

State Mental Health Systems for Children

A Review of the Literature and Available Data Sources

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July 2010



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EXECUTIVE SUMMARY

States play an important role in serving those with a need for mental health services and thus evaluating the mental health service system at the state level is an important task. In 2009, the National Alliance on Mental Illness (NAMI) produced a report evaluating state mental health systems for adults, but did not consider how states serve children with mental health needs. Children differ in many ways from adults in the mental health conditions they face, the services they receive and the outcomes they experience. This report therefore explores the potential motivation for producing a separate evaluation for children and further examines the feasibility of collecting the necessary data for a state-based analysis.

As a first step, we review the recent literature on children's mental health and the findings are quite compelling. Evidence exists of high levels of need for mental health services as well as for access limitations and disparities in service use. More limited evidence exists on the effectiveness of mental health services and on the best measures of outcomes for children with mental health needs. Therefore, children are clearly not immune to the challenges of mental illness and they share many of the difficulties of their adult counterparts in accessing effective services. We therefore conclude that a separate evaluation of state mental health systems for children is warranted.

This report then explores in great detail the availability of secondary data sources that may be used to generate a comprehensive evaluation of state mental health systems for children. Available state-level data on the prevalence of mental health needs, the availability and accessibility of mental health services and the utilization and effectiveness of these services for children is explored. Data on the following state-level characteristics of mental health services for children are found to be available:

- *Prevalence of mental health needs.* State-level data on the proportion of children suffering from a variety of specific mental health conditions are available. Such conditions include, but are not limited to, ADHD, depression, anxiety and conduct disorders. Additional data are available on the prevalence of less specific emotional and behavioral difficulties.
- *Availability of mental health services.* County-level data on the number of physicians and hospitals, including child psychiatrists and psychiatric hospitals are also available. State-level data on public clinics providing mental health services also exist.
- *Accessibility of mental health services.* State-level data on the insurance coverage distribution of all children, as well as children with mental health needs, are available from several sources. Survey data on the level of unmet need for mental health services for children is also available at the state-level. Additional data on state policies supporting mental health care including mandated benefits, parity laws and Medicaid benefits can also be obtained.
- *Utilization of mental health services.* Survey based measures of the use of mental health care or counseling are available from several sources. Provider discharge data and insurance claims also provide some detailed measures of utilization of inpatient and outpatient services. Medicaid claims data is particularly relevant for this population and can be obtained for every state.
- *Effectiveness of mental health services.* Available state-level data on the quality of health care services provided to children with mental health needs include measures of family-centeredness, cultural sensitivity, and care coordination. Additional data on individual outcomes for these children are also available. These measures include, but are not

limited to, missed school days and repeated grades, social activities and health outcomes including hospital readmissions and self-reported health status.

While the availability of the data described above is promising for a state-by-state evaluation, several limitations exist. For some of the measures of interest, state-level estimates may be based on relatively small samples and may thus be imprecise. Data on the availability of providers at the state-level would benefit from additional detail on child-specific providers. Furthermore, while estimates of insurance coverage are available and reliable, the data do not usually indicate the generosity of the coverage for mental health services. Moreover, while national estimates of utilization of mental health services are quite comprehensive, state-level data on these measures are more limited. Data on children needing and receiving services outside the traditional healthcare system, including those in the special education, child welfare, and juvenile justice systems, are also somewhat lacking. The most striking limitation however is the lack of an established set of quality measures for mental health care for children. A set of quality measures needs to include indicators of effective services as well as measures of successful outcomes. Some potential quality measures are currently available from existing sources, but it is somewhat unclear which measures should be used for this particular population.

Despite these limitations, compiling the available data on mental health systems for children to create a state-by-state comparison is a worthwhile endeavor. At present, there is enough available data to produce a reasonably thorough comparison of state mental health systems. Using the existing data sources investigated in this report would also allow for regular and consistent monitoring of the systems over time. Furthermore, as the available data come from many different sources, an effort to consolidate this information could enhance the awareness of

complementary sources and improve the ability to study the relationships between various system characteristics. Finally, any effort to collect such a comprehensive set of measurements will inevitably uncover elements that are missing or measured poorly. This creates an opportunity that could ultimately lead to better measurement and improved data collection in the future.

Children with mental health conditions and challenges are an especially vulnerable population. Evidence suggests that mental illness in children is relatively common and that many affected children are unable to access the care they need and poor health, educational and social outcomes can result. States play a significant role in the mental health care system and this indicates a need to further evaluate the children's mental health system at the state-level. A great deal of data exists that would allow for a detailed analysis of the need for services and the availability, accessibility, utilization and effectiveness of these services. Producing such an analysis would contribute to a better understanding of the relationships between measures of prevalence, access, utilization and outcomes at the state-level. It would also help to determine where the data is poor or lacking on children's mental health issues and could eventually lead to improvements in measurement and data collection.

AUTHORS AND ACKNOWLEDGMENTS

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The authors would like to thank Darcy Gruttadaro, Ron Honberg, and Jenny Kenney for advice and helpful suggestions, Juliana Macri and Abby Kahn for research assistance and Eva Hrubá for assistance in manuscript preparation.

This report was funded by the National Alliance on Mental Illness (NAMI). The views expressed are those of the authors and should not be attributed to the NAMI or to the Urban Institute, its trustees or its funders.

INTRODUCTION

States are important players in the mental health arena. Many states fund mental health services directly through state-owned and operated facilities, including inpatient psychiatric hospitals and community health centers. All states also administer and partially fund expenditures for mental health services through their Medicaid programs. Furthermore, states are responsible for administering additional federal funds, provided in the form of block grants, for the purpose of providing mental health services. In 2003, roughly 50 percent of all expenditures on mental health services were either directly funded or administered by the states (Mark et al., 2007).

As a result of the critical role played by states, evaluating the provision of mental health services at the state-level is an important task. In 2009, the National Alliance on Mental Illness (NAMI) produced *Grading the States: A Report on America's Health Care System for Adults with Serious Mental Illness* (Aron et al., 2009). The report evaluated the state mental health care systems in all 50 states and the results were not encouraging. The study found evidence of limited insurance coverage for mental health services in many states as well as a lack of focus on evidence-based practices, cultural competence and other markers of system performance. Perhaps of most concern, the study found that, in many cases, states were lacking the necessary data to perform a proper evaluation of their mental health service system. With the available data inconsistent across states, the ability to produce meaningful comparisons was somewhat limited. Despite these concerns, however, the report provides a convincing argument that state mental health systems are not performing to a high standard and that additional information on system performance would be valuable.

The target population of the NAMI report was adults with serious mental illness, and thus it did not address how the mental health care system serves children with mental health needs. A number of characteristics make reporting on the mental health system for children unique compared to that for adults. In many cases, the diagnosis of mental health conditions in children is less clear than for adults. As children age and develop, many emotional and behavioral changes occur that are generally considered part of normal development. In some cases however, these changes may be signs of emerging mental illness. Therefore, it is more difficult to identify the prevalence of mental illness among children.

In addition, children access health care services in more varied ways than their adult counterparts. For instance, many children access health services through the school system. This may be particularly important for children with mental health needs as schools typically provide an assortment of social workers, psychologists and other counselors to address these needs. Furthermore, special populations of children, such as those involved with the child welfare or juvenile justice systems, are especially likely to have emotional and behavioral issues and to receive some elements of care through these systems.

Finally, evaluating the ultimate outcomes of mental health care for children will be different than for adults. While adult outcomes may focus on work status or the ability to live independently, child outcomes may include school performance or measures of social interests and activities. As a result of these differences, a unique approach, compared to that used for adults, is likely necessary to adequately evaluate state mental health systems for children.

The goal of this report is to determine the feasibility of evaluating the public mental health system for children at the state level. We first review the current literature on mental health services for children and concentrate on clarifying our knowledge of the prevalence of mental

health needs for children, the services that children utilize and the outcomes they experience. This information is useful in understanding how children differ from adults in their mental health needs and also for identifying the types of data necessary to perform a state-based evaluation for children. We then explore the availability of secondary data sources that may be used to create a state-by-state comparison of mental health systems for children. Potential data sources are screened for their ability to provide consistent, state-level information on the need for mental health services for children and the availability and effectiveness of these services. We conclude with a discussion of the potential value of collecting the available data and performing a comprehensive state-based analysis of mental health systems for children.

LITERATURE REVIEW OF RECENT FINDINGS ON CHILDREN'S MENTAL HEALTH

In 1999, the Surgeon General produced a report that includes, among many other topics, a comprehensive review of the literature from the 1970s, 1980s, and 1990s on what is known about children's mental health status and services up to that date (Substance Abuse and Mental Health Services Administration [SAMHSA], 1999). The report reveals that the prevalence of mental health needs in children is high, and that about one in five children have a diagnosable mental health condition in a year. In addition, the report suggests that a "Systems of Care" approach—whereby multiple sectors collaborate in identifying and caring for children and youth with emotional difficulties—is potentially the best approach, although research evidence for the effectiveness of such services remains unclear.

Since the time of the Surgeon General's report the field of children's mental health research and practice continues to evolve. The National Alliance on Mental Illness (NAMI) requested that the Urban Institute review the literature from the first decade of the 21st century to

summarize more recent findings on this important topic. To accomplish this, we reviewed findings contained in articles in the peer-reviewed literature, as well as in the “grey literature”, such as government reports.

We searched for papers that provided new information on three broad topics:

- The *prevalence of mental health needs* in children and youth ages 4 to 19, as well as the major predictors and types of such needs. As noted, defining mental illness in children is somewhat more difficult than for adults. As such, we classify a broad range of emotional and behavioral issues as potential indicators of mental health needs in children. Where possible, we provide detail on the severity of, and level of impairment from, such issues.
- The *types of mental health services provided* to children and youth, concentrating particularly on children served by public programs such as Medicaid, state public mental health programs, schools, juvenile justice, child welfare, and collaborations between such agencies (“Systems of Care”). We also searched for papers that show differences in service use between groups of children, as well as differences across states. Service use may include inpatient or outpatient provider visits, medication usage, and measures of school-based and public sector utilization.
- The *outcomes* experienced by children with mental health problems and how those can be improved with effective programs. Outcomes may be defined as a reduction in symptoms, changes in problem behaviors or by school-based outcomes.

To identify the papers reviewed, we searched the formal literature using Pubmed and Google Scholar. Key terms used in the search were: child, youth, and adolescent mental health, combined with prevalence, service use, utilization, accessibility, unmet need, or expenditures. We then scanned the websites for government agencies, particularly the Substance Abuse and Mental Health Services Administration and the Department of Education’s Office of Special Education Programs. We also examined the web sites of key trade associations.

Once potential materials were identified, we reviewed abstracts and summaries to identify the papers to be thoroughly reviewed and abstracted findings for approximately 90 papers, as listed in Appendix Tables 1-3 and the attached bibliography. For each study, we provide: authors, date of publication, place and date of study, population covered, data source, and key

findings. As indicated in the tables, because of lags in publication, most of the findings are from studies conducted in the 1990s or the first half of the 2000s. Ten of these papers are comprehensive literature reviews summarizing findings from multiple well-designed studies.

Prevalence

Appendix Table 1 summarizes findings from 29 papers on the prevalence of children's mental health needs and the key factors determining this prevalence.

Prevalence in the General Population. Diagnosing mental health conditions in children is difficult, and most general prevalence studies have relied on detecting emotional or behavioral issues by asking caregivers or teachers about the child's experiences that are symptoms of underlying mental health conditions. Numerous screening tools, such as the Child Behavior Checklist and others, have been used for this purpose. However, the results from these prevalence studies vary in the proportion of children identified due to the variety of settings, populations, and screening tools used in the studies.

Studies consistently point to a high prevalence of emotional and behavioral issues in the general population of U.S. children and youth, consistent with the Surgeon General's report from the late 1990s. Two comprehensive literature reviews (Institute of Medicine, 2009; Brauner & Stephens, 2006) show that the prevalence of an emotional or behavioral problem ranges from 7% to 26% of children. The mean prevalence across the studies reviewed by the Institute of Medicine is 17% (median 17.5%), with half the studies in the range of 12-22%. One of the best-designed community prevalence studies is the Great Smoky Mountain Study of Youth (GSMSY), a longitudinal study over ten years beginning in the early 1990s in western North Carolina. That study found that a longitudinal perspective is important, since over a three month

period, the prevalence of mental health problems is only 13.3%, whereas over three years the prevalence rises to 36.7% (Costello, Mustillo, Erkanali, Keeler, & Angold, 2003).

National-level population-based studies also show that many children experience emotional and behavioral difficulties during their childhood and adolescence. For example, according to the National Health Interview Survey, 14.5% of children have a parent who spoke with a health care provider or school professional about their child's emotional or behavioral difficulties in the past 12 months (Simpson, Cohen, Pastor, & Reuben, 2008). The Youth Risk Behavior Surveillance System, a survey of high school students, shows even higher rates of emotional distress when data are reported by the youth themselves and not by caregivers. Fully 35.8% of girls and 21.2% of boys report feeling sad or hopeless in the past month (Eaton et al., 2008). This age group may also be more prone to emotional difficulties than younger children.

This emotional distress has profound consequences for many children and their families. Summarizing results from five different data sources, Pergamit (2010) found that from 6.4% to 7.6% of youth run away from home in a year. The prevalence over the full adolescent period is much higher, with about 20% running away at least once and 10% running away two or more times (Pergamit, 2010).

