U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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The Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances

Report to Congress 2014

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The Comprehensive Community Mental Health Services for Children and Their Families Program

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Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

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Summary of Findings

Data from grantees that are part of the Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances program, initially funded in fiscal years (FY) 2009 and 2010 ("the CMHI Cohort"), are the focus of this report. Results indicate that children and families made substantial gains in many areas. Specifically, data gathered from this CMHI Cohort as of June 11, 2014, demonstrate that systems of care:

- provide services and promote positive outcomes for many children and youth typically underserved by the mental health system;
- improve behavioral and emotional health outcomes of children and youth;
- enhance family outcomes such as reduced levels of caregiver strain;
- expand the availability of effective supports and services;
- reduce expenditures on residential treatment, inpatient hospitalization, and juvenile justice services;
- continue to implement and maintain fidelity to the system of care principles; and
- protect special populations of children and youth such as those who are involved in bullying or identify as LGBTQI2-S.

As in any system improvement effort, grantees face many challenges in sustaining their efforts to effectively serve children with serious emotional disturbance and their families, and in effecting broad system-level changes after federal funding ends. Such challenges include:

- building a culturally and linguistically competent workforce;
- promoting cross-agency collaboration to serve the needs of children, youth, and families;
- developing and sustaining an efficient structure for collaboration among multiple agencies; and
- implementing multiple strategies for sustaining systems of care and their services over time.

Despite these challenges, this CMHI Cohort of grantees continued to provide quality care that resulted in significant improvements and positive outcomes for children, youth, and their families.

Introduction

The Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances, also known as the Children's Mental Health Initiative (CMHI), is a cooperative agreement administered by the Child, Adolescent and Family Branch in the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA) in the U.S. Department of Health and Human Services. The CMHI was authorized by Public Law 102-321 to provide funds to public entities to promote recovery and resilience for children and youth who have a serious emotional disturbance (SED)[1] and their families. From FY 1993 through FY 2014, the program has supported a total of 276 grants and cooperative agreements and served over 129,000 children.

Pursuant to section 1912(c) of the Public Health Service Act, as amended by Public Law 102-321, "children with a serious emotional disturbance are persons from birth up to age 18 who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of

sufficient duration to meet diagnostic criteria specified within DSM-III-R (or its subsequent revisions) that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities" (Federal Register, p. 29425)

Between 13 and 20 percent of children and youth face the challenges of a diagnosable mental, emotional, or behavioral disorder, which costs the public $247 billion annually (National Research Council and Institutes of Medicine, 2009; Perou et al., 2013). There are significant advantages to early identification, referral, and treatment of problems because approximately one-half of all diagnosed mental health concerns found in adults started by age 14 and three quarters by age 24 (Kessler et al., 2005), yet fewer than half of the children and youth in need of mental health services receive adequate assistance (Merikangas et al., 2011).

The daily challenges faced by children and youth[2] with serious mental disorders place them at a greater risk for substance use disorders (Manteuffel, Stephens, Brashears, Krivelyova, & Fisher, 2008), encounters with the juvenile justice system (Cocozza, Skowyra, Burrell, Dollard, & Scales, 2008), difficulties in employment later in life (Parks, Svendsen, Singer, Foti, & Mauer, 2006), and poor educational outcomes (McLeod & Fettes, 2007), compared with their peers who do not have a serious mental disorder. Unfortunately, only about one-third of youth admitted to substance use disorder treatment who have other mental health conditions receive any care for their conditions (Chan, Godley, Godley, & Dennis, 2009). Students with serious mental disorders are more likely to fail classes, earn low grades, miss days of school, and have higher dropout rates than are students with other disabilities (Clark et al., 2008; Epstein, Nelson, Trout, & Mooney, 2005; Wagner & Cameto, 2004). These poor outcomes are particularly the case in children and youth who experience bullying or identify as lesbian, gay, bisexual, transgendered, questioning, intersex, or two-spirit (LGBTQI2-S; Seil, Desai, & Smith, 2014; Turmer, Exum, Brane, & Holt, 2013). Recent data about these populations of children and youth have focused SAMHSA's attention on meeting their mental health care and service needs.

