appropriate services; treat parents as experts and with respect; include family therapy; offer family support groups); and
- Provide ongoing support and aftercare for the child and family (involve residential staff in wraparound and other home and community-based care; see residential care as services for stabilization and treatment planning through family and community partnerships; locate home and community-based services such as family support at residential treatment centers; expand residential respite options and related services for families; focus on the well-being of the child and family; and develop models that serve the whole family during and after residential care).

The hope in expanding home and community-based services is that fewer children will be served in out-of-home settings and fewer families will struggle in attempts to secure effective and appropriate services. However, if children require short-term out-of-home care, family-centered residential treatment programs certainly promise to produce better outcomes for children and their families.

In communities with a broad array of home and community-based services, residential treatment is used only for short-term stabilization and while an appropriate treatment plan can be developed that includes intensive home and community-based services.

The good news is that in difficult fiscal times, many states and communities closely examine their budgets to help justify that the funding they spend on services leads to positive outcomes. This can lead to work on meaningful reform. It can also be a double-edged sword, with public officials being forced to reduce or cut essential services.

The family voice is critically important as communities continue to work on systems reform and on expanding the availability of effective home and community-based services.

# Families Can Help Drive the Expansion of Home and Community-Based Mental Health Services and Supports

The movement to expand the array of effective services and supports that are available to children and their families continues to grow. Many families are playing key roles in that movement.

The following are ideas for families interested in becoming more involved in working to expand home and community-based services and supports in their communities:

• **Data Counts.** Much can be learned from the numbers. What do the service costs and outcomes data look like in your community?

Does the budget show that adequate funds are being invested in effective home and community-based services? What is the funding break-down when it comes to the array of services? How many children and youth are being served? It is important to gather this information from the mental health system, but also from other child-serving systems, including child welfare, juvenile justice, and the school system. Many children and youth with mental health treatment needs are required to seek services through these other systems, often because that is where the money is.

Outcomes data is important, however not always collected and available. It is important to know whether children and youth are improving from the services they receive. Data helps to make the case for expanding effective services and for reducing ineffective services with state and local officials and with legislators. The failure to collect outcomes data should be addressed and families are in a key position to do so.

Families in the ten states participating in the CMS *Community Alternatives to Psychiatric Residential Treatment Facilities (PRTF)*Demonstration Project (Alaska, Florida, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia) can ask state officials for information on the expansion of services, the number of youth being served through the project, the cost data, and more. All of this must be reported to CMS by these states, so they will have this information available. Families outside of the ten states can also request the information to help make the case in their states on the value of effective community-based services as an alternative to residential treatment facilities.

• Learn about Effective Home and Community-Based Services. Much has been written about research showing the effectiveness of home and community-based services. NAMI developed another family guide titled, Choosing the Right Treatment: What Families Need to Know About Evidence-Based Practices (EBP guide), that provides information about effective interventions and resources families can access to learn more about evidence-based practices. The EBP guide can be accessed online at www.nami.org/caac. The more that families

know about effective mental health services and supports, the more they can make the case for shifting resources to these services.

- Build Your Coalition. Many families and youth work with mental health and disability coalitions in their communities. Several of the communities featured in this Guide referenced the importance of involving families, youth, and other key stakeholders in working to expand the array of services and supports available to children, youth, and their families. Some of the obvious important stakeholders, in addition to families and youth, include state and community mental health authorities, mental health provider organizations, child welfare and juvenile justice officials, education leaders, judges, Medicaid officials, law enforcement, and others. Provider groups should include both home and community-based providers and residential treatment and group home providers to learn from each other and to get buy-in on reform work.
- Judicial Power. Do not underestimate the power of judges. They can be a strong partner for change. Many youth with serious mental health treatment needs get entangled with law enforcement and the juvenile justice system. Judges see these young people appear before the court. They also know it can be extremely difficult to access mental health services. Judges have broad discretion to order mental health and/or substance use services and can influence the expansion of intensive home and community-based services. It is also important to bring them into coalitions designed to increase effective home and community-based services so that they can learn more about the effectiveness of these services, can use their leadership and power to push reforms that include these services, and will consider ordering these services when youth appear before the court.
- Who are the Medicaid and Financing Experts? From the states that have used the Medicaid 1915(c) Home and Community-Based Waiver and other innovative financing options, it is clear that financing experts were instrumental in helping those states design the flexible funding necessary to increase the availability of a broader array of services. Families should see whether Medicaid community-

based financing experts are available in their states and communities and, if not, should consider asking officials to bring in consultants who have worked with other states and communities in structuring funding for expanding home and community-based services and supports.