While some of the mental health conditions experienced by children are mild or transitory, many are severe. The National Survey on Drug Use and Health (NSDUH) shows that over one year, 4.1% of youth age 12-15 have a major depressive episode, climbing to 11.5% of 16-17 year olds. About 70% of those with any depressive episode have a severe or very severe episode (SAMHSA, 2008a). These mental health problems in children often predict a lifetime of difficulties. The National Comorbidity Survey of adults found that 75% of all mental health disorders over a lifetime have their onset before age 25, and 50% of disorders have their onset

before age 15 (Kessler, Berlund, Demler, Jin, Merikangas, & Walters, 2005). These results point to a clear need to prevent mental health problems early in life, and to identify and treat those that do occur as early as possible.

Recent national trends in the prevalence of mental health conditions among children and youth are unclear. For example, the percentage of youth who have seriously considered suicide in the past year has declined, from 29.0% in 1991 to 14.5% in 2007 (Centers for Disease Control and Prevention, 2010). However, the proportion of child emergency department admissions attributable to mental health problems is increasing while the rate of admissions for other chronic health conditions is decreasing (Grupp-Phelan, Harman, & Kelleher, 2007). In addition, the recognition and diagnosis of certain conditions is increasing. For example, in one community study, the identified prevalence of autism spectrum disorders rose by 60% from 2002 to 2006 alone (Rice, 2009).

Prevalence among Youth served in Public Sectors. The prevalence of mental health needs is even higher among children and youth served in public sector programs such as special education, child welfare or juvenile justice. This is not surprising since such sectors are either designed specifically to address mental health concerns (the public mental health and special education sectors), to address some of the consequences of mental health issues (the juvenile justice sector), or to serve children who have been abused or neglected and are thus at high risk for mental health problems (the child welfare sector). Medicaid often provides financing for children who are treated in other public sectors as well as for children receiving mental health services in ambulatory, residential, and inpatient care settings.

A study in San Diego, California used the Diagnostic Interview Schedule for Children to assess the presence and type of mental health disorders among children in five public systems:

alcohol and drug services, mental health, child welfare, juvenile justice, and special education. Just over half (54%) met the criteria for a serious mental health disorder. Almost all of the children with any disorder met the criteria for either a disruptive behavior disorder (eg. conduct disorder) or Attention Deficit Hyperactivity Disorder (ADHD). There is a much lower prevalence of anxiety (10% of all those in public sectors) or depression (7%) among these children (Garland et al., 2001).

Other studies have shown that the prevalence of serious mental health conditions is very high for youth in the juvenile justice system, even after taking into account the prevalence of their behavioral problems, such as conduct disorder, which lead to their contact with the system. A review of 25 studies shows that the prevalence of a psychosis is 10.6% for boys and 2.7% for girls in the correctional system (Fazel, Doll, & Langstrom, 2008). The prevalence of less serious disorders is much higher, over 50% in several studies (Hartney, McKinney, Eidlitz, & Craine, 2003; Teplin, Abram, McClelland, Dulcan, & Mericle, 2002; Shufelt & Coccozza, 2006).

The rate of mental health problems among children in the child welfare system is also very high. The GSMSY finds that 37.5% of children who are ever in foster care have a serious emotional disturbance, compared to 4% of all children (Farmer et al., 2001).

Factors Associated with Mental Health Conditions. Several socio-economic factors are associated with the presence of a mental health disorder in children. First, gender plays a clear role. Boys are more likely than girls to have a mental health need (Costello et al., 2003; Howell & McFeeters, 2008; Howell & Teich, 2008; Simpson et al., 2008). The prevalence of specific disorders also differs by gender. Boys have a much higher prevalence of disruptive disorders (Pastor & Reuben, 2008) and autism spectrum disorders (Eaton et al., 2008), while girls are more prone to anxiety and depression (Fazel et al., 2008). The consequences of severe mental health

issues also differ by gender. For example, while both girls and boys are similarly prone to running away some time in adolescence (Pergamit, 2010), girls are more likely to come to the emergency department having attempted suicide (SAMHSA, 2010) and boys are more likely to have disruptive behavior that puts them in contact with the juvenile justice system (Uniform Crime Reporting Program, 2003).

The prevalence of mental health problems generally rises with age (SAMHSA, 2008a; Howell & McFeeters, 2008). This varies by condition however. The prevalence of some specific conditions, such as separation anxiety and ADHD, decreases over childhood, while the prevalence of other conditions rises (Costello et al., 2003).

Additionally, poverty is a strong predictor of mental health needs in children and youth. (Farmer et al., 2001). According to the National Survey of America's Families (NSAF), 11.7% of poor children have an emotional/behavioral issue using parent reports from the Child Behavior Checklist, while only 6.4% of non-poor children have such issues (Howell, 2004). Moving out of poverty is associated with a reduction in behavior disorders, but not in a reduction in anxiety or depression in youth (Costello et al., 2003).

After controlling for poverty, there is no association between race/ethnicity and the prevalence of mental health needs, according to the NSAF (Howell & McFeeters, 2008) and the GSMSY (Angold et al., 2002). In addition, after controlling for adverse life events and being raised by a single parent, the association between poverty and mental health is much weaker (Costello, Keeler, & Angold, 2001). The stress of poverty leading to parent's mental health problems is undoubtedly a mediator for children's mental health, since parental substance abuse (SAMHSA, 2007a) and poor parent mental health status (Lesesne, Visser, & White, 2003) are strong predictors of children's mental health needs.

Finally, there is some evidence of differences across states in the prevalence of mental health conditions in children and youth. State-specific studies that rely on measures of “treated prevalence” (ie. the percent of children who had contact with a provider for a mental health problem) all show substantial variation across states. For example, two studies using Medicaid data from selected states show a large variation in the percent of children who use any behavioral health service, from 4.5% to 13.9% across 10 states (Buck, Teich, Bae, & Dilonardo, 2001) and from 6% to 17% across 23 states (Howell & Teich, 2008). However, these large state variations are due in part to the characteristics of state Medicaid programs that differentially cover mental health services and consequently provide different incentives to parents to enroll their children in Medicaid once mental health needs arise (Howell, 2004).

National population-based studies also show state variation in the presence of children’s mental health needs. Analysis of the NSAF across 13 states shows that the proportion of children and youth with an emotional/behavioral issue ranges from 5.6% in New Jersey to 7.5% in Mississippi (Sturm, Ringel, & Andreyeva, 2003). Another analysis of data across all states from the NSDUH shows variation in depression prevalence in youth from 7.2% in Louisiana to 10.4% in Idaho (SAMHSA, 2007c). Thus, while the differences across states are smaller in population-based studies, there remain apparent differences in the rate of child mental health needs from place to place.¹

Mental Health Services for Children and Youth

Appendix Table 2 shows results from the review of 53 studies of access, use, quality, and cost of mental health services for children and youth. These studies portray a picture of limited

¹ Some caution must be taken in interpreting such differences as not all differences will be statistically significant.

and widely varying access to care, relatively low but increasing rates of use, disparities in service use, less than desirable quality of care, and a high cost of services.

Access and Use. Studies show that only a portion of children needing mental health services receive them (Burns et al., 2004; Howell, 2004; Witt, Kasper, & Riley, 2003). For example, one study using data across three national-level data sources, found that only about 20% of children needing mental health services receive any (Kataoka, Zhang, & Wells, 2002). As additional evidence, while data presented above show a high rate of need, only 7.4% of children in the U.S. have any mental health visits in a year, ranging from 5.1% to 11.6% depending on the state (Sturm et al., 2003). The NSDUH shows higher rates of service use than cited above, with almost 20% of youth receiving some mental health counseling during a year--13.3% in a specialty mental health setting (SAMHSA, 2005).

The entry into mental health services often begins in a school setting (Farmer, Burns, Phillips, Angold, & Costello, 2003), whether the service is counseling for a mild mental health concern or services for children with severe emotional disturbance through special education programs. In responses to a national survey of schools, 90% of school administrators indicate that their school provides assessment and referral for mental health services and three-quarters provide direct counseling to their students (by either psychologists, social workers, or nurses). However, they usually do not provide a full range of mental health services, since only about one-third provide medication management (Foster et al., 2005). Meeting a full range of mental health needs for children thus requires good linkages to specialty mental health services, but those linkages are often weak (Farmer et al., 2003).

Some schools have formal school-based health centers. In one study of inner-city high school students being served in such a setting, mental health services were more accessible to

students in a school-based health center than services in a community primary care clinic (Juszczak, Melinkovich, & Kaplan, 2003). Still, while almost all school-based health centers provide physical health services, fewer provide mental health therapy (67%) or are able to diagnose and treat mental health conditions (51%) (Lear, 2007).

Children being served by public sectors are more likely than other children to receive mental health services, with 87% having at least one mental health service in one study in California. In that study, service use is highest for those in the education and mental health sectors and lowest for those in juvenile justice (Hazen, Hough, Landsverk, & Wood, 2004). In addition to outpatient care, the use of psychotropic medication for children and youth served in the public sector is high. One study found that 67% of youth in therapeutic foster care and 77% in group homes take at least one psychotropic medication (Breland-Noble et al., 2004). In a national study of children in the child welfare system, most receive their mental health services from either the specialty mental health sector (35%), schools (23%) or both (22%) (Farmer et al., 2010).

There are indications that use of mental health services is increasing among children without an increase in prevalence (Sturm, Andreyeva, & Phil, 2005), with similar results from the NSDUH (SAMHSA, 2008b). In a Tennessee study of children on Medicaid in the late 1990s, the rate of use of any mental health service increases over time but there is a decline in the volume of visits per user (Saunders & Heflinger, 2003). The use of inpatient care was decreasing, and the use of psychotropic medication was increasing, including that prescribed by office based physicians (Ringel & Sturm, 2001; Olfson, Blanco, Liu, Moreno, & Laje, 2006; Martin & Leslie, 2003).

Some of this shift in care patterns is associated with an increase in mental health managed care programs which have sought to reduce costly inpatient care. One study examining managed care programs in six states finds that children in managed care have lower rates of both inpatient care and medication use, but equivalent use of outpatient mental health care (Cook et al., 2004). Another study in Massachusetts finds that children in a special managed care plan for children with mental health needs have higher rates of use than other disabled children in the first year of the program, but lower rates thereafter (Grimes, Kapunan, & Mullin, 2006). A Florida study shows that children in managed care have half the mental health service use of other children with similar mental health service needs (Mandell, Boothroyd, & Stiles, 2003). In another study, children with special healthcare needs enrolled in managed care have more unmet need than other children (Tang et al., 2008). Finally, a review of seven studies of the effect of managed care on children's mental health suggests that, while costs decline under managed care, there is some evidence that managed care increases access to care for children with milder mental health disorders (Hutchinson & Foster, 2003). Thus, the evidence is mixed on the overall effect of the move to managed mental health care on children's access and use.

Another policy change that might be expected to improve access to care for children is mental health parity. One study examining parity laws in the late 1990s finds no impact of the presence of such laws on the probability that a child with mental health needs will receive outpatient mental health services (Barry & Bush, 2008). But another study by the same authors finds that being in a state with mental health parity reduces the financial burden on families with children with mental health needs (Barry & Bush, 2007).

Disparities in Service Use. Not all children receive the same level of mental health services according to their needs. Numerous studies point to lower rates of service use among minority

children and youth. While African-American and white youth have a similar prevalence of mental health problems after controlling for other factors such as poverty, most studies show that their use of services is lower (Angold et al., 2002; Burns et al., 2004; Kodjo & Auinger, 2004). The same is true for Latino youth in most studies (Hough et al., 2002; Howell & McFeeters, 2008; Zimmerman, 2005; Garland et al. 2005; Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007). In a review of 10 studies, seven show that minority youth have lower rates of mental health service use (Elster, Jarosik, VanGeest, & Fleming, 2003). However, public systems may serve to reduce some of these disparities. For example, there are no racial/ethnic disparities in receipt of mental health services among foster care children in California, while such disparities are evident among other children (Snowden, Massland, Fawley, & Wallace, 2009).

There are other factors associated with use of mental health services in children. For example, caregivers with depression or substance abuse are less likely to seek and obtain mental health care for their children (Gaskin & Mitchell, 2005; Whitson, Connell, Bernard, & Kaufman, 2010). Also, children at different ages are likely to obtain different types of services, with the use of medication higher among school age children and the use of inpatient psychiatric care higher for adolescents. While gender differences with respect to services are not as pronounced as for prevalence, one study shows that girls receive fewer services than boys after controlling for their conditions (Zimmerman, 2005).

Medicaid enrolled children with mental health problems have higher use of mental health services than privately insured or uninsured children (Howell, 2004). The variations across states that are observed for prevalence are mirrored in even larger variations in mental health services for children, undoubtedly driven by differences in both delivery systems and financing (Howell & Teich, 2008; Larson, Miller, Sharma, & Manderscheid, 2004; Lutterman et al., 2003).

Quality of Care. While access and service use appear to be improving some, multiple studies point to a continued need to improve the quality of care for children's mental health services. For example, many children receive care in inpatient/residential settings where the quality of services is mixed. States vary in how they certify and monitor such facilities (Ireys, Achman, & Takyi, 2006) and rates of identified abuse are high in some facilities. The U.S. Government Accountability Office (2008) recommends increased oversight of the quality of care in such facilities. Rates of readmission in state psychiatric hospitals are about as high for children as for adults (Lutterman et al., 2003). While 75% of facilities implement some kind of quality control procedures, only a small minority (under 15%) have family and youth involved in the care process (Allen, Pires, & Brown, 2010). In addition, the length of stay in such facilities does not appear to be directly related to children's needs, but rather to facility characteristics (Gifford & Foster, 2008).