CMHI funds are provided to states, county and local governmental entities, U.S. territories, Indian tribes and tribal organizations, and other American Indian/Alaska Native communities. The funds are used to promote the transformation of the multiple systems—including mental health, primary care, education, child welfare, and juvenile justice—that serve children and youth 0–21 years of age who have been diagnosed as having a serious emotional disturbance, as well as their families. Grantees receive funding from SAMHSA to establish and administer a comprehensive spectrum of mental health and other necessary services and supports organized into a coordinated network (i.e., system of care) to meet the multiple and changing needs of children and their families (Stroul, Goldman, Pires, & Manteuffel, 2012).

The system of care (SOC) framework is grounded in evidence demonstrating that services are more effective when they are both comprehensive and coordinated across all child-serving entities. The underlying principle that guides systems of care is that all services provided should be:

- family driven;
- individualized, strengths based, and evidence informed;
- youth guided;
- culturally and linguistically competent;

- provided in the least restrictive environment;
- community based;
- accessible; and
- collaborative and coordinated across an interagency network (Stroul et al., 2012).

Purpose of the Evaluation

National evaluation of the CMHI is mandated by Public Law 102-321, Section 565 of the Public Health Service Act for the purpose of describing, monitoring, and chronicling the progress of the program. The goal is to assess the outcomes of children and youth and their families who are served by CMHI-funded grantees. Details on "longitudinal studies of outcomes of services provided by such systems, other studies regarding such outcomes, the effect of activities under this part on the utilization of hospital and other institutional settings, the barriers to and achievements resulting from interagency collaboration in providing community-based services to children with a serious emotional disturbance, and assessments by parents of the effectiveness of the systems of care" are required by law (Public Law 102-321, 42 U.S.C. 290ff–4(c)).

Additionally, the law mandates that "[t]he Secretary shall, not later than 1 year after the date on which amounts are first appropriated under subsection (c) of this section, and annually thereafter, submit to the Congress a report summarizing evaluations carried out pursuant to paragraph (1) during the preceding fiscal year and making such recommendations for administrative and legislative initiatives with respect to this section as the Secretary determines to be appropriate" (Public Law 102-321, 42 U.S.C. 290ff–4(c)).

The evaluation provides useful data for decision making at all levels of government and providers across the range of agencies that serve children and youth. Evaluation findings have been instrumental in identifying critical and emerging issues in children's mental health and initiating changes to mental health policies related to children and youth nationally.

Description of Children, Youth, and Their Families at Intake into System of Care Services

This Cohort of CMHI-funded system of care grantees continue to serve a diverse group of children, youth, and families, including many families from traditionally underserved populations. The following data describe the children and youth who enrolled in these systems of care as of June 11, 2014. Data are from the 28 demonstration grantees that were initially funded in 2009 and 2010 and were funded at the time data were downloaded for this report. Data from previously funded demonstration grants as well as expansion grants are not included.

- The majority of caregivers (64.8 percent) whose children received services reported family incomes that placed them below the federal poverty threshold for their location and family size.[3]
- Among the children and youth served, 39.9 percent identified as White/Caucasian, 28.0 percent as Black/African-American, 19.0 percent as Hispanic/Latino(a), 3.0 percent as American Indian/Alaska Native, 1.8 percent as Native Hawaiian/Pacific Islander, and 1.1 percent as Asian. In addition, 7.2 percent identified as members of more than one of these groups.
- 57.4 percent of children and youth served were male.
- The program served children and youth in a wide range of ages. Nearly one-quarter (22.7 percent) of those served in a system

of care were young children from birth to 5 years of age. More than a quarter (30.5 percent) served were transition-age youth 16 to 21 years of age.