States and communities that have developed innovative funding options to increase home and community-based services also pointed to the importance of having a close working relationship between the Medicaid agency and the agency providing mental health services for children and their families. Families may be able to help foster a closer connection between these two agencies through coalition work.

- Where is the Leadership? A number of communities and states point to the critical need for strong leadership. They also cite the importance of having a shared vision, a strong set of common beliefs, and common agreement on the outcomes that are important to children, their families, and community leaders. It is not enough to develop strategic plans for change or reform—leadership comes with implementation, evaluation, and an ongoing commitment to continuous quality improvement in services and supports. Families can help find, encourage, and support strong leaders to put the expansion of effective mental health services and supports on their agenda. Funders can also assume leadership roles in reform and become involved on boards, panels, and in other decision-making positions.
- Communicate Clear Rationale and Success in Other Communities. Families and youth can play a key role with legislators and state and local officials in communicating a clear rationale for increasing home and community-based services. They can also share positive outcomes that other states and communities have achieved in expanding the array of services for children and their families. Youth and families are also uniquely positioned to communicate the importance of early identification and intervention so that children do not lose critical developmental years to undiagnosed and untreated mental illness. Families and youth can define the in-



home services and supports that should be provided to avoid unnecessary out-of-home services. Personal stories are powerful in bringing about change—especially positive stories that profile how effective services turned a young person's life around.

• Ask Leaders from other Communities and States to Share Their Recipe for Success. Although community and state leaders are extremely busy, they are often willing to make time to share information about their keys to success. It is also possible to access public documents that communities have developed in applying for

Medicaid waivers, that come from litigation and more—that define the process used to expand the array of home and community-based services. No need to reinvent the wheel. Information is available online about how states and communities are working to transform their systems.

- Define the Outcomes that Matter Most to Youth and Families. It is important for youth and families to inform systems change by defining the outcomes that matter most to them. Systems should be developed by taking those outcomes and developing services and supports that will help children and their families meet those outcomes. In Hampton, Virginia, they did just that. Their primary outcome was keeping children with their families and in their communities. The community then worked with youth and families in designing the services necessary to make that happen. There are a core set of services that can be offered in homes and communities that promise to help more children and youth live at home with their families.
- Track Outcomes, Share Successes, and Insist on Reinvestment in Systems of Care (SOC). It is essential that communities track service outcomes to ensure that the investment they are making is leading to improved outcomes for children, youth, and their families. Data, combined with personal stories, is powerful in making the case for a continued investment in effective services. Without data, it is far easier to cut services. Also, it is important to show cost savings whenever possible, which appeals greatly to state legislators and other state leaders. If expansion of home and community-based services leads to a savings in out-of-home services, it is important to document that and to share it. However, it is also equally important that any cost savings be reinvested in sustaining and expanding a broader array of effective services and supports.

These funds can be used for training, supervision, and ongoing monitoring of providers in new and effective interventions. Also, in developing and upgrading data systems to track outcomes across child-serving systems (like mental health, child welfare, juvenile jus-

tice, and education) and in expanding the array of services and supports that are available for children and their families.

• Look Beyond the Usual Suspects for Funding. A number of communities that are engaged in systems reform have secured public and private funding for their work. This includes funds from private foundations interested in investing in the health and well-being of children. Foundations are much more likely to consider funding reform efforts when they see the development of a well-thought out plan, the right stakeholders at the table, that the state or community is ready for roll-out, and that the political will exists for reform. It helps when their funding is the final catalyst for change.

The voice of youth and families must continue to be loud and clear on the need to expand home and community-based services for children and youth with mental health treatment needs and their families. Families are encouraged to review the resources included at the end of this guide for updates and to learn more about successful reform efforts.

## Resources Related to Expanding Home and Community-Based Mental Health Services and Supports

#### Residential and Out-of-Home Services

- The Bazelon Center for Mental Health Law, Fact Sheet ~ Children in Residential Treatment Centers: www.bazelon.org/issues/children/fact-sheets/rtcs.htm
- Building Bridges Between Residential and Community Based Service Delivery Providers, Families and Youth: <a href="www.nami.org/caac">www.nami.org/caac</a> (Click on "Research, Services & Treatment" and "Other Resources")
- U.S. General Accountability Office, Child Welfare and Juvenile Justice ~ Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services: www.gao.gov/new.items/d03397.pdf