Systems of Care (SoC) approaches that attempt to improve access and bridge the gaps across sectors have had some positive results, such as reducing racial/ethnic disparities in access (Miech et al., 2008). Still, even the SoC programs have not consistently implemented accepted principles for quality programs such as involvement of youth in care planning (Gyamfi, Keens-Douglas, & Medin, 2007) and the use of evidence based treatment is still low. For example, only 35.4% of community-based providers in 26 SoC sites around the country implement Cognitive Behavioral Therapy² according to a full treatment protocol, and frequently providers are not fully trained in the services they provide (Sheehan, Walrath, & Holden, 2007).

Such quality problems are experienced more broadly in public sector mental health services. A survey of state agencies providing mental health services finds a wide variety in the capability

² See the website for the National Association of Cognitive –Behavioral Therapists (<http://www.nacbt.org>) for a discussion of these techniques.

of state agencies. Only 12 states mandate evidence-based treatment approaches, and only eight of those have taken steps to enforce the mandates. As additional evidence that state oversight is weak, 13 states can not identify how much they spend for children's mental health services (Cooper et al., 2008). Another study of child welfare agencies finds that the annual federal reviews of state agencies score "mental health of the child" as an area needing improvement in 30 states, and only 2 states are viewed as strong in service provision. The scoring is based on whether the agency screens for mental health needs and assures service provision when needed (McCarthy, Marshall, Irvine, & Jay, 2004).

Quality problems are not restricted to children in public programs, however. A study using both Medicaid and private insurance claims finds that only 28.2% of Medicaid youth and 33.6% of privately insured youth who receive psychotropic medication also receive any psychotherapy within six months of initiating medication (Mark, 2008).

Cost of Services. In the United States, mental health problems are the most expensive conditions for children, costing \$8.9 billion per year compared to the next most expensive condition, asthma, at \$8.0 billion. Mental health conditions in children are more than three times as expensive as infectious diseases (\$2.6 billion a year). About one-third of these costs are paid by Medicaid and about one-third by private insurance, with the remainder of costs paid by other public sectors and families. Medicaid is a disproportionate payer for mental health services when compared to other conditions such as infectious disease, for which private insurance pays 60% of the cost in children (Soni, 2009).

Within a given payer source, children with mental health problems are substantially more costly than other children. For example, while children with mental health claims represent only

6.6% of covered children in a private insurance data base, these children incur about 35% of inpatient costs and 20% of total costs for children (Larson, Miller, Fleming, & Teich, 2007).

Outcomes of Programs to Prevent and Treat Mental Health Problems in Children

In spite of a clear need for improved services that are effective, the evidence on the effectiveness of programs that prevent and treat mental health conditions in children and youth remains weak. A further problem is that, while evidence on the effectiveness of some programs is emerging in research settings, the dissemination of knowledge widely into the public and private systems that provide such services is still limited. Appendix Table 3 provides the results from 11 recent studies or research syntheses that address the effectiveness of mental health services for children and youth.

In one review of over 100 studies and syntheses, the authors conclude that evidence on effective services is limited. While in that review two or more studies identified effective treatments for depression, anxiety disorders, ADHD, conduct disorders, and phobias, there are many other conditions, such as bipolar disorder and anorexia, for which the evidence base for treatment effectiveness is weak. The most consistently positive evidence is for the effectiveness of multi-systemic therapy (Multisystemic Therapy Services, 2007) when providers are adequately trained in the techniques (Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001).

However, more recent work provides an emerging body of more positive evidence. A recent review by the American Academy of Pediatrics Task Force on Mental Health (2010) finds a range of therapies that have strong support for effectiveness from rigorous studies. These include Cognitive Behavioral Therapy (CBT), Multi-systemic Therapy, and Functional Family

Therapy³ among others. Evidence is also emerging of potentially effective programs for children with more severe problems. A large multi-center randomized trial for treatment of depressed youth showed that CBT combined with medication provides the most improvement when compared to either CBT or medication alone (The Treatment of Adolescents with Depression Study Team, 2007). A review of randomized trials of multi-dimensional treatment in four settings for children in foster care shows positive school outcomes and reductions in caregiver stress (Leve, Fisher, & Chamberlain, 2009). Another randomized trial shows that 16 weeks of intensive training of foster parents significantly reduces child behavior problems (Chamberlain et al., 2008).

Given the negative consequences of children's mental health problems, there is a strong need to identify effective programs that prevent the onset of mental health conditions or address them before they become severe. One review of rigorous studies of prevention programs identified seven highly cost-effective programs (SAMHSA, 2007a). Another review of 89 studies of programs in school settings, where children's mental health needs are often first identified, also finds some programs with positive outcomes. Strong programs include those with strong parent/teacher/peer involvement and programs that are integrated into the regular classroom (Rones & Hoagwood, 2000).

On the other hand, a review of 17 studies of mental health treatment within primary care settings finds little evidence to date that child mental health outcomes improve (Bower, Garralda, Kramer, Harrington, & Sibbald, 2001). And, while there has been a very large federal investment in grants to local communities around the nation to develop Systems of Care (SoC) to improve mental health services for children and youth, such programs have not been rigorously evaluated. A recent report from the national evaluator of SoC grants to local communities by the

³ See <http://www.fftinc.com> for more information on this approach.

Substance Abuse and Mental Health Services Administration reports on the mental health of children in the programs. According to the Child Behavior Checklist, the mental health of only about half of children in the SoC programs studied improves after 18 months, while for the remainder mental health status either remains the same (40%) or declines. In addition, there is a high rate of attrition by 18 months, and the outcomes for SoC children have not been rigorously compared to a matched comparison group not in the programs (SAMHSA, 2007a). Consequently, despite a large investment in the SoC programs, it is not clear what their impact has been on child outcomes.

Summary

The review of recent literature finds that the prevalence of mental health conditions among children is high and that many children with mental health needs face substantial barriers to accessing mental health services. In some cases, services with a positive impact on outcomes have been identified, but in others, the effectiveness of specific services or programs has not been well-established. In general, however, the literature review supports the notion that children experience significant mental health needs and that their needs, the services they use and the outcomes they experience are different from adults with mental health conditions. Thus, a separate evaluation of state mental health systems for children would appear to be worth pursuing. The available literature also helps to categorize the types of data necessary for such an evaluation. The following section explores the availability of such data at the state-level.

DATA TO STUDY STATE DIFFERENCES IN CHILD MENTAL HEALTH

The importance of states in mental health service provision as well as the unique aspects of children's mental health needs suggests that a state-level evaluation of mental health systems for children is warranted. In 2008, Janice Cooper and colleagues at the National Center for Children and Poverty (NCCP), produced a report that examined children's mental health policies across the United States in an effort to understand how well states were serving children with mental health needs (Cooper et al., 2008). The results were mixed. Some states showed signs of promotion of evidence-based practices and culturally-competent care, while many states were unable to report certain critical data elements necessary for an evaluation.

The NCCP report represents one approach towards evaluating mental health systems for children at the state-level, but additional research remains necessary. The NCCP analysis relies primarily on a survey of child mental health directors to draw its conclusions. Such survey data may be very useful for specific questions, but it cannot capture all of the various elements necessary to perform a comprehensive evaluation of the mental health service system. Furthermore, designing and implementing such a survey for a specific study requires a significant investment and does not allow for analysis of trends over time.

An alternative approach to producing a state-by-state analysis is exemplified by the Annie E. Casey Foundation's well-known KIDS COUNT project (Annie E. Casey Foundation, 2009). KIDS COUNT collects a wide variety of data from numerous sources that relate to the well-being of children in the United States. The data is compiled at the state-level to present a detailed picture of child well-being across the country. The advantage of such an approach is that the data comes from existing surveys and sources that generally use well-established and validated measurement techniques. Furthermore, many of these existing surveys are repeated on a regular basis and can thus be used to study trends over time. This section seeks to determine

the feasibility of producing a similar compilation of data with a focus on the children's mental health system. We focus our attention on establishing the level of need for mental health services among children and on assessing the availability and effectiveness of these services at the state-level.

Characteristics of Desired Data

In order to perform comparisons across states, we require data sources with state identifiers, preferably for all states. In the case of survey data, we must also consider details of the survey design including state sample sizes in order to determine the validity of state estimates. Furthermore, because the ability to track state performance over time is desired, we prefer data sources that are consistently collected. Finally, while all available sources that meet the above criteria are reviewed, those that are publicly available at low cost are considered superior. As in the literature review, our priority population is children ages four to nineteen, and we exclude those with the need for substance abuse services only from our population of interest.

Isolating the need for *public* mental health services and the use of such services is more difficult. The public sector mental health system encompasses services delivered by government-operated providers, but also those services that are funded by public resources such as Medicaid. State and local mental health funding may be used to provide services to those without insurance coverage or who have exhausted private coverage as well as for those ineligible for Medicaid benefits. Therefore, children of any income or insurance type may ultimately be eligible for and use the public mental health system. We therefore consider the availability of state-level data on mental health needs and service use for all children. Where possible however we note any details on the availability of data by funding source and/or

provider ownership to distinguish the role of the public system in serving children's mental health needs.

Existing data generally come in one of two forms. Cross-sectional data captures the characteristics of a particular population at a point-in-time. Repeated cross-sectional data examines the same category of individuals, children with special health care needs for example, at different points in time. Longitudinal data, on the other hand, follows the same individuals for a specified length of time. Longitudinal data sources provide an enormous amount of useful information about a specific group of people and offer the best opportunities for studying long-term outcomes for individuals. Such data does not lend itself well to studying trends over time, however. A longitudinal survey, for example, may survey a group of children in middle school and then survey this same set of children again in high school and then college. Such data would not allow us to understand how the characteristics of middle school children and their health care experiences change over time. For the purposes of this analysis, we therefore focus on repeated cross-sectional data sources. Additional details and links to more information on all of the data sources discussed in the following sections can be found in Appendix Table 4.

Establishing the Level of Need for Mental Health Services for Children

In order to begin evaluating the mental health service system for children, it is important to establish the level of need for services. As has been noted, this is no easy task, especially for children. Children can be broadly classified as having a need for mental health services in two major ways. A child may be diagnosed by a health care provider or other professional as having one of many conditions or disorders that would indicate a need for mental health care. Alternatively, a child or their parent may describe their mental health status and indicate feelings

or behaviors that suggest the presence of a mental health condition. While both methods of measuring the prevalence of mental health needs are valid, we marginally prefer the latter because it avoids the potential complication of relying on the utilization of health services to establish the need for said services. That being said, it will also be of interest to establish the prevalence of a variety of specific conditions among children and this requires that a diagnosis be present at some point. We therefore review the available data on both types of prevalence measures.

A pair of surveys sponsored by the Maternal and Child Health Bureau (MCHB) provides periodic estimates of child health statistics at the state level and we will cite these surveys repeatedly in this report. The National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN) contain an extensive amount of useful information on American children with a special focus on their health care needs and experiences. The NSCH surveys a representative sample of all children in the United States while the NS-CSHCN identifies a subset of children with special health care needs and surveys these children in more detail. Both surveys are performed by telephone and ask parents about several child health concerns and conditions that may be classified as mental health problems. The main benefit of both surveys is that they were designed to provide large samples at the state level and thus contain a sufficient number of observations to provide state estimates for all states. This is quite rare among national surveys and obviously very useful for this task.

Several concerns exist, however, regarding the validity of the state estimates from these surveys. The surveys are conducted by telephone and the sample is selected through a Random Digit Dialing (RDD) technique. Children in households with cellular telephones only and those with no telephone will not be adequately represented. Response rates as well as survey

completion rates also vary by state and may contribute to bias in state estimates. In general, the sample of surveyed children may not be representative of the target population due to a variety of factors related to sample design and survey collection. While a formal analysis of non-response bias is being conducted by the National Center for Health Statistics (NCHS), it may be possible to ease some of these concerns with additional research. By using a survey with a stronger sample design and collection methods, such as the National Health Interview Survey (NHIS), a set of national and regional benchmarks could be established and the estimates from the NSCH and NS-CSHCN could be compared to these benchmarks. For instance, if the level of unmet need for mental health services at the regional level on the NSCH is consistent with that measured on the NHIS, we would have more confidence in the estimates from the NSCH at both the regional and the state level. While such an exercise was beyond the scope of the current project, it would be an important step in validating the use of these two surveys for producing state-level estimates for children with mental health problems.

Despite the noted concerns, the NSCH and the NS-CSHCN do provide large samples of children at the state-level and can be used to produce state-level estimates. The NSCH surveys the general population of children and establishes state-level estimates of the prevalence of various conditions including ADD/ADHD, depression and anxiety disorders, conduct problems and other conditions. These conditions are identified by the child's parent as ones that they have been told that their child is experiencing.⁴ This implies that they have been diagnosed by a health care provider or other professional although this is not explicitly stated. An additional set of questions on the NSCH also identifies possible indicators of more general mental health needs, as discussed above. Such measures might include identifiers of children who are

⁴ Respondents are parents in the great majority of cases although, in some cases, the respondent is the most knowledgeable adult in the household.

frequently stubborn, sullen, irritable or disobedient. These behaviors are identified by the parent and do not require a consultation with a health care provider. Therefore, they may provide an indication of mental health need for those who have not sought medical advice.

The NS-CSHCN screens a large population of children using a federally approved definition of children with special health care needs (CSHCN). One of the five screening questions that determine a child's special needs status involves the presence of a chronic emotional, behavioral, or developmental issue. Thus, the survey allows the identification, at the state level, of the proportion of all children who have a special need involving such an issue. The sample for the majority of the survey is then limited to those children identified as having any special health care need. The sample size in each state allows for precise state-level estimates for this population, but because the proportion of CSHCN suffering from an emotional, behavioral or developmental condition is in the range of 25 to 30 percent across states, the error surrounding state-level estimates of this subpopulation may be somewhat larger. Nonetheless, such estimates will still prove useful. One can specifically examine the prevalence of mental health problems on this survey by exploring what proportion of all CSHCN report a need for mental health care or counseling, among other indicators.