- Nearly all children and youth lived with at least one parent (84.4 percent).
- More than one-half of children and youth (54.0 percent) had at least one biological family member who had experienced a drug or alcohol problem, and 40.7 percent of children and youth had been exposed to domestic violence at some point in their life.
- Among children and youth entering systems of care, 67.8 percent had a biological family member who had been diagnosed as having depression, and almost three quarters (73.9 percent) lived with someone who had shown signs of depression in the 6 months before entering services.
- Caregivers reported that, within the 6 months prior to entering a system of care, 29.9 percent of children and youth had run away from home and 14.1 percent had attempted suicide at some point.
- Most children and youth (78.2 percent) who entered system of care services attended school at least 80 percent of the time in the 6 months before intake. More than one-fifth of children and youth (20.4 percent) who received traditional letter grades received an average grade of D or F on their most recent report card.
- Children and youth entered system of care services with a variety of behavioral and emotional symptoms and met the criteria for a range of clinical diagnoses assigned by professionals, as defined by the 4th and 5th editions of the *Diagnostic and Statistical Manual for Mental Disorders* (*DSM-IV-TR;* American Psychiatric Association, 2000; *DSM-5;* American Psychiatric Association, 2013). The most commonly diagnosed mental health concerns in this group were mood disorders (40.6 percent of children and youth), attention-deficit/hyperactivity disorder (31.8 percent), and oppositional defiant disorder (18.7 percent).

Outcomes of Children, Youth, and Families

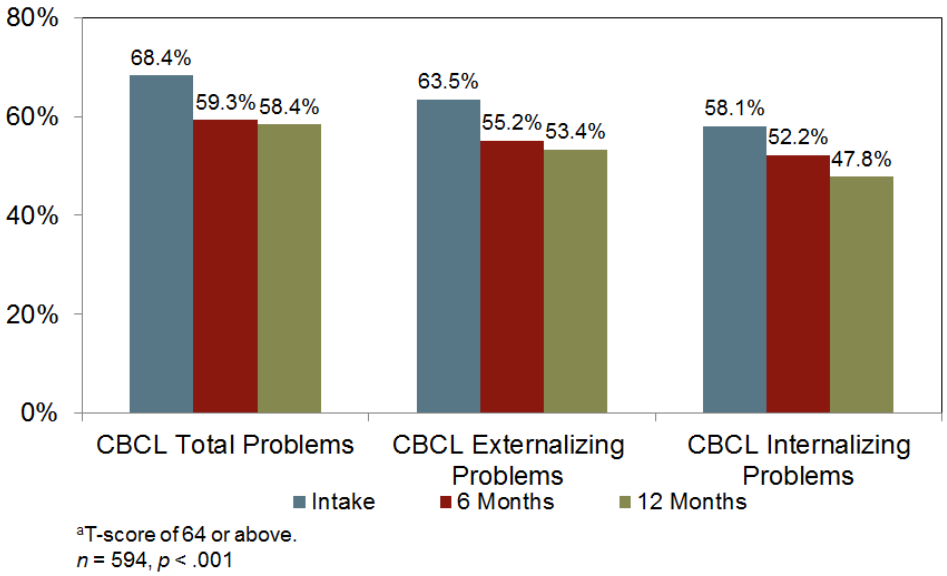
Children, youth, and their families from this CMHI Cohort were assessed at intake into services and at 6-month intervals for a period of up to 24 months. Of the 9,280 children and youth who received services from grantees, 3,343 eligible children and youth and their families participated in the Longitudinal Outcome Study, from which these findings are drawn. As of June 11, 2014, 43.8 percent of the 2,361 eligible children and youth who were eligible to complete a 12-month follow-up interview had done so. Attrition analyses showed that children and youth who had not completed both 6- and 12-month follow-up interviews and thus were not included in the analyses differed at baseline from those who had completed all interviews at the three intervals on only one measure. Those who did not complete all three interviews were more likely to report fewer symptoms of depression.[4]

For children and youth 1½ to 18 years of age, behavioral and emotional symptoms were assessed using the Child Behavior Checklist (CBCL 1½–5; Achenbach & Rescorla, 2000; CBCL 6–18; Achenbach & Rescorla, 2001). Young adults aged 19 and older were not included in these findings. Among the improvements found within the first 12 months of services:

- Children and youth who received system of care services showed steady improvement in their behavioral and emotional symptoms. Figure 1 shows that the percentage of children and youth whose scores on the CBCL Total

Problems Scale were in the clinically significant range, indicating significantly high levels of emotional and behavioral problems upon entering services (i.e., a T-score of 64 or above), decreased over time. The percentage of children and youth whose levels of externalizing symptoms, such as aggression or rule-breaking, fell within the clinically significant range, also decreased over time. Improvements were also seen for internalizing symptoms such as depression or anxiety.