- The National Survey on Drug Use and Health Report, *Out-of-Home Services for Emotional or Behavioral Problems among Youths Aged 12 to 17: 2002 to 2006:*<a href="mailto:download.ncadi.samhsa.gov/prevline/pdfs/NSDUH08-0918.pdf">download.ncadi.samhsa.gov/prevline/pdfs/NSDUH08-0918.pdf</a>
- U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *State Regulation of Residential Facilities for Children with Mental Illness:*<a href="https://www.samhsa.gov/News/NewsReleases/residfacilchildrenFinal.pdf">www.samhsa.gov/News/NewsReleases/residfacilchildrenFinal.pdf</a>
- The Alliance for the Safe, Therapeutic and Appropriate Use of Residential Treatment (A START): astart.fmhi.usf.edu

# Financing A Broad Array of Home and Community-Based Services Medicaid Financing

- The Bazelon Center for Mental Health Law, An Advocate's Guide to Overcoming State Barriers and Obtaining a Home-and Community-Based Waiver for Children with Mental Health Needs:

  www.bazelon.org/issues/children/publications/3statewaivers/3statewaivers.pdf
- National Health Policy Forum, Kansas' HCBS-SED Waiver PowerPoint Presentation: www.nhpf.org/library/handouts/Denney.slides 10-07-05.pdf
- National Alliance on Mental Illness (NAMI), Community-Based Alternatives to Psychiatric Residential Treatment Facilities Grants: <a href="https://www.nami.org/caac">www.nami.org/caac</a> (Click on "Federal and State Policy & Legislation" and "Medicaid")
- Centers for Medicare and Medicaid Services, National Evaluation of Medicaid Demonstration ~ Home-and Community-Based Alternatives to Psychiatric Residential Treatment Facilities: www.cms.hhs.gov/DeficitReductionAct/Downloads/ CBAImplementationStatus Report.pdf

#### **Other Financing Options**

- The Bazelon Center for Mental Health Law, *Wraparound and Therapeutic Foster Care and Their Implications for Taxpayers:* www.bazelon.org/issues/children/wraparoundTFC.htm
- University of South Florida, *Effective Strategies to Finance a Broad Array of Services and Supports*: <a href="mailto:rtckids.fmhi.usf.edu/rtcpubs/hctrk-ing/pubs/briefs/RTCstudy3IBrief01.pdf">rtckids.fmhi.usf.edu/rtcpubs/hctrk-ing/pubs/briefs/RTCstudy3IBrief01.pdf</a>
- The Georgetown University Center for Child and Human Development, Financing Children's Mental Health Services ~ Coping with a Changing Fiscal Environment:

  www.gucchd.georgetown.edu/programs/ta\_center/TrainingInstitutes/
  SpecialForums
- National Center for Children in Poverty, Unclaimed Children Revisited
   ~ Towards Better Behavioral Health for Children, Youth and Their
   Families, Financing that Supports Knowledge: www.nccp.org/publications/pub 804.html
- U.S. Department of Health and Human Services, Public Financing of Home and Community Services for Children and Youth with Serious Emotional Disturbances ~ Selected State Strategies: www.aspe.hhs.gov/daltcp/reports/2006/youthSED.pdf

### Home and Community-Based Services

- Bazelon Center for Mental Health Law, Olmstead Planning for Children with Serious Emotional Disturbance ~ Merging System of Care Principles with Civil Rights Law: <a href="www.bazelon.org/olmsteadchildren2.pdf">www.bazelon.org/olmsteadchildren2.pdf</a>
- Big Brothers Big Sisters: www.BigBrothersBigSisters.org
- Blueprints for Violence Prevention: <u>www.colorado.edu/cspv/blueprints</u>
- Functional Family Therapy Online: www.fftinc.com
- MST Services: www.mstservices.com

- Multi-dimensional Treatment Foster Care: www.mtfc.com
- National Alliance on Mental Illness (NAMI), A Family Guide on Choosing the Right Treatment ~ What Families Need to Know About Evidence-Based Practices: www.nami.org/Content/ContentGroups/CAAC/ChoosingRightTreatment.pdf
- National Dissemination Center for Children with Disabilities, Briefing Paper ~ Respite Care:
   www.nichcy.org/InformationResources/Documents/NICHCY%20PUB S/nd12.pdf
- National Mentoring Center: www.nwrel.org/mentoring
- National Wraparound Initiative: www.rtc.pdx.edu/nwi
- New York State Office of Mental Health, Evidence-Based Practices for Children and Families: www.omh.state.ny.us/omhweb/ebp/children.htm
- $\bullet \quad \text{Strengthening America's Families: } \underline{www.strengtheningfamilies.org}$
- Substance Abuse and Mental Health Services Administration's Systems of Care: <a href="https://www.systemsofcare.samhsa.gov">www.systemsofcare.samhsa.gov</a>
- Substance Abuse and Mental Health Services Administration's National Registry of Evidence-based Programs and Practices: www.nrepp.samhsa.gov
- Washington State Institute for Public Policy: www.wsipp.wa.gov