Both the NSCH and the NS-CSHCN contain additional questions that may be used to further identify mental health needs among children. A few other sources also allow for state-level estimates of specific prevalence measures. SAMHSA's National Survey on Drug Use and Health (NSDUH), for instance, provides state-level estimates of adolescents with one or more major depressive episode (MDE) in the past year. Because the NSDUH is not designed to produce state-level estimates, the MDE estimates are based on a statistical model and not all survey characteristics can be presented at the state-level. However, since the estimates of MDE

represent very specific diagnostic criteria as opposed to the broader definitions of conditions on the NSCH and NS-CSHCN, the NSDUH data is a nice supplement to the sources already mentioned. Other data with state-level availability include both Medicaid claims data, and hospital discharge data organized through AHRQ's Healthcare Cost and Utilization Project. These data are capable of producing state-level estimates of treated prevalence, or the number of visits to various providers for specific mental health diagnoses, and will be discussed further in subsequent sections of this report.

Many other surveys are capable of providing national estimates of mental health needs for children and some of these surveys have state identifiers available as well. A few worth noting are the National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (MEPS). These data sources may have some unique elements not found on the surveys already discussed, but it is important to be cautious in using estimates based on the small state samples available on these surveys. This is true particularly for comparison purposes, as even large estimated differences between states may not be statistically different at acceptable significance levels. Appendix Table 4 contains a detailed list of the data sources discussed above, their mental health measures and state-level availability.

Assessing the Availability and Accessibility of Mental Health Services for Children

After using the best possible data to establish the level of need for mental health services for children, the next logical step in evaluating the state mental health system is to consider what types of services are available to meet these needs and whether such services are accessible to those who need them. Children with mental health needs may require services from a variety of health care providers or other professionals. As noted in the introduction, children access mental

health care in a wider variety of settings than their adult counterparts. In addition to traditional settings, children may access services through the public school system and through other public agencies including child welfare and juvenile justice. Capturing the availability of traditional health care providers is more straightforward than identifying the services provided through other public sector programs, however. We therefore primarily report on the data availability at the state level on health care providers of various types, paying special attention to any indicators of child/adolescent or psychiatric care. We also note, where possible, the presence of data on public sector providers including government hospitals and clinics. Additional data on alternative sources of mental health care for children are also explored.

Availability of Mental Health Services for Children. The Bureau of Health Professions, a division of the Health Resources and Services Administration/Department of Health and Human Services, compiles a very useful set of statistics on the health resources available in each county in the United States. The data can then be aggregated to the state level for the purposes of this evaluation. This Area Resource File (ARF) includes data from the American Medical Association's physician master file and the American Hospital Association's (AHA) annual survey of hospitals, among many other sources. Through these two sources alone, however, the ARF is able to produce estimates of the number of physicians and hospitals in a state in a given year. The AHA data on the ARF also includes the number of hospitals that provide a variety of specialized services which include general psychiatric services, psychiatric emergency services as well as child/adolescent psychiatric services. The AMA data on the ARF provides information on the number of primary care doctors, pediatricians, psychiatrists and child psychiatrists in an area. The ARF also contains information on the number of Federally Qualified Health Centers (FQHCs) and community mental health centers in an area. Taken

together, this data can paint a fairly detailed picture of the number and types of health care providers available in a state at a point in time. While not every data item is available each year, most measures of provider availability are consistently repeated. When paired with the prevalence data discussed in the previous section, estimates of provider availability per child with mental health needs can also be estimated.

While the ARF captures much of the most general information from AHA annual survey, the survey itself is also available to provide more detailed information on the availability of hospitals by ownership type, bed size and specific services provided. For instance, the AHA annual survey is able to provide estimates of the number of beds in public psychiatric hospitals in a state in a given year. It can also provide more detailed information on the types of services provided in a hospital which, in addition to the availability of psychiatric inpatient services, may include the existence of support groups, teen outreach services and psychiatric outpatient and education services. A major drawback to the AHA data is its cost however. Each year of data costs approximately \$7,000 (with discounts available for universities, hospitals and health systems). There are options to purchase only a few variables which may be more reasonable, however.

Another useful resource for measuring the availability of mental health care to children is data from Bureau of Primary Health Care's Uniform Data System (UDS) which captures information from all recipients of federal grants for the Community Health Center (CHC) program, which includes school-based health centers. CHCs provide primary care and other preventive care services to low-income individuals throughout the U.S. They also play a substantial role in providing behavioral health services. Each year the federal grantees are required to report on the sites and services that they provide and much of the data from these reports is available, at the state level, on the UDS website. Most relevant for this report, the

grantees provide information on the number of patients who used mental health services as well as the number of encounters for such patients. Information is also provided on the staffing of the centers including the number of mental health providers such as psychiatrists, clinical psychologists, clinical social workers and other mental health staff. The number of patient encounters by provider type is also included. Unfortunately, no detail on pediatric specialists is included in this data. Because CHCs cater to a low-income population and, on average, provide approximately 40 percent of their services to Medicaid beneficiaries, evaluating the strength of this system at the state-level may be important when considering the quality of the public mental health system. Related to the UDS data is information from HRSA on the number of mental health professional shortage areas in the state and the estimated underserved population. Again, while this data is not child-specific, it may be indicative of broader access problems to mental health care at the state level. More information on these sources can be found in Appendix Table 4.

The data described above is capable of producing a detailed picture of the availability of traditional healthcare services in a state although not all of the data provides the level of specificity on children's services that might be desired. Furthermore, details on the availability of mental health services in the school, juvenile justice and child welfare systems may not be adequately captured by the data sources discussed.

Accessibility of Mental Health Services for Children. In addition to knowing the numbers and types of providers available at the state-level, any information on the accessibility of these providers to those who need them would also be quite useful. Having a supply of physicians or hospitals that appears sufficient to meet demand is meaningless if there are barriers to accessing those providers. Insurance coverage is critical for accessing any type of medical care. It can be

particularly important for mental health needs as coverage policies often vary for mental and physical health care services. In order to assess the ability of children to access the mental health services in their area, we review data availability on the insurance coverage distribution of children with mental health needs and the generosity of that coverage. We also consider information on state policies towards mental health coverage which include mandated benefits, parity laws and Medicaid coverage details.

The best source for local estimates of the insurance distribution for all children is the American Community Survey (ACS). New health insurance questions on the ACS allow for robust state and sub-state estimates of insurance coverage starting in 2008. No information on health status is available on the ACS however so in order to isolate access measures for those with mental health needs, other sources will be necessary. Furthermore, the ACS does not provide information on the generosity of insurance coverage for mental health services specifically. It only tabulates the presence or absence of coverage and the distribution by major source of coverage.

Several of the data sources already considered are also useful in determining the accessibility of mental health services for children with a need for such services. Both the NSCH and the NS-CSHCN provide data on the insurance coverage distribution of children. When limiting the sample population to those with specific mental health needs, these estimates become less precise, but nonetheless useful. Further insight into a child's ability to access needed mental health services is also provided by very specific questions on each survey. The NSCH asks parents whether there was any time in the past 12 months when the child needed mental health care, but delayed getting it or did not obtain it at all. The NS-CSHCN asks a similar question of its target population and also includes a follow-up question that indicates the level of unmet

need. Furthermore, the NS-CSHCN includes estimates of unmet needs for family mental health counseling in addition to that for the individual child. These questions provide a general sense of whether or not children with mental health problems are getting the care they, or their family, feel that they need.

Two other national surveys are worth mentioning regarding the assessment of access to needed services. The Medical Expenditure Panel Survey (MEPS) is a nationally representative survey which provides a wealth of information on the health care use and expenditures of the US population. The MEPS compiles information from individual survey responses as well as from providers and employers in order to create a complete profile of insurance, utilization and expenditures. For the purpose of this analysis, the MEPS data allows the exploration of the expenditures on and sources of payment for mental health conditions for children. One interesting use of this data would be to explore the proportion of children's mental health expenditures that are not covered by any type of insurance and are thus paid out-of-pocket by the child's family. This provides one way to estimate the generosity of mental health benefits for those with insurance coverage. Unfortunately, the MEPS data is not state representative so producing state estimates of such a measure would be limited to larger states or require some pooling of data or more sophisticated statistical methods. Furthermore, accessing the state identifiers on the MEPS data requires access to the AHRQ Data Center. The uniqueness of this potential measure, however, could potentially prove useful.

The National Health Interview Survey (NHIS) also provides some useful information on the accessibility of care for children with mental health problems. Children who needed mental health care or counseling in the last 12 months, but did not get it due to cost are identified by their parent. Like the MEPS, the NHIS does not have state identifiers on its public-use files and

would not allow for estimates for all states due to small sample sizes. The measures from this survey however might be useful in benchmarking the estimates of unmet needs from the NSCH and the NS-CSHCN, as discussed briefly above.

Beyond the individual-level data on insurance coverage, unmet needs and out-of-pocket costs, state-level data on the accessibility of mental health services also exist. The Kaiser Family Foundation maintains a Medicaid benefits database on their website that provides information on state-level policies for covering a variety of mental health services. This includes coverage of inpatient and outpatient services as well as any information on cost-sharing or other limitations to coverage. Specific benefits for children are addressed here as well. For those with private coverage, the National Conference of State Legislatures regularly reviews state policies on mandated benefits that must be included in all insurance plans as well as the details of mental health parity laws that states have passed. These measures are useful as indicators of state support for mental health services. Along with the individual-level measures of insurance coverage and unmet needs, these measures should produce a good estimate of the ability of children and their families to access the mental health services available in their state. Details of all of the data sources discussed above can be found in Appendix Table 4.

Examining the Utilization and Effectiveness of Mental Health Services for Children

Understanding the need for mental health services and the ability of children to access available services naturally leads to a desire to know which services are ultimately used by children with mental health needs and the effectiveness of these services. We first address the available data on utilization and then turn to measures of effectiveness.

Utilization of Mental Health Services for Children. Information on utilization of services is some of the most extensively collected health-related data. There are two general types of utilization data; that which has been obtained through population-based surveys such as the NSCH and the NS-CSHCN and that which has been compiled from insurance claims or provider discharge records. The benefit of survey-based measures is that they often measure the use of services more broadly. This may allow for a better sense of the total amount of mental health care provided to children through the various sectors in which it can be accessed. Claims or discharge data from various providers however often include very specific diagnosis, procedure and medication information because the data are submitted by healthcare providers as opposed to by parents or children themselves. This type of data is generally already being collected by the provider and needs only to be standardized for use by researchers. Claims or discharge data is therefore often available for very large samples or even for entire populations, including Medicaid beneficiaries, for instance. We review a few of the potentially useful sources of data on utilization of mental health services for children.

The NSCH and NS-CSHCN are able to provide state-specific estimates of the use of a variety of health care services. As has been noted, however, more research is necessary to assess the validity of the state-level estimates. The NSCH generates an estimate of the proportion of children who received ‘any mental health care or counseling’ in the past 12 months. The benefit of such a general measure, as indicated above, is that this may include the types of services that are provided through the school system or other public sector providers and not just those provided by a physician in a more traditional setting. The NS-CSHCN also provides details on mental health use as well as some more general information on doctor and emergency room visits. In both surveys, it is also possible to examine utilization patterns for subsets of children

with various behavioral problems or specific conditions. As was the case for prevalence and access measures, many other nationally representative surveys including the NHIS and the MEPS contain additional measures of utilization, but do not have large state samples.

Beyond survey measures of mental health care use, many sources of outpatient and inpatient claims and discharge data exist which track the details of patient visits to specific medical providers. Such data can be used in a variety of ways from estimating ‘treated prevalence’ of certain conditions to evaluating outcomes. Their most appropriate use however is to estimate the number and types of mental health care services being used by patients. Mental health care utilization is generally identified based on the diagnosis code(s) entered on a discharge record. Additional information on such records is usually fairly limited to procedure codes, charges, and basic patient demographics including age, sex, and race as well as expected payer. Furthermore, such data often contains information on the type of provider or the physician specialty. For instance, hospital discharge data often contains, or is able to be linked to, data on hospital ownership. Physician claims data typically has information on physician specialty and setting, such as office-based, clinic-based, etc... This information may be particularly useful in trying to estimate the use of public hospitals or clinics.

National estimates of the number of doctor visits, by children, for a mental health condition can be obtained from the National Ambulatory Medical Care Survey (NAMCS). A related database, the National Hospital Ambulatory Medical Care Survey (NHAMCS) can produce similar estimates for utilization of outpatient services provided through hospital outpatient (OPD) and emergency departments (ED). The Healthcare Cost and Utilization Project - Kids’ Inpatient Database (HCUP-KID) provides national estimates of inpatient admissions for children, including those with a mental health diagnosis. Reliable state-level estimates are not

available from any of the above sources, however. The HCUP State Inpatient Databases (SIDs), from which the sample for the HCUP-KID is drawn, provide data on all inpatient discharges from participating states. The accessibility of each participating state's HCUP-SID varies however. Some states make their SIDs quite readily available while others provide limited access or charge very high fees to obtain the data. Furthermore, not all states participate in the HCUP data collection effort and therefore a 50 state comparison cannot be generated using this data.