Figure 1. Percentage of Children and Youth with Clinical Levels[a] of Behavioral and Emotional Symptoms at Intake, 6 Months, and 12 Months



[a]T-score of 64 or above.
$n = 594$, $p < .001$

The Columbia Impairment Scale (CIS; Bird et al., 1993) was used to assess the overall level of impairment that children and youth experienced with their functioning at home, in school, and in their communities.

- Within 6 months of intake into CMHI-funded systems of care, the proportion of children and youth who were rated as being in the significantly high range of the CIS fell from 69.8 percent to 63.6 percent. By the 12-month follow-up, the rate had fallen further to 58.5 percent.[5]

Youth 11 years of age and older provided information about their symptoms of anxiety and depression using the Revised Children's Manifest Anxiety Scale: Second Edition (RCMAS–2; Reynolds & Richmond, 2008), a standardized measure of symptoms of anxiety, and the Reynolds Adolescent Depression Scale: Second Edition (RADS–2; Reynolds, 1986), a standardized measure of symptoms of depression.

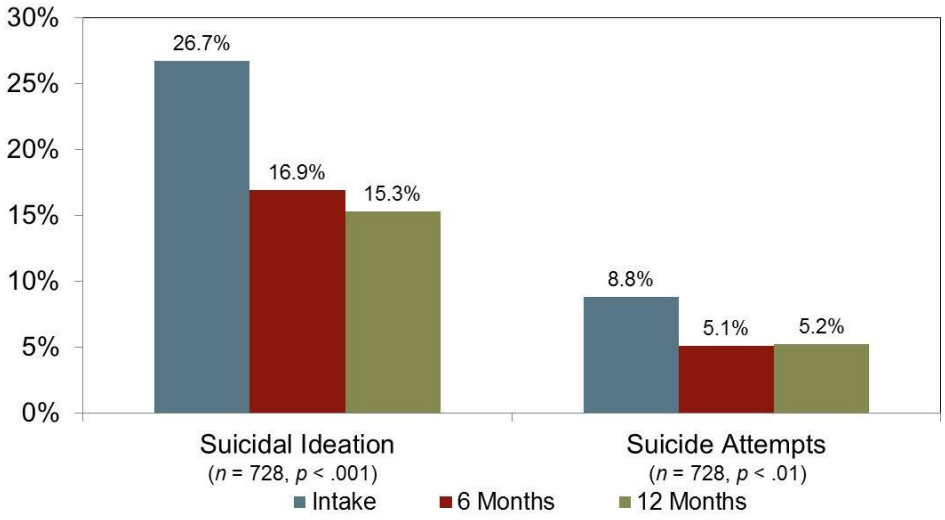
- Symptoms of anxiety decreased for youth enrolled in system of care services. At intake, 28.0 percent of youth reported significantly high levels of symptoms of anxiety. By the 6-month follow-up, this proportion had fallen slightly to 25.0 percent. At the 12-month follow-up, the proportion reporting clinically significant levels of anxiety was 24.1 percent.

- Youths' self-reported symptoms of depression improved over time. At intake, 27.8 percent of youth reported symptoms of depression in the elevated range. Within 6 months, 17.7 percent reported symptoms of depression in the elevated range. This proportion increased slightly to 19.4 percent after 12 months.[6]

At intake, caregivers were asked whether their child or youth had expressed thoughts of suicide or if they had made a suicide attempt within the past 6 months. Youth 11 years of age and older were also asked the same questions.