### Home and Community-Based Services Expanded Through Legal Action

• Rosie D., Reforming the Mental Health System in Massachusetts, a web site developed by the Center for Public Representation: <a href="https://www.rosied.org">www.rosied.org</a>

- Children's Behavioral Health Initiative, a Web site developed by the Commonwealth of Massachusetts in response to the *Rosie D*. case: <a href="https://www.mass.gov/masshealth/childbehavioralhealth">www.mass.gov/masshealth/childbehavioralhealth</a>
- J.K. v. Eden: www.bazelon.org/incourt/docket/JK.html

#### References

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- <sup>2</sup> National Institute of Mental Health Press Release titled *Mental Illness Exacts Heavy Toll, Beginning in Youth.* June 6, 2005 (accessed at *www.nimh.nih.gov*).

  <sup>3</sup> U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Health, National Institute of Mental Health, 1999.
- <sup>4</sup> SAMHSA/CMHS News Release: Helping Youth Thrive in the Community. May 8, 2008 (accessed at www.systemsofcare.samhsa.gov).
- <sup>5</sup> U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Health, National Institute of Mental Health, 1999. New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. Committee on Quality of Health Care in America, Institute of Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, D.C.: National Academy Press.
- <sup>6</sup> Isaacs, M.R., Huang, L.N., Hernandez, M. & Echo-Hawk, H. (2005). *The Road to Evidence: The Intersection of Evidence-based Practices and Cultural Competence in Children's Mental Health*. Washington, D.C.: National Alliance of Multi-Ethnic Behavioral Health Association.

- <sup>7</sup> Martinez, K.J. (2008). *Community Defined Evidence: What is it? And What Can it Do for Latinas/os?* El Boletin: The Newsletter of the National Latina/o Behavioral Health Association. Fall/Winter Edition.
- <sup>8</sup> President's New Freedom Commission on Mental Health, *Policy Options Subcommittee on Children and Family ~ Promoting, Preserving, and Restoring Children's Mental Health.* February 5, 2003 (accessed at www.mentalhealthcommission.gov).
- <sup>9</sup> Rosie D. v. Romney, information accessed at www.rosied.org.
- <sup>10</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.
- <sup>11</sup> National Center for Mental Health and Juvenile Justice. Blueprint for Change: A Comprehensive Model for the Identification and Treatment of Youth with Mental Health Needs. 2006.
- <sup>12</sup> To learn more about effective and evidence-based practices (EBPs) in children's mental health, NAMI developed a family guide on EBPs, titled *A Family Guide on Choosing the Right Treatment ~ What Families Need to Know About Evidence-Based Practices*, that can be accessed at <a href="https://www.nami.org/caac">www.nami.org/caac</a>.
- <sup>13</sup> GAO report on Custody Relinquishment/Bazelon Report on Custody Relinquishment. Keeping Families Together Act.
- <sup>14</sup> Preliminary Children's Mental Health Plan issued by the New York State Office of Mental Health, October 2007.
- <sup>15</sup> Information obtained from presentation to the National Health Policy Forum, Washington, D.C., October 7, 2005. Presenters included Eric Van Allen (TA Coordinator/SRS-HCP Children's Mental Health Team) and Krista Cowger (Program Consultant II/Training Specialist/SRS-HCP Children's Mental Health Team).
- 16 Id.
- 17 Id.
- <sup>18</sup> Preliminary Children's Mental Health Plan issued by the New York State Office of Mental Health, October 2007.
- <sup>19</sup> New York State Office of Mental Health Division of Children and Families. Home and Community Based Services Waiver Guidance Document. (accessed at www.omh.state.ny.us)
- <sup>20</sup> The Bazelon Center for Mental Health Law. *Advocates Guide to Obtaining a Home and Community-Based Waiver.* (accessed at www.bazelon.org).