Perhaps the most important claims data for children with mental health needs is that collected for the Medicaid population. Each state is required to participate in the Medicaid Statistical Information System (MSIS) and the reported data are released in five files known as the Medicaid Analytic Extracts (MAX); an enrollment file and four claims-based files. The claims are divided into inpatient, long-term care, drug and other therapy categories. The other therapy category includes physician visits, labs, x-rays and clinic visits. Like all claims data, the details are fairly limited to basic demographics and various diagnosis, procedure and discharge information. One additional notable limitation for Medicaid claims data is that it under-reports data for those beneficiaries enrolled in managed care programs. Managed care penetration within the Medicaid program varies by state, but can be substantial, especially for children, and thus it is important to recognize this limitation. It is also necessary to obtain permission to use the MAX files through an application to CMS with details on the research purpose as well as evidence of funding. Obtaining all files for all states would cost at least \$30,000 per year. Limiting the claims files or the number of states could reduce this cost, but to provide a meaningful group of states for a state-based comparison, the costs would be non-trivial.

State Medicaid programs are also required to separately report one additional data element that is relevant to the population of children with mental health needs. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program provides extensive coverage of preventive and primary care for children up to age 21 in the Medicaid program. Each state is required to report the population of children eligible for the program and the proportion that receive the recommended screening procedures. This data is submitted on CMS Form 416 and is available for all 50 states from the CMS website. This information should provide a good indication of the outreach efforts at the state level to screen children for a variety of physical and mental health problems, but inconsistencies across states and problems with data quality may significantly limit its usefulness.

Some additional data on utilization is available through the Office of Special Education Programs and the Children's Bureau of the Administration on Children, Youth and Families. These data address the utilization of specialized services by children with disabilities and those who have suffered some form of maltreatment, respectively. The available data provide less conventional measures of service utilization, but may be useful because they capture additional information on these particularly vulnerable populations. The Individuals with Disabilities Education Act (IDEA) data includes counts of children with various disabilities in each state that receive specialized education services under the IDEA. The disability categories include emotional disturbance and autism, among several other categories. The data is also available by age and race. While this data does not specifically measure the use of mental health services, it measures the use of some specialized services within the education system delivered to children with mental health challenges. Comparing such estimates to some of the available prevalence

measures may allow for some indication of how well the education system is serving children with mental illness.

The National Child Abuse and Neglect Data System (NCANDS) Child File provides child-level information on investigated reports of maltreatment submitted by state child protective services agencies. The data includes a variety of information on both the child and the perpetrator of the abuse. Of particular interest for this report is information on the presence of certain risk factors for maltreatment. These include emotional disturbance and behavior problems, among other conditions. The data also includes information on services that were provided to the child as a result of the maltreatment and include mental health services as well as family support services. This data can provide information on whether children with mental health needs who experience episodes of abuse or neglect are being provided with access to mental health or other support services. Again, this data addresses the mental health needs and service utilization for a very vulnerable population.

A great deal of data on service utilization exists for children with mental health needs. The review of such utilization data indicates that generating 50 state comparisons based on claims or discharge data would prove challenging, however. The HCUP files have some potential to create state estimates using the SIDs, but not all states participate. The NAMCS and the NHAMCS do not have state identifiers available and their documentation specifically claims that they are not able to produce reliable state estimates. Medicaid claims data is available for all states, but the uncertainty surrounding the data on managed care claims makes it less than ideal. Thus, although estimates of utilization from survey data are somewhat limited in their specificity with respect to diagnosis and/or provider information, they are more likely to be readily available for all states. Furthermore, when using survey data to examine utilization measures, data on

children with no utilization is also available. This is not the case when using discharge or claims data. Additional details on the utilization measures in all reviewed sources are included in Appendix Table 4.

Effectiveness of Mental Health Services for Children. Data on the prevalence of mental health needs, access to mental health services, and utilization of these services provides evidence on whether and how mental health services are being delivered to those who need them. The final element necessary in evaluating the state mental health system is to consider the effectiveness of the services being provided. Effectiveness can be measured in a variety of ways. We can observe clinical outcomes, such as hospital readmission rates, or more general indicators of mental health status, which might include school or social outcomes measures. Such individual outcomes measures may indicate if mental health treatments are successful in reducing morbidity and improving general quality of life. Information on the quality of the services themselves, independent of individual outcomes, is also useful. Positive mental health outcomes may take a long time to generate and have many confounding factors. Thus, measuring the quality of the services provided is critical to evaluating the system. For mental health services for children, such measures might include whether care is generally found to be family-centered, culturally sensitive, and well-coordinated. A variety of sources provide some ability to evaluate both types of effectiveness measures.

The NSCH and NS-CSHCN once again have some useful data in this area. The NSCH has several measures of school-based outcomes which might be particularly useful for children. Data on missed school days is available for school-aged children as is additional data on education outcomes. Such outcomes include repeating a grade and engagement in school. Comparing state-level data on such measures for children with mental health needs may give

some indication of how successful their mental health care has been, but in doing so it would be very important to control for other characteristics that affect these outcomes as well as the likelihood of obtaining effective services. Additional relevant outcomes on the NSCH include participation in activities outside of school as well as measures of work and volunteer activities for adolescents. Similar individual outcomes measures are available on the NS-CSHCN.

Recognizing again that mental health treatment may take time to produce positive outcomes and that many other variables will influence the outcomes measures noted above, information on the characteristics of the care being provided to children may be more important in evaluating the effectiveness of the system. The NSCH provides detailed data in this area although it is not necessarily specific to a child's mental health care experience. A series of questions seek to determine whether or not a child has a 'medical home'. This is based on the definition that a medical home includes care that is "accessible, continuous, comprehensive, family-centered, coordinated and compassionate." Some specific questions include those on whether the child received family-centered and well-coordinated care. Similar measures are also available on the NS-CSHCN. Indicators of 'family-centered care', for instance, include care that is culturally sensitive and where doctors spend enough time and treat the family as a partner. Well-coordinated care is measured by satisfaction with the communication between a child's doctors as well as that between doctors and schools or other programs. Both surveys therefore include a variety of individual outcomes as well as some indicators of the quality of the services being provided for children. All of these are available at the state level and can be estimated for a subpopulation of children with mental health needs although, as has been noted, state-level estimates have not been validated and estimates for the subset with mental health needs become less precise.

One additional source of individual-level data with the ability to produce state estimates is the Youth Risk Behavior Surveillance System (YRBSS). Although it is currently able to produce estimates for only 39 states, it provides unique outcomes data. The YRBSS surveys students in grades 9-12 and, among other things, gathers information on their feelings of sadness or hopelessness. It measures very little related to students' interactions with the healthcare system, but does include one notable outcome measure. Students are asked whether they have ever seriously considered suicide as well as whether they have formulated a plan or ultimately attempted suicide. Such outcomes cannot be directly attributed to the mental health care system, but if a larger proportion of students with feelings of sadness and hopelessness contemplate or attempt suicide in certain states, this might be worthy of further investigation as it may indicate that they are not receiving sufficient support for their mental health problems. More detailed data on suicide deaths among children and adolescents in every state are also available from the CDC WISQARS Injury Mortality Reports.

Another indirect measure of outcomes of the mental health system for children can be found in the form of arrest statistics for those under 18 years old. The Office of Juvenile Justice and Delinquency Prevention (OJJDP) provides access to the FBI's Uniform Crime Reports for each state for juvenile offenders. The EZAUCR data captures the number of juvenile offenders in a state in a given year by category of the offense. This data does not include any information on the mental health status of the offenders, but again a correlation between high mental health needs in the state and high juvenile arrest rates would be cause for further investigation to determine if a lack of mental health care might contribute to such problems.

More clinical outcomes of mental health care services may be obtained from hospital discharge data. For instance, in some states, HCUP data can be used to identify whether children

admitted to the hospital for a mental health condition were readmitted to a hospital within a specified period of time. Since inpatient admissions are relatively rare for children, particularly because we have excluded the substance abuse element from our population of interest, this may not be a particularly informative outcome measure for children. Furthermore, in 2007, the person-level identifiers necessary to create a readmission indicator were only available for twelve states on the HCUP surveys. Given the presence of a unique beneficiary identifier on the Medicaid claims data, readmissions would be identifiable for all states, but other limitations to this data have already been noted. Thirty- and 180-day readmission rates for children are also compiled at the state-level as part of SAMHSA's Center for Mental Health Services (CMHS) Uniform Reporting System as two of the National Outcomes Measures (NOMS).

Other data collected and distributed at the state-level may also be useful in evaluating the effectiveness of the state mental health system. The CMHS NOMS were mentioned above and represent SAMHSA's attempt to standardize the measures of system performance across states. In addition to the readmission measures already mentioned, the NOMS include measures of child/family satisfaction with their service outcomes as well as indicators of the provision of specific evidence based practices (EBPs) for children. While this collection of measures has the potential to be very useful, some concerns exist. Not all states respond with information on all measures and the consistency of measurement across states is unclear. States may differ in their interpretation or measurement of particular indicators which can then make comparisons across states less meaningful. Data of a similar nature is also compiled and distributed by the National Association of State Mental Health Program Directors (NASMHPD) Research Institute (NRI) and the same concerns exist. The data discussed above are described in more detail in Appendix Table 4.

Gaps in the Existing Data

Data on the level of need for mental health services among children as well as on the availability, accessibility, utilization and effectiveness of these services are all important components in evaluating the performance of the state mental health system for children. The information presented above indicates that there is actually a substantial amount of existing data in each of these areas. In fact, due to the existence of the two large national surveys of children, the state-level data availability for children may be superior to that for adults. While the sources considered above surely do not represent a completely comprehensive list, we believe that they do represent many of the most reliable and accessible sources of state-level data on children with mental health needs and the services they receive. Nonetheless, gaps in the data still exist and this section will consider where we found the information to be lacking.

Data on the prevalence of mental health needs are widely available both in reference to specific conditions as well as to more general behavioral and emotional difficulties. Such data would benefit however from a more standardized definition of mental health needs. Information on the availability of mental health service providers is also relatively easy to access for providers in the mainstream health care system. More information on child-specific providers would be beneficial however. Data on insurance coverage and unmet needs provide good estimates of accessibility of general health services, but additional details on coverage for mental health services would add value. Furthermore, the levels of provision of mental health services to children through other public sector programs are not easy to obtain. While a few very specific characteristics of these populations can be measured, more general data on the numbers

of children's mental health providers, as well as the utilization of services by children, in the education, child welfare and juvenile justice systems would be particularly useful.

Existing data on utilization of all types of inpatient and outpatient mental health services is quite comprehensive at the national level. Various sources of claims data as well as hospital discharge abstracts can be used to make national estimates of the use of many mental health related services. At the state-level, however, many limitations exist which make it difficult to produce estimates of inpatient and outpatient service use for comparison across states. Survey data is available however to produce state-level estimates of utilization.

In this review of available data sources, information on the effectiveness of the services being provided by the state mental health system was found to be the most difficult to identify. This is due in part to a broader difficulty in defining effective services and determining a useful set of outcome measures for children with mental health problems, but also due to data limitations. The necessary steps to eliminating these deficiencies must first include developing a standardized set of quality measures for children's mental health and then collecting data on such measures.

Quality measures need to include indicators of effective services as well as measures of successful outcomes. While several measures of service quality related to medical homes are currently included on existing surveys, one area that is noticeably lacking is any measurement of clinical appropriateness of care. Process measures can be used in conjunction with evidence on service effectiveness to measure the appropriateness of the care being provided. In diabetes care, for example, evidence indicates that diabetics should receive regular eye and foot exams to test for the presence of diabetes complications. Thus, a measure of the proportion of diabetics that receive such recommended care is an indicator of quality. These types of process measures

should be developed for children's mental health conditions to determine if individuals are getting the appropriate care for their mental health needs. Such measures could then be included on existing surveys or potentially tracked using claims data. For example, if all children taking a prescription medication for ADHD should receive one or more counseling visits, this would constitute a process measure that could be added to existing surveys. Furthermore, several educational and social outcomes measures appear on the various surveys reviewed in this report, but it is unclear which of these are most sensitive to mental health treatment. Before we can identify data sources that can measure the effectiveness of mental health services delivered to children, a consistent set of quality measures for this population must be established.

In general, this review of data availability focused very heavily on the child as a unit of observation and then aggregated such information to the state-level. We sought to describe the available population-based data on the level of need for mental health services and the availability and effectiveness of these services for children. We did not fully evaluate the availability of system-level performance data that might reflect the intermediate steps towards creating accessible and effective services for children. Such measures might include funding information for the state mental health agency or other measures of system resources. Collecting such data may also be important to a state-level evaluation.

CONCLUSIONS

The proportion of children and youth in the U.S. who have mental health problems is high, with over a quarter of them having a serious mental health problem sometime in their childhood. Many of the children and youth served in public systems have severe mental health problems. While the availability and use of mental health services for children appears to have increased in

recent years, there are still many children and youth who are underserved, particularly members of racial/ethnic minority groups. In addition, the quality of services is often poor, and the cost can be very high. While the effectiveness of some mental health prevention and treatment programs has been demonstrated, the adoption of evidence-based practices is not yet widespread.

In order to improve the state of mental health systems for children in the United States, it is necessary to be able to perform more consistent evaluations of the need for mental health services for children and the availability and effectiveness of these services. Because states play such an important role in the provision and funding of mental health services, analysis at the state-level is considered particularly desirable. A wide array of data sources provides the ability to obtain much of the information necessary to perform such an evaluation. While data at the state-level is not always available or fully validated, state-specific estimates of the prevalence of mental health problems as well as information on the availability and accessibility of mental health services for children do exist. Even with some of the concerns surrounding state-level estimates, the available data is valuable and has the potential to be compiled and presented in order to draw reasonable, if qualified, conclusions regarding the performance of state mental health systems.