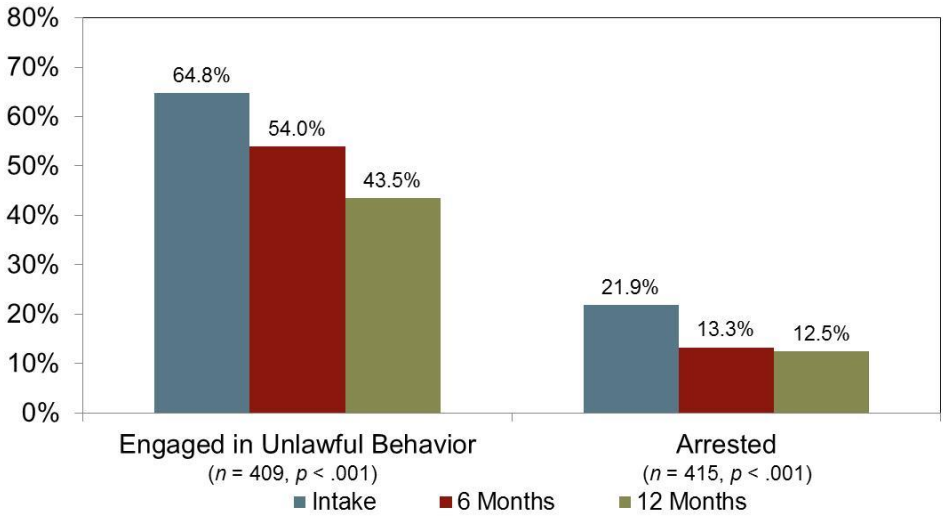
Figure 2 shows that the percentage of children and youth who either were reported by caregivers to have had thoughts of suicide or reported having these thoughts themselves in the previous 6 months fell significantly from intake to 12-month follow-up after children and youth entered services.

Figure 2. Percentage of Children and Youth Experiencing Suicidal Thoughts and Suicide Attempts at Intake, 6 Months, and 12 Months



- Among children and youth receiving system of care services and who were enrolled in school, the proportion who attended school regularly, defined as attending 80.0 percent of school days or more, rose from 76.5 percent in the 6 months before intake to 85.0 percent in the 6 months after intake. Within 12 months of enrolling in system of care services, the proportion attending school regularly remained steady at 83.7 percent.[7]
- The academic performance of children and youth improved. At intake, 65.4 percent of children received passing grades, defined as a grade average of C or better, on their most recent report card. After 6 months, 66.4 percent received passing grades, and the percentage continued to increase to 74.3 percent after 12 months.[8]
- Figure 3 shows that the percentage of youth who reported that they engaged in unlawful behavior or that they had been arrested in the previous 6 months fell from entry into services to 12-month follow-up

Figure 3. Percentage of Youth Involved in the Juvenile Justice System at Intake, 6 Months, and 12 Months



The strengths of children and youth were measured using the Behavioral and Emotional Rating Scale—Second Edition (BERS–2; Epstein, 2004).

- Caregivers reported a significant increase in their child's strengths over the first 6 months of services with 27.2 percent reporting that their child improved in their behavioral and emotional strengths. After 12 months, this proportion increased to 32.2 percent.[9]

Parenting stress was assessed using the Parenting Stress Index—Short Form (PSI/SF; Abidin, 1995).

- At intake, 68.8 percent of parents of children between the ages of 1 month and 12 years reported levels of parenting stress in the *severe* range. This proportion significantly decreased to 48.4 percent at 12 months.[10]

Outcomes for LGBTQI2-S Youth in Systems of Care

Youth who self-identified as LGBTQI2-S reported improvement in outcomes after enrolling in systems of care. Based on data gathered by grantees as of June 11, 2014, at intake into system of care services, youth 11 to 21 years of age who participated in the Longitudinal Outcome Study were asked to identify their gender and sexual orientation. They were given the option to identify their gender as male, female, transgendered, or other, and to identify their sexual orientation as heterosexual, bisexual, homosexual, or other.

Within the first 6 months of entering system of care services, 24.6 percent of youth who identified as LGBTQI2-S experienced a significant improvement in their overall behavioral and emotional symptoms as measured by the CBCL. In addition, 18.0 percent reported a significant improvement in symptoms of anxiety as measured by the RCMAS–2, and 22.6 percent reported significant improvement in their symptoms of depression as measured by the RADS–2.

LGBTQI2-S youth also reported improvement in suicidal thoughts and suicide attempts. At intake, 48.1 percent of youth who identified as LGBTQI2-S reported that in the previous 6 months, they had experienced thoughts of suicide. This

proportion fell to 34.3 percent in the 6 months after entering services.[11] Additionally, 25.0 percent of youth reported that they had made a suicide attempt in the 6 months prior to entering system of care services. This percentage fell somewhat to 18.5 percent in the 6 months after entering services.