- <sup>21</sup> National Evaluation of Medicaid Demonstration: Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities. *Implementation Status Report as of October 1, 2008.* Submitted to the Center for Medicare and Medicaid Services and prepared by IMPAQ International and Westat, Inc. (accessed at www.cms.hhs.gov/DeficitReductionAct/20\_PRTF.asp).
- <sup>22</sup> Stroul & Pires. Financing Children's Mental Health Services: Coping with a Changing Fiscal Environment. July, 2006 (accessed at gucchd.georgetown.edu).
- <sup>23</sup> Presentation to the Summit on Public/Private Partnerships, September 2008. Presentation provided by Bruce Kamradt, Director, Wraparound Milwaukee.
- <sup>24</sup> Presentation to the Coalition for Juvenile Justice Spring Conference, April 2008. Presentation provided by Bruce Kamradt, Director, Wraparound Milwaukee.
- <sup>25</sup> Stroul, B.A., (2007) Issue Brief 1: Effective Strategies to Finance a Broad Array of Services and Supports. University of South Florida, Louis de la Parte Florida Mental Health Institute (FMHI), Research and Training Center for Children's Mental Health. (accessed at rtckids.fmhi.usf.edu/study03.cfm)
- <sup>26</sup> Lawyers from the Center for Public Representation represented the children and families in the *Rosie D*. lawsuit against the Commonwealth of Massachusetts, and created a Web site that includes many valuable resources related to the case, the Court's decision, and action being taken by the state to improve services for children and families. You can access the Web site by visiting *www.rosied.org*.
- <sup>27</sup> Information accessed at www.rosied.org.
- <sup>28</sup> Chapter 321 of the Acts of 2008 titled An Act Relative to Children's Mental Health.
- <sup>29</sup> Information accessed from www.rosied.org and from the CBHI Web site at www.mass.gov/masshealth/childbehavioralhealth.
- <sup>30</sup> Information accessed at www.rosied.org and from the Court Judgment, accessed at www.mass.gov/masshealth/childbehavioralhealth.
- <sup>31</sup> Summary statement on the *J.K. v. Eden* lawsuit issued by the Bazelon Center for Mental Health Law, which represented the plaintiff class of children, along with the National Center for Youth Law and the Arizona Center for Disability Law (accessed at *www.bazelon.org*).
- <sup>32</sup> Summary statement on the *J.K. v. Eden* lawsuit issued by the National Center for Youth Law (accessed at www.youthlaw.org).

- <sup>33</sup> Olmstead v. L.C., 527 U.S. 581 (1999).
- <sup>34</sup> The Bazelon Center for Mental Health Law has created an *Olmstead* information center that includes much information about the U.S. Supreme Court's decision in the case. Information about the case can be accessed at <a href="https://www.bazelon.org/olmstead">www.bazelon.org/olmstead</a>.
- <sup>35</sup> Information obtained from a phone interview with Michael Terkeltaub, who currently serves as a consultant to local and state agencies working on systems reform, and served as the Hampton Virginia Family Assessment and Planning Team Coordinator (FAPT) and Coordinator of Comprehensive Services.
- <sup>36</sup> Report Commissioned by the Hampton Community Policy and Management Team, *Historical Perspective, Data, Outcomes and Practice Improvement Project.* Prepared by Triad Training and Consulting Services.
- <sup>37</sup> Hampton Virginia Comprehensive Services Act Community Policy and Management Team, *The Hampton Approach to Child Centered, Family Focused, Community Based Practice,* November 2007 (accessed at *dls.state.va.us/GROUPS/CSA/meetings/112007/hamptonsystem.pdf*).
- 38 Id.
- <sup>39</sup> Id.
- <sup>40</sup> Ireys, HT, Achman L, Takyi A. *State Regulation of Residential Facilities for Children with Mental Illness*. DHHS Pub. No. (SMA) 06-4167. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2006.
- <sup>41</sup> National Survey on Drug Use and Health. *Mental Health Service Use among Youths Aged 12 to 17: 2005 and 2006.* September 25, 2008 (available online at oas.samhsa.gov).
- <sup>42</sup> Abt Associates, Inc. *Characteristics of Residential Treatment for Children and Youth with Serious Emotional Disturbances*. A report prepared for the National Association for Children's Behavioral Health and the National Association of Psychiatric Health Systems. Summer 2008.
- <sup>43</sup> NAMI developed a resource to help families considering residential treatment for their child titled *A Resource Guide for Families Considering Residential Treatment Programs for their Children* that is available at www.nami.org/caac.

  <sup>44</sup> Id
- <sup>45</sup> To review the Joint Resolution, visit the CMHS Child, Adolescent and Family Branch Web site at www.systemsofcare.samhsa.gov (click on "Hot Topics" and then "Issues in Residential Care.").



## NOTES

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