Our investigation finds that the most limited measures are related to the effectiveness of mental health services themselves and the outcomes of these services for children. Additional information on these measures would allow for a more complete evaluation of mental health systems. Despite some of the limitations in the data, we conclude that collecting the available data for the purpose of creating a state-by-state comparison of mental health systems for children is a worthwhile goal. In addition to creating a set of the best possible measures on which to compare the performance of state mental health systems, the compilation of measures from a

variety of sources could create awareness of complementary data elements that have not previously been analyzed together. This could improve future analyses related to children's mental health. Furthermore, the process of collecting the available data would inevitably lead to an even better understanding of the gaps in the data as well as a deeper knowledge of any measurement problems with those data elements that exist today. Altogether, such a data gathering project could ultimately lead to vast improvements in both the measurement of key characteristics of the mental health system for children as well in the future availability of data on this important topic.

With the high prevalence of mental health conditions for children and the dire consequences of a lack of affordable, accessible services to treat these conditions, it appears that consolidating the available data on the current status of state mental health systems is a worthwhile venture. While the data is imperfect, it is able to provide a starting point in evaluating state mental systems and, in the process, to increase the awareness of the need for better data on this vulnerable population.

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APPENDICES

Appendix Table 1: Articles/Reports on Prevalence of Mental Health Problems in Children and Youth

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Buck, J.A., Teich, J.L., Bae, J., & Dilonardo, J.	2001	10 states, 1993	Children ages 6-14	Medicaid claims	Users of mental health and substance abuse services constitute from 4.5% (Delaware) to 13.9% (Vermont) of all Medicaid children.
Brauner, C.B., & Stephens, C.B.	2006	Literature review	Children	Research literature	The prevalence of serious emotional disturbance varies from 7% to 26% depending on the study.
Centers for Disease Control and Prevention (CDC)	2010	U.S., 1991-2007	Youth in grades 9-12	Youth Risk Behavior Survey (YRBS)	The percentage of youth who seriously consider suicide in the past year decline from 29.0% in 1991 to 14.5% in 2007.
Costello, E.J., Keeler, G.P., & Angold, A.	2001	Four counties in Western North Carolina, 1992-2003 (see Costello et al., 1996, for methods)*	Youth ages 9-13 at intake	Longitudinal survey of families/Great Smoky Mountains Study of Youth (GSMSY)	After controlling for other factors associated with poverty, such as being raised by a single parent and negative life events, the association between poverty and presence of a mental health disorder is weak.
Costello, E.J., Mustillo, S., Erkanali, A., Keeler, G. & Angold, A.	2003	Western North Carolina, 1992-2003	Youth ages 9-13 at intake	GSMSY	Although 3-month prevalence of any disorder only is 13.3%, over three years it is 36.7%, with 3-year prevalence for boys (42%) higher than girls (31%). The prevalence of certain disorders increases over time (anxiety, panic, depression, and substance abuse), while the prevalence of others decreases (separation anxiety and ADHD).
Costello, E.J., Compton, S.N., Keeler, G., & Angold, A.	2003	Western North Carolina, 1992-2003	Youth ages 9-13 at intake	GSMSY	Moving out of poverty is associated with a reduction in behavior disorders (eg. conduct disorder) but not in anxiety or depression.
Eaton, D.K., Kann, L., Kinchen, S., Shanklin, S., Ross, J., Hawkins, J., Harris, W.A., Lowry, R., McManus, T., & Chyens, D.	2008	U.S., 2007	Youth in grades 9-12	Youth Risk Behavior Survey (YRBS)	35.8% of girls and 21.2% of boys felt sad or hopeless in the past month. The percentage of youth feeling sad or hopeless range from 17.% (North Dakota) to 32.5% (Arizona). The percentage of youth seriously considering suicide ranges from 8.1% in North Dakota to 17.8% in Wyoming.

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Farmer, E.M.Z., Burns, B.J., Chapman, M.V., Phillips, S.D., Angold, A., & Costello, E.J.	2001	Western North Carolina/1992-2003	Youth ages 9-13 at intake	GMSY	37.5% of children ever in foster care have a Serious Emotional Disturbance (SED), compared to 24.0% of poor children, and only 4% of all children.
Fazel, S., Doll, H., & Langstrom, N.	2008	Literature review	Youth (ages 10-19) in juvenile detention and correctional facilities	Review of 25 studies meeting inclusion criteria	The prevalence of psychosis is 10.6% for boys and 2.7% for girls. Girls have higher rates of major depression (29.2%) than boys (11.7%), but the same rate of conduct disorder (52.8%).
Garland, A.F., Hough, R.L., McCabe, K.M., Yeh, M., Wood, P.A., & Aarons, G.A.	2001	San Diego, CA, 1997-1999	Youth ages 6-18 served in one of five public sectors: alcohol and drug services; child welfare; juvenile justice; mental health; and special education.	Assessments of mental health problems using the Diagnostic Interview Schedule for Children (DISC)	Just over half of children in public systems (54%) have at least one mental health disorder. Most have ADHD or disruptive behavior disorders (50%), with much lower prevalence of anxiety (10%) or depression (7%).
Grupp-Phelan J., Harman, J.S., & Kelleher, K.J.	2007	US, 1995-2001	Representative sample of hospital emergency rooms	National Hospital Ambulatory Medical Care Survey	Children with mental health problems constitute about 5% of all emergency department admissions, increasing during the time period, while the rate of ED admissions for other chronic conditions remains stable.
Hartney, C., McKinney, T., Eidlitz, L., & Craine, J.	2003	California, 2003	Youth in the juvenile justice system in 51 counties	Survey of probation officers	29% of youth in detention, 44% of youth in placement, and 28% of youth under field supervisions have a formal diagnosis of a serious mental health problem.
Howell, E.	2004	U.S.,2002	Children ages 6-17	National Survey of America's Families (NSAF)	11.7% of poor children have emotional/behavioral health problems according to parent reports of problems, compared to 6.4 % of non-poor children; rates are highest (12.4%) for children enrolled in Medicaid or SCHIP.
Howell, E., & McFeeters, J.	2008	U.S.,1997, 1999, and 2002	Children ages 6-17	NSAF	After controlling for other child characteristics, prevalence of mental health problems does not differ by race/ethnicity or urban/rural residence. Adolescents have a significantly higher prevalence of problems compared to school-aged children, as do boys compared to girls.

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Howell, E.M., & Teich, J.	2008	23 states, 1999	Children ages 6-18	Medicaid claims data	The proportion of children with a mental health diagnosis reported on claims varies from 5.8% in girls to 9.9% in boys. The percentage by state varies from under 6% in Texas to 17% in Maine.
Institute of Medicine	2009	Literature review	Children ages 1-18	National and international literature from the 1990s and 2000s	The mean prevalence of an emotional or behavioral disorder is 17% (median=17.5%) across studies. Half of the studies fall in the range of 12-22%. There is considerable variability across studies in methods, age groups, and locations.
Kessler, R.C., Berlund, P., Demler, O., Jin, R., Merikangas, K.R., & Walters, E.E.	2005	U.S., 2001-2003	Adults	National Co-morbidity Study	75% of all mental health disorders over a lifetime have their onset before age 25, and 50% of disorders have onset before age 15.
Lesesne, C.A., Visser, S.N., & White, C.P.	2003	U.S., 1998	Children ages 4-17	National Health Interview Survey (NHIS)	Poor maternal mental health is significantly associated with a diagnosis of ADHD in school-aged children
Pastor, P.N., & Reuben, M.A.	2008	U.S., 2004-2006	Children ages 6-17	NHIS	About 5% of children have Attention Deficit/Hyperactivity Disorder (ADHD), about 5% have a learning disability without ADHD, and about 4% have both. Boys have a higher prevalence of both disorders. Among insurance groups, Medicaid children have the highest prevalence.
Pergamit, M.R.	2010	Literature review and U.S. 1997	Children age 12-18 at time of survey	Review of four other data sources and analysis of National Longitudinal Survey of Youth/97	The range of estimates of the number of youth who have run away from home in a given year ranges from 6.4% (Add Health) to 7.6% (Youth Risk Behavior Survey). The longitudinal nature of the NLSY allows for studying prevalence throughout adolescence. 18.3% of boys and 20.6% of girls run away some time. About half of those do so more than once.
Rice, C.	2009	Autism and Developmental Disability Monitoring Sites in 11 States, 2006	Children age 7	Abstraction of health and education records followed by clinician review	The prevalence of autism spectrum disorders is close to 1% of all children age 8, and is rising, with the rate in 2006 1.6 times as high as the rate in 2002. The prevalence is 5 times higher for boys than girls, and varies by site.
Shufelt, J.J. & Cocozza, J.J.	2006	Louisiana, Texas, and Washington, 2006	Youth in the juvenile justice system	Interviews using the DISC	70.4% of youth had at least one mental health disorder; rates are higher for females. The most common disorders are anxiety for girls (56%) and disruptive disorders for boys (44.9%). Over half have multiple disorders.

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Simpson, G.A., Cohen, R.A., Pastor, P.N., & Reuben, C.A.	2008	U.S., 2005-2006	Children ages 4-17	NHIS	14.5% of children have a parent who has spoken with a health care provider or school professional about their child's emotional or behavioral difficulties in the past 12 months. The rate is 17.6% for boys and 11.2% for girls.
Sturm, R., Ringel, J.S. & Andreyeva, T.	2003	13 U.S. States	Children ages 6-17	NSAF	The proportion of children with a mental health problem according to the Child Behavior Checklist ranges from 5.6% (New Jersey) to 9.4% (Mississippi). The U.S. average is 7.5%.
Substance Abuse and Mental Health Services Administration (SAMHSA)	2007	US, late 1990s	Children enrolled in Systems of Care programs	Surveys of families in programs	Children in the SOC programs have a high severity of mental health problems. About a third are involved in the juvenile justice system and a third have run away from home. They come from families with a high rate of substance abusing parents (70%).
SAMHSA	2007	US, 2004-2005	Youths ages 12-17	National Study of Drug Use and Health (NSDUH)	The prevalence of major depressive episodes varies from 7.2% (Louisiana) to 10.4% (Idaho).
SAMHSA	2008	US, 2004-2006	Youths ages 12-17	NSDUH	The percentage of youth who experience a major depressive episode over the past year climbs from 4.1% for 12 year olds to 11.5% for 16 and 17 year olds. About 70% of those with an episode have either a severe or very severe episode. The very severe episodes endure an average of two months.
SAMHSA	2010	US, 2008	Youth ages 12-17	Drug Abuse Warning Network (DAWN)	8.8% of drug-related emergency department visits for youth are for suicide attempts. 72.3% of such drug-related suicide attempts are by females.
Teplin, L.A., Abram, K.M., McClelland, G.M., Dulcan, M.K., & Mericle, A.A.	2002	Cook County, Ill, 1995-98	Youth in juvenile detention	Interviews using the DISC	Nearly 60% of males and more than two-thirds of females in juvenile detention meet diagnostic criteria for one or more psychiatric disorders.

* Costello, E.J., Angold, A., Burns, B.J., Stangl, D.K., Tweed, D.L., Erkanli, A., & Worthman, C.M. (1996, December). "The Great Smoky Mountains Study of Youth. Goals, design, methods, and the prevalence of DSM-III-R disorders." *Archives of General Psychiatry*, 53(12), 1129-1136.

Appendix Table 2: Articles/Reports on Access and Services for Children and Youth with Mental Health Problems