Outcomes for Youth involved in Bullying in Systems of Care

Many youth who enter systems of care have been involved in bullying, as either the victim or the perpetrator of bullying—and in some cases as both. Data gathered as of June 11, 2014, from this CMHI Cohort indicate that almost one-third (31.0 percent) of youth who participated in the Longitudinal Outcome Study reported that they had been a victim of bullying, and 26.4 percent reported having bullied others in the 6 months before entering system of care services. After receiving services for 6 months, the proportion of youth who reported that they were victims of bullying or cyberbullying fell to 25.5 percent, and the proportion of those who bullied others fell to 19.2 percent.

Youth who reported that they were involved in any aspect of bullying were more likely to report higher levels of behavioral and emotional symptoms on the CBCL.[12] However, these symptoms were less frequently reported by youth after receiving system of care services. Among youth who were victims of bullying, 24.1 percent showed significant improvement in behavioral and emotional symptoms in the first 6 months after entering services. Additionally, 18.7 percent of those who were perpetrators of bullying and 17.5 percent who were both victims and perpetrators of bullying showed significant improvement in behavioral and emotional symptoms.

Service Use by Children, Youth, and Families Served by CMHI Grantees and Associated Costs

For this CMHI Cohort, the services that children, youth, and families were most likely to use within the first 6 months of entering CMHI grant-funded services were individual therapy (68.5 percent), case management (62.1 percent), assessment or evaluation (56.6 percent), and medication treatment monitoring services (51.7 percent). Caregivers reported that the most common places where they received services were mental health settings (69.8 percent) and their homes (59.7 percent).

Data from nine grantees, initially funded in FY 2009, were gathered between August 2010 and April 2014. Only grantees that submitted data for the Services and Cost Study are included in these findings. The findings show that the total amount paid for services was $5,636,770, based on 50,618 service events with payment data, or 95.6% of all service events. Medicaid, the majority payer, paid 68.9 percent of the total payments. The total amount paid for services declined by 25.9 percent by the end of the first year, from $1,556,740 to $1,152,774. This reduction was driven primarily by a decrease in payments for community-based therapeutic services.

In these nine grantees the average length of time during which children and youth received system of care services was 13.8 months (median = 12.5 months). The average total cost associated with the services provided during this time was $4,185 per child or youth (median = $1,759), or an average cost of $464 per child or youth per month (median = $241). The number of services and supports received by children and youth over this time averaged 53.45 events (median = 30).

In the overall sample of 28 grantees, the average number of days that children and youth receiving system of care services spent in inpatient hospital care decreased by 0.56 days, from 1.21 days in the 6 months prior to intake, to 0.65 days between 6 months and 12 months after intake,[13] representing a 53.8 percent reduction in average per-child inpatient hospitalization costs. The average number of times that youth had been arrested in the previous 6 months decreased from 0.42 arrests in the 6 months prior to intake to 0.19 arrests between 6 months and 12 months after intake.[14] The average overall cost per youth due to arrest decreased to an average estimated cost per youth of $1,103 between 6 months and 12 months after intake. This represents a 45.7 percent reduction in overall average per-youth costs over the 3½-year period in which data were collected.

Caregiver and Youth Assessments of the Effectiveness of Systems of Care

Consistent with the authorizing legislation's mandate, caregivers assessed the effectiveness of systems of care. Caregivers and youth (11 years of age and older) in this CMHI Cohort responded to questions about their service experience and satisfaction with services.

- Among caregivers and youth, 83.5 percent of caregivers and 81.9 percent of youth reported overall satisfaction with services after the first 6 months of services. Both caregivers and youth (97.6 percent for each) reported satisfaction with the cultural and linguistic sensitivity of the services that they received. Levels of satisfaction remained high after 12 months, with 85.1 percent of caregivers and 92.7 percent of youth reporting that they were satisfied with services.

System Change

CMHI-funded grantees are expected to implement systems that are capable of promoting and sustaining improvement in infrastructure and service delivery domains in accordance with system of care principles (see pages 1–2 for a list of principles). Assessments are conducted every 18 to 24 months over the funding period for the cooperative agreements, beginning in the second year of funding. Grantees are rated by trained reviewers on a scale of 1 (no progress made toward implementing the principle) to 5 (significant progress).

Within this CMHI Cohort, grantees initially funded in FY 2009 showed the most improvement overall, from the first assessment in 2011 to the second assessment in 2013, in implementing the principle of individualized care within the infrastructure domain, with the average rating increasing from 2.79 to 3.76. Activities in the infrastructure domain include:

- having and using flexible funds to support the provision of services to meet the unique needs of children, youth, and families;
- training program staff, partnering agency staff, and private providers on the concept of individualized care;
- developing a complete array of services in the community; and
- collecting information on the extent to which services are provided in an individualized manner across the service array, and on child and youth outcomes.

Grantees initially funded in FY 2009 also improved their programs in eight of nine principles assessed in the service delivery domain. Overall ratings were higher in the service delivery domain than in the infrastructure domain, except for the principle of cultural and linguistic

competence. The principles of providing family-driven with an average rating of 4.41 and youth-guided care with an average rating of 4.38 received the highest ratings at the second assessment in the service delivery domain. In the service delivery domain, this CMHI Cohort of grantees showed similar improvement from the first assessment to the second in the principles of youth-guided care with an average rating of 3.68 at the first assessment and 4.38 at the second assessment. On the principle of interagency involvement, grantees received an average rating of 2.95 at the first assessment, and 3.37 at the second assessment, and interagency coordination and collaboration rated 3.41 at the first assessment, and 3.92 at the second in the service delivery domain.

Expansion Grants

In FY 2011, SAMHSA adopted a new approach to CMHI by funding 1-year "Expansion Planning" grants and 4-year "Expansion Implementation" grants. The CMHI Expansion Planning and Implementation Grants are intended to help achieve broader, more sustained implementation of the SOC approach throughout the nation. The new CMHI approach fits within SAMHSA's Theory of Change framework (SAMHSA, 2014), through which SAMHSA operationalizes its mission to reduce the impact of substance abuse and mental illness on America's communities. The Theory of Change framework is organized into five phases: Innovation, Translation, Dissemination, Implementation, and Widescale Adoption. Each of these phases encompasses a range of strategies, activities, programs, and tasks, which pave the way toward evidence-based behavioral health system change.

The new approach is designed to take the CMHI to the next level by placing greater emphasis on effective, widescale adoption and sustainable implementation. The revised program is intended to make SOC services and supports available throughout larger geographic regions and SAMHSA will be evaluating the impact of this new strategy. It is anticipated that data collection for these two grant types will begin in FY 2015, and that preliminary evaluation findings will be published in next year's (2015) Report to Congress.

Recommendations for Administrative and Legislative Initiatives

In keeping with SAMHSA's goal of promoting the expansion and widescale adoption of CMHI, the following administrative and legislative initiatives are recommended:

- Continue to allow the provision of technical assistance for non-grantees in order to expand and sustain systems of care. By doing so, SAMHSA will provide opportunities for states and other jurisdictions not funded by CMHI to adopt the principles of systems of care and thus expand the reach of the system of care framework.
- Explore the possibility of focusing CMHI efforts more specifically on special populations. For example, how can the system of care approach be used to improve outcomes for youth at "clinical high risk" (Prodrome phase) for a first episode of psychosis.

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[1] The authorizing legislation for the CMHI uses the phrase *serious emotional disturbance*. This report uses *serious mental disorder* or *serious mental health condition* as these terms have become more preferred since the legislation was created.

[2] The authorizing legislation defines child as "an individual not more than 21 years of age." In this report, the term *child* refers to someone younger than 11 years old, whereas the term *youth* refers to someone 11–21 years of age. This is done to differentiate the age group as individuals 11 years of age and older provide self-report information.

[3] U.S. Department of Health and Human Services, 2014.

[4] $p < .05$

[5] $p < .001$

[6] $p < .001$

[7] $p < .01$

[8] $p < .01$

[9] $p = .058$

[10] $p < .001$

[11] $p < .05$

[12] $p < .001$

[13] $p > .05$

[14] $p < .05$

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