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Allen, K.D., Pires, S.A., & Brown, J.	2010	U.S., 2009	Residential treatment facilities for children and youth	Survey of facilities	75% of facilities implement a range of quality control procedures such as regular case reviews with a quality review committee; however a small minority (under 15%) implement family-driven and youth-guided care principles in the care process. This includes including family and youth in care process decisions.
Angold, A., Erkanli, A., Farmer, E.M., Fairbank, J.A., Burns, B.J., Keeler, G. & Costello, E.J.	2002	Western North Carolina, 1992-2003	Youth ages 9-13 at intake	Great Smoky Mountains Study of Youth (GSMSY)	While African-American and white youth have similar prevalence of mental health problems, use of specialty mental health services is significantly lower for African-Americans.
Barry, C.L., & Busch, S.H.	2007	U.S., 2000	Children ages 0-17	National Survey of Children with Special Health Care Needs	Living in a state with mental health parity significantly reduces the financial burden on families of children with mental health conditions.
Barry, C.L., & Busch, S.H.	2008	U.S., 1997-2002	Children ages 6-17	National Survey of America's Families (NSAF)	State parity laws do not affect the probability of a child receiving outpatient mental health services during this time period.
Breland-Noble, A.M., Elbogen, E.B., Farmer, E.M.Z., Dubs, M.S., Wagner, H.R., & Burns, B.J.	2004	North Carolina, 1999-2001	Youth (mean age 14.1) in therapeutic foster care or group homes	Interviews with caregivers	During the four study months, 67% of youth in therapeutic foster care and 77% in group homes took at least one psychotropic medication.
Burns, B.J., Phillips, S.D., Wagner, H.R., Barth, R.P., Kolko, D.J., Campbell, Y., & Landsverk, J.	2004	U.S., 1999	Children ages 3-14 in the child welfare system and their caregivers	National Survey of Child and Adolescent Well-being (NSCAW)	Only one-fourth of children with mental health needs in child welfare systems receive mental health services. African-American children are significantly less likely to receive services.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Cook, J.A., Heflinger, C.A., Hoven, C.W., Kelleher, K.J., Mulkern, V., Paulson, R.I., Stein-Seroussi, A., Fitzgibbon, G.	2004	MS, Ohio, OR, PA,NY, TN, 1997	Children ages 4-17	Interviews with caregivers	Children enrolled in managed care plans have lower use of inpatient services and medication, but equivalent use of outpatient services, to those in fee-for-service.
Cooper, J.L., Aratani, Y., Knitzer, J., Douglas-Hall, A., Masi, R., Banghart, P., & Dababnah, S.	2008	U.S., 2009	State agencies providing mental health services to children	Survey of states	There is wide variety in the capabilities of states to provide adequate mental health services using System of Care principals. Only 12 states mandate evidence-based mental health treatment for children, and only 8 of those have taken steps to enforce these mandates. Thirteen states do not know how much they spend for children's mental health.
Elster, A., Jarosik, J., VanGeest, J., & Fleming, M.	2003	Literature review	Children and youth	10 articles published in 1992-2003	Most studies show that minority youth have lower rates of mental health service use, but one study shows higher rates for black youth and two studies show no difference.
Farmer, E.M.Z., Burns, B.J., Phillips, S.D., Angold, A., & Costello, E.J.	2003	Great Smoky Mountains Study of Youth	Youth ages 9-13 at intake	Survey of families	54% of youth with a mental health problem never use a mental health service either prior to or during the three year study period. The education sector is the most common point of entry and provider of mental health services. The linkage between education and other sectors (eg. specialty mental health services) is weak.
Farmer, E.M.Z., Mustillo, S.A., Wagner, H.R., Burns, B.J., Kolko, D.J., Barth, R.P., and Leslie, L.K.	2010	U.S., 1999	Children ages 3-14 in the child welfare system	NSCAW	Among children served, most receive services from specialty mental health (35%), schools (23%), or both (22%).
Foster, S., Rollefson, M., Doksum, T., Noonan, D., Robinson, G., & Teich, J.	2005	U.S., 2002-2003	Random sample of schools in the U.S.	Mail survey of school representatives	Almost all (about 90 percent) of elementary, middle, and high schools provide assessment and referral for mental health services and three-quarters provide direct counseling for students (either by psychologists, social workers, or nurses). But only about a third provide medication management.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Garland, A.F., Lau, A.S. Yeh, M., McCabe, K.M., Hough, R.L., & Landsverk, J.A.	2005	San Diego, CA, 1997-1999	Youth ages 6-18 served in one of five public sectors: alcohol and drug services; child welfare; juvenile justice; mental health; and education.	Interviews with caregivers and youth	Minority group youth are significantly less likely to have any mental health services than white youth.
Gaskin, D.J., & Mitchell, J.M.	2005	District of Columbia, 2002	Medicaid children with special health care needs	Interviews with caregivers	Caregivers with depression are 26.3% more likely to report an unmet health care need for their children, and 55.1% more likely to report an unmet mental health care need.
Gifford, E. & Foster, E.M.	2008	Tennessee, 1996-2001	Youth, ages 12-21	Medicaid claims	In a multivariate model, more than half the variance in psychiatric inpatient length of stay is explained by the facility, not the characteristics or diagnoses of the youth.
Grimes, K.E., Kapunan, P.E., & Mullin, B.	2006	Massachusetts, 2001-2004	Children at risk of out-of-home placement ages 3-19	Medicaid claims data	Children in a special managed care program have higher rates of use of primary and specialty care in the first year of the program compared to Medicaid disabled children, but their rates are lower in three subsequent years.
Gyamfi, P., Keens-Douglas, A., & Medin, E.	2007	Selected Systems of Care sites, 2004	Youth and youth coordinators	Focus groups	Effective involvement of youth in service planning is very limited in SoC programs.
Hazen, A.L., Hough, R.L., Landsverk, J.A., & Wood, P.A.	2004	San Diego, CA, 1997-1999	Youths served in one of 5 sectors	Interviews of youth and caregivers	Youth in public sectors have a high lifetime rate of mental health services, with 87% having at least one outpatient mental health service. Service use is highest among those in the education and specialty mental health sectors. Youth in juvenile justice have the lowest rate of use.
Hough, R.L., Hazen, A.L., Soriano, F.L., Wood, P. McCabe, K., & Yeh, M.	2002	San Diego, CA, 1997-1999	Hispanic youth ages 6-18 served in one of five public sectors	Interviews with caregivers and youth	Latino youth enter specialty mental health services at a later age and have fewer specialty mental health visits than whites.

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
Howell, E.	2004	U.S., 2002	Children ages 6-17	National Survey of America's Families (NSAF)	Among poor children with emotional/behavioral problems who are enrolled in Medicaid, 44.1 % receive mental health services, while only 18.1% of poor privately insured children with emotional/behavioral problems have mental health services and only 10.8% of uninsured children.
Howell, E., & McFeeters, J.	2008	U.S., 1997, 1999, 2002	Children ages 6-17	NSAF	After controlling for other characteristics, urban black children have a lower rate of mental health service use than urban white children; both rural and urban Hispanic children have a lower rate of use than white children.
Howell, E.M., & Teich, J.	2008	23 states, 1999	Children ages 6-18	Medicaid claims data	Among children with a mental health diagnosis, mental health service use varies by age. Use of psychotropic medication (including for ADHD) is highest among children ages 6-12, and the use of the emergency room and psychiatric hospitalization is highest among adolescents. Medicaid expenditures for mental health care vary greatly across states.
Hutchinson, A.B. & Foster, E.M.	2003	Literature review	Children with MH/SA disorders in managed care	Seven studies	All studies show decreases in total cost, inpatient care costs, and inpatient services use associated with managed care. Evidence also suggests that managed care increases access to care for mental health services for those with less serious conditions.
Inkelas, M., Raghavan, R., Larson, K., Kuo, A.A., & Ortega, A.N.	2007	U.S., 2001	Children with special health care needs	National Survey of Children with Special Health Care Needs	Children with chronic emotional and behavioral needs have more unmet need than children with episodic mental health needs. Hispanic children have greater unmet mental health needs.
Ireys, H., Achman, L., & Takyi, A.	2006	U.S., 2003	Residential treatment facilities for children with mental health problems	Survey of facilities	There are 3,628 residential treatment facilities for children with mental health problems in the U.S. with 50,507 beds (average of 14 beds per facility); states vary considerably in the types of facilities they certify, in their monitoring of quality of care, and in the length of stay at such facilities.
Juszczak, L., Melinkovich, P. & Kaplan, D.	2003	New York City, 1989-1993	Inner-city high school students	Medical records	Students relying on a school-based health center for primary care are substantially more likely to initiate visits for mental health reasons than students receiving care at a community health center.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Kataoka, S.H., Zhang, L., & Wells, K.B.	2002	U.S., 1996-1998	Children, ages 3-17	Community Tracking Survey, NSAF, and National Health Interview Survey (NHIS)	Of children needing mental health services, only about 20% receive services. Rates of unmet need are higher among Latino children and uninsured children.
Kodjo, C.M., & Auinger, P.	2004	U.S., 1994-1995	Adolescents	National Longitudinal Study of Adolescent Health	Emotionally distressed black adolescents are significantly less likely to receive counseling than similar white or Hispanic adolescents.
Larson, M.J., Miller, K., Sharma, S., & Manderscheid, R.	2004	Michigan, New Jersey, and Washington, 1994 and Pennsylvania, 1993	Children ages 2-19	Medicaid claims and caregiver survey	The proportion of children with a mental health/substance abuse claim and their Medicaid cost varies substantially across states. Children with MH/SA claims are 3.5 times or more as expensive as other children, depending on the state.
Larson, M.J., Miller, K., Fleming, K.J., & Teich, J.L.	2007	U.S., 1999	Privately insured children under age 19 whose parents work for large firms	Health insurance claims in the Marketscan database	While children with mental health claims represent only 6.6% of all children, they incur about 25% of all inpatient costs and about 20% of all outpatient, pharmacy, and total costs for children.
Lear, J.G.	2007	U.S., 2001-2002	School health centers	School-based Health Center Census	Almost all school-based health centers provide physical health services such as treatment of acute illness (96%), but fewer provide brief mental health therapy (67%) or mental health diagnosis (51%).
Lutterman, T., Ganju, V., Schacht, L., Shaw, R., Monihan, K. & Huddle, M.	2003	Sixteen states participating in a special SAMHSA Project, 2000	Children under age 19	State survey	Across 16 states, the median rate of utilization of state psychiatric hospitals is 34 per 100,000 children under age 19; the median rate of use of community-based programs is 1627 per 100,000. Rates vary considerably across states.
Mandell, D.S., Boothroyd, R.A., & Stiles, P.G.	2003	Florida, 1998-1999	Children ages 5-12	Medicaid claims and caregiver survey	After controlling for caregiver's assessment of mental health status using the Pediatric Symptom Checklist and other child characteristics, children in the HMO group have half the mental health use of the fee-for-service group.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Mark, T.L., & Buck, J.A.	2006	U.S., 2001	Children ages 4-17	NHIS	Private insurance covers about 40% of children with serious emotional disturbance, while Medicaid covers about one-third.
Mark, T.	2008	Seven states (Medicaid) and selected private employers around the U.S., 2004-2006	Youth ages 13-17 enrolled in Medicaid or selected private insurance plans	Claims/encounter data	Only 28.2% of Medicaid youth and 33.6% of privately insured youth with a psychotropic medication receive any psychotherapy within 6 months of initiating medication.
Martin, A., & Leslie, D.	2003	U.S., 1997-2000	Privately insured children under age 18	Marketscan database of private insurance claims	The rate of mental health inpatient days and outpatient visits declines in the late 1990s for children, and the rate of use of psychotropic medication increases.
McCarthy, J., Marshall, A., Irvine, M., & Jay, B.	2004	32 U.S. States, 2001-2002	Children under care of child welfare agencies	Content analysis of annual reports from child welfare agencies	The category "mental health of the child" is scored as a "need for improvement" in programs in 30 states and in only 2 states it is considered a strength. This category involves whether the state routinely screens for mental health problems, whether parents are included in care planning, and whether needed services are consistently provided.
Miech, R., Azur, M., Dusablon, T., Jowers, K., Goldstein, A.B., Stuart, E., Walrath, C., & Leah, P.J.	2008	45 Systems of Care program around the US, 1997-2005	Children in SOC programs ages 5-18	Program data systems	SoC programs attract a higher proportion of minority group children than the proportion in their catchment areas, offering the potential to reduce racial/ethnic disparities in use of services and outcomes.
Olfson, M., Blanco, C., Liu, L., Moreno, C., & Laje, G.	2006	U.S., 1993-2002	Children ages 0-19	National Ambulatory Medical Care Survey	There has been a sharp increase in the prescription of anti-psychotic medication by office-based physicians during the study period.
Ringel, J.S., & Sturm, R.	2001	U.S., 1993-1998	Children ages 1 to 17	13 different national-level sources of data on child mental health use and expenditures	There has been a decline in expenditures for inpatient mental health care for children. Outpatient care now accounts for a majority of mental health expenditures for children.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Saunders, R.C., & Heflinger, C.A.	2003	Tennessee, FY 1995-2000	Children ages 4-17	Tennessee Medicaid administrative records	The rate of use of mental health services increases, but the volume of care for service users decreases, during the study period.
Sheehan, A.K., Walrath, C.M., & Holden, E.W.	2007	26 Systems of Care sites around the U.S., 2003-2004	Community-based providers of children's mental health services; 77% were licensed mental health professionals	Survey of providers	The use of evidence based treatment approaches is low. For example, only 35.4% of providers implement Cognitive Behavioral Therapy according to the full treatment protocol. Frequently, providers are not fully trained in the type of therapy they provide.
Snowden, L.R., Massland, C., Fawley, K., & Wallace, N.	2009	California, FY 1999-2001	Children ages 1-17	California Medicaid claims and foster care records	There are no racial/ethnic disparities in use of mental health services for children in foster care. For children on Medi-Cal and not in foster care, African American, Asian, and Latino children are significantly less likely to receive mental health services than white children. There are no significant differences between white and Native American children.
Soni, A.	2009	U.S., 2006	Children ages 0-17	Medical Expenditures Panel Survey	Mental health problems are the most expensive conditions for children (\$8.9 billion per year in the U.S.), ahead of asthma (\$8 billion) and three times as expensive as infectious diseases (\$2.9 billion). About one-third of mental health costs are paid by private insurance and about one-third by Medicaid. In contrast, about 60% of the cost of infectious disease for children is paid by private insurance.
Sturm, R., Andreyeva, T., & Phil, M.	2005	13 states, 1997 and 2002	Children ages 6-17	NSAF	The percentage of children who receive any mental health services increases by 25% during the 5 year time period, without an increase in the percent of children needing mental health services.
Sturm, R., Ringel, J.S. & Andreyeva, T.	2003	13 U.S. States, 1997-1999	Children ages 6-17	NSAF	The proportion of children with a mental health visit ranges from 5.1% (California) to 11.6% (Massachusetts). The U.S. average is 7.4%.
Substance Abuse and Mental Health Services Administration (SAMHSA)	2005	U.S., 2004	Youth age 12-17	National Survey on Drug Use and Health (NSDUH)	In 2004, 5.7 million youths aged 12 to 17 (22.5 percent) receive treatment or counseling for emotional or behavior problems in the year prior to the interview. This is higher than the estimates for 2002 (19.3 percent) and 2003 (20.6 percent).

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
SAMHSA	2008	U.S., 2005-2006	Youth age 12-17	NSDUH	Each year 13.3% of youth receive services for an emotional or behavioral health problem in a specialty mental health setting; 12% receive such services in a school setting, and 3% in a general medical setting.
Teich, J.L., Buck, J.A., Graver, L., Schroeder, D., & Zheng, D.	2003	Delaware, Oklahoma, and Washington, 1996	Children ages 0-17	Medicaid claims matched to state mental health authority encounter records	Children with selected diagnoses indicating serious emotional disturbance constitute from 8.8 to 22.4% of all child mental health users. In Delaware and Oklahoma, expenses for a majority of the children with SED are covered by Medicaid only (67.2 and 55.9% respectively), while in Washington a majority (60.6%) have joint Medicaid and state mental health system funding.
US Government Accountability Office	2008	U. S. States, 2006	Children in residential treatment	One-time survey of state Child Welfare, Education and Juvenile Justice Agencies	There are just over 200,000 children and youth receiving mental health residential treatment in 2006. About half are in facilities administered by child welfare agencies, and most of the rest are in facilities administered by juvenile justice agencies. There are 1503 reported cases of abuse in residential treatment. The GAO recommends improved state oversight of quality of care in such facilities.
Whitson, M.L., Connell, C.M., Bernard, S., & Kaufman, J.S.	2010	Bridgeport, Connecticut, 2003-2007	Children ages 11-17 in a System of Care program	Program database	Youth with a family history of substance abuse and mental illness receive more services.
Witt, W.P., Kasper, J.D., & Riley, A.	2003	U.S., 1994-1995	Children ages 6-17	NHIS	Only 2 in 5 disabled children with poor psychosocial adjustment receive mental health services. The school setting reduces barriers to mental health services.
Zimmerman, F.J.	2005	U.S., 2000	Children ages 7-14	National Longitudinal Survey of Youth	After controlling for depression, girls are significantly less likely to have a specialty mental health visit than boys. Other significant factors in lower use are Latino ethnicity and the presence of a father in the household.

Appendix Table 3: Articles/Reports on Outcomes of Treatment for Children and Youth with Mental Health Problems

Author(s)	Year Published	Setting/Time Period	Population	Data source	Findings
American Academy of Pediatrics Task Force on Mental Health	2010	Literature review	Children ages 0-17	Review of studies	Among 10 disorders covered in the review, 9 have documented therapies that are considered effective with "Level 1 - Best Support" evidence, or "Level 2 - Good Support" evidence. However, numerous therapies have moderate, minimal, or no support for effectiveness.
Bower, B., Garralda, E., Kramer, T., Harrington, R., & Sibbald, B.	2001	Literature review	Children ages 1-17	Review of 17 studies	There is little evidence from rigorous studies that mental health treatment within primary care settings improves child mental health outcomes.
Chamberlain, P., Price, J., Leve L.D., Laurent, H., Landsverk, J.A., & Reid, J.B.	2008	San Diego, CA	Families of children ages 5-12 in foster care randomized to treatment	Interviews with parents	16 weeks of intensive training of foster parents significantly reduces child behavior problems in the treatment group, while behavior problems increase in the control group.
Hoagwood, K., Burns, B.J., Kiser, L., Ringeisen, H., & Schoenwald, S.K.	2001	Literature review	Children ages 1-17	Review of 100 studies and syntheses	The evidence on effective mental health services for children is limited. Effective treatments have been identified in 2 or more studies for depression, anxiety disorders, ADHD, conduct disorders, and phobias, but not for many other conditions such as autism, anorexia, bipolar disorder, and others. The most consistently positive evidence is for multi-systemic therapy, when providers are adequately trained. Most results are from research settings rather than community settings.
Leve, L.D., Fisher, P.A., & Chamberlain, P.	2009	Literature review	Children in foster care	Review of four randomized trials	Four multidimensional interventions improved child resilience outcomes (eg. school success) and reduced caregiver stress.
Lutterman, T., Ganju, V., Schacht, L., Shaw, R., Monihan, K. & Huddle, M.	2003	Sixteen states participating in a special SAMHSA project, 2000	Children under age 19	State survey	Of children (age<19) discharged from state psychiatric hospitals, 5.6% are readmitted within 30 days and 11.1% are readmitted within 180 days. Rates vary considerably across states. Comparable rates for adults are 9.2% and 20.0%.

Author(s)	Year		Population	Data source	Findings
	Published	Setting/Time Period			
Rones, M., & Hoagwood, K.	2000	Literature review	School-aged children and youth	Review of 89 U.S. studies from 1985-1999	There is evidence that some school-based programs have a positive impact on emotional/behavioral problems. Characteristics of strong programs include parent/teacher/peer involvement and integration of program content into the classroom.
Substance Abuse and Mental Health Services Administration (SAMHSA)	2007	Systems of Care programs around the U.S. in the late 1990s	Children in SOC programs	Surveys of families in programs	About half of children in SoC programs improve after 18 months, and another 40% stay the same, according to the Child Behavior Checklist. However, there is a high rate of attrition by 18 months (over half), and those who leave are lost to follow-up. Findings are inconsistent across sites.
SAMHSA	2007	Literature review	Children	Seven studies	Several example programs to prevent mental health problems in children are highly cost-effective, with benefit-cost ratios of up to \$45 saved for every \$1 spent.
Tang, M.H., Hill, K.S., Boudreau, A.A., Yucel, R.M., Perrin, J.M., & Kuhlthau, K.A.	2008	U.S., 2000-2002	Children with special health care needs (CSHCN), ages 3-17	National Survey of CSHCN	Children with emotional/behavioral problems enrolled in Medicaid who are in a managed care programs have higher rates of unmet need than other CSHCN.
Treatment for Adolescents with Depression Study (TADS) Team	2007	Multi-center randomized trial conducted in centers around the U.S., 2000-2003	Depressed youth ages 12-17	Cross-site clinical data	Children with combined cognitive behavioral therapy (CBT) and medication improve fastest, followed by drug treatment alone, and then by CBT alone.

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children

Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
National Survey of Children's Health (NSCH)	Children < 18 yrs (n=86,000 – 102,000)	50 states	2003, 2007	Diagnosed conditions including ADD/ADHD, depression/anxiety, conduct problems, autism, etc...; behavior problems, social competence, parental mental health, SDQ impact supplement	Insurance coverage distribution,	Received mental health care/counseling; doctor visits, ER visits and unmet needs for mental health	School outcomes include missed days, repeating grades, engagement and activities;	Random Digit Dialing (RDD) sample design may produce biased state estimates; Additional validation is necessary
National Survey of Children with Special Health Care Needs (NS-CSHCN)	Children <18 years; 5,500-8,500 screened per state; 750 CSHCN surveyed with detailed questions	50 states	2001, 2005-2006	Chronic emotional, developmental, behavioral condition; self-reported need for mental health care/counseling	Insurance coverage distribution,	Unmet needs for mental health and reason; parental unmet needs; doctor visits, ER visits	Family involvement in decision-making; medical home; satisfaction;	RDD sample design may produce biased state estimates; Additional validation is necessary

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Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
National Health Interview Survey (NHIS)	Children <18 (n=12,000 – 14,000)	State identifiers	1997-2008	Diagnosed conditions (ever and current) including: depression, phobia/fears, anxiety/stress, etc...; SDQ/Impact Supplement; mental health indicator scale	Insurance coverage;	Contact with provider/school staff re: emotional/behavioral problems; Unmet needs due to cost		In-person interviews; Most detailed measures available post-2005; state identifiers only available at NCHS data center
Medical Expenditure Panel Survey (MEPS)	Children under 18	State identifiers	1996+;	Diagnosed conditions and self-reported mental health status; CSHCN screen	Insurance distribution; Expenditures by source including OOP, i.e. uncovered expenses	Measures of inpatient, outpatient and Rx drug use	CAHPS measures on quality of care; providers listen, spend time, respect patients, etc...	In-person interviews; State data require access to AHRQ data center;
SAMHSA National Survey on Drug Use and Health (NSDUH)	Age 12-17,	State estimates are model-based and pool two years of data	2002-2003 through 2006-2007	At least one Major Depressive Episode in the past year				Other variables are not estimated at the state level and/or for the adolescent age group

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Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
Youth Risk Behavior Surveillance System	Students grades 9-12	39 participating states in 2007	1991-2007; every other year	Feelings of sadness, hopelessness		Suicide attempt treated by doctor	Suicide consideration, attempts, plans,	Only available for 39 states in 2007
American Hospital Association Annual Survey (AHA)	6,000+ hospitals	State identifiers	Annual		Hospital ownership and provision of specialty services including child/adolescent psychiatric services			Complete survey data is quite expensive, but selected variables can be purchased at more reasonable rates
Area Resource File (ARF)	Data for each county in the US	County data can be aggregated to state level	Annual		# of psychiatrists, child psych. # of hospitals with psych, psych ED, and child/adolescent psych. # of community mental health centers			

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children								
Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
<u>Bureau of Primary Health Care Uniform Data System (UDS)</u>	Includes all grantees in the state	Grantee information can be aggregated to state level	Annual		Number of CHCs and proportion providing mental health services	Number of patient encounters with mental health staff		Some information on mental health staffing, but not at the individual CHC level
<u>Bureau of Health Professions Mental Health Professional Shortage Areas</u>	State-level data	All 50 states	Current at point-in-time		Number of mental health professional shortage areas in the state			Not specific to children
<u>National Conference of State Legislatures</u>	State-level summary	All states	Current		State parity laws and mandated benefits			
<u>Kaiser Family Foundation Medicaid Benefits Database</u>	State-level data	All states	Current		Medicaid coverage policy for various mental health services			

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children

Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
<u>American Community Survey</u>	Children, all ages	All states	2008		Insurance coverage distribution			Does not specify children with mental health problems or coverage for mental health services
<u>National Ambulatory Medical Care Survey (NAMCS)</u>	3,000 to 5,000 visits for children <15	No state availability	1973-2007	Diagnosis codes and patient complaints for office-based ambulatory care visit, including chronic conditions	Physician specialty; payer	Received mental health treatment at visit; medications		Up to 3 diagnoses, may include psychoses, neurotic, personality and non-psychotic mental disorders
<u>National Hospital Ambulatory Medical Care Survey (NHAMCS) - OPD</u>	6,000-9,000 visits per year for children < 15	No state availability	1992-2007	Diagnosis codes and patient complaints for ambulatory care visit to Outpatient Department, including chronic conditions	Physician specialty; payer	Received mental health screening/treatment at visit; medications prescribed		Up to 3 diagnoses, may include psychoses, neurotic, personality and non-psychotic mental disorders

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children								
Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
<u>National Hospital Ambulatory Medical Care Survey - ED</u>	5,000-8,000 visits per year for children < 15	No state availability	1992-2007	Diagnosis codes and patient complaints for ambulatory care visit to Emergency Department of Hospital, including chronic conditions	Wait time;	Mental status exam, Medications, discharge status		Up to 3 diagnoses, may include psychoses, neurotic, personality and non-psychotic mental disorders
<u>Healthcare Cost and Utilization Project (HCUP) – Kids Inpatient Database (KID)</u>	Children under 20, (n=2 to 3 million discharges per year from a sample of hospitals	Varying number of states represented depending on year, designed for national representativeness	1997, 2000, 2003, 2006	Diagnosis codes	Hospital ownership/ specialty; payer	Procedure codes;	Readmission; discharge status	Can be used to track inpatient utilization and readmissions for mental health problems

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children

Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
<u>Healthcare Cost and Utilization Project (HCUP) – State Inpatient Databases (SID)</u>	All discharges from sample states (40 states currently)	State representative;	Annual	Diagnosis codes	Hospital ownership/ specialty; payer	Procedure codes;	Readmission; discharge status	Access to individual states data varies; Can be used to track inpatient utilization and readmissions for mental health problems;
<u>HCUP Nationwide Emergency Department Sample (NEDS)</u>	Sample of ED encounters that did and did not result in admission (26 million per year)	Nationally representative, state identifiers	2006, 2007	Diagnosis codes	Hospital ownership/ specialty; payer	Procedures and admission	Discharge status	Can be used to track ED use for mental health problems
<u>Medicaid Analytic Extract (MAX)</u>	Beneficiary-level with under-reporting of managed care enrollees	50 states	1999+	Diagnosis codes	Provider specialty,	Procedures, drugs	Discharge status	Separate files for inpatient, long-term care, drugs and other services.

Appendix Table 4: Potential Data Sources for Evaluating State Mental Health Systems for Children								
Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
CMS Form 416 on EPSDT Participation	State-level	50 states	2005-2007 available online			Proportion of children, by age group, who receive EPSDT screening services		
Individuals with Disabilities Education Act (IDEA) Data	Children with disabilities	All states	1998-2008			Number receiving education services under the IDEA		
National Child Abuse and Neglect Data System (NCANDS)	Children with an investigated report of maltreatment	Voluntary state participation	2000-2007	Presence of risk factors for maltreatment including emotional disturbance and behavior problems		Mental health services provided to children as a result of the maltreatment		
CDC WISQARS Injury Mortality Reports	Age groups include 10-14, 15-19	50 states	1999-2006				Suicide deaths	

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Data Source	Sample population	State-level availability	Available years	Selected prevalence measures	Selected access measures	Selected utilization measures	Selected outcomes measures	Limitations and other details
Easy Access to FBI Arrest Statistics (EZAUCR)	Children under 18	All states	1994-2007				Estimated arrests, by category of offense	
SAMHSA CMHS Uniform Reporting System – National Outcomes Measures (NOMS)	State-level reports	All states				Readmission rates; hospital and community utilization rates	Child/family positive about outcomes; child/adolescent EBP; improved social connectedness	
NASMHD Research Institute State Profiles	State-level reports	All states	2001, 2002, 2004, 2005, 2007		SMHA operated or funded providers	Child utilization rate	Use of Evidence-based practices	