

Evaluation of a Methodology to Estimate the Prevalence of Serious Emotional Disturbance in Idaho

Nathaniel J. Williams, PhD
Boise State University

Executive Summary

Objective: The purpose of this report is to evaluate a methodology proposed by the Idaho Department of Health and Welfare to estimate the number of youth who experience serious emotional disturbance (SED) in the State of Idaho.

Method: The report describes the Department's proposed estimation methodology, reviews scientific literature relevant to evaluating the methodology's assumptions and overall prevalence estimate, evaluates the methodology with regard to scientific evidence and principles, and presents recommendations.

Results: In general, this evaluation found mixed support for the proposed methodology in terms of its congruence with evidence from the scientific literature and with well-established scientific approaches to estimating SED prevalence. Strengths of the proposed methodology included empirically supported assumptions regarding (a) the systematic covariation between SED prevalence and youth insurance coverage, and (b) the use of a service contact cut score (i.e., 10 or more service contacts) that is likely to differentiate between youth with and without SED from among those who participate in mental health services. Weaknesses included incongruence between the proposed method and scientific evidence regarding (a) the specific rates of SED across insurance types, and (b) the method's reliance on medical claims data which likely undercounts youth with SED who do not participate in billable mental health services. The overall prevalence rate of 4.8% proposed by the methodology was outside the range of SED prevalence estimates published by SAMHSA and supported by meta-analyses of population representative studies in the US; however, synthetic estimates based on these studies are not gold-standard and there is at least one published study reporting a lower SED prevalence estimate.

Conclusions and Recommendations: Overall, this report recommends (a) using the proposed estimation methodology as an interim strategy for monitoring progress toward meeting the needs of youth with SED in Idaho, while (b) working to leverage data collected by national surveys conducted by the Centers for Disease Control and Prevention to develop a more robust Idaho estimate of SED. The report concludes with specific recommendations for how scientifically defensible, replicable, and low cost estimates of SED can be derived through the use of State level data on youth psychopathology available through the National Health Interview Survey conducted by the CDC.
(November 1, 2017)

Introduction

The purpose of this report is to evaluate a methodology proposed by the Idaho Department of Health and Welfare to estimate the number of youth who experience serious emotional disturbance (SED) in the State of Idaho. Under terms specified by the Jeff D. Settlement Agreement, the State of Idaho is required to develop and implement a sustainable, accessible, comprehensive, and coordinated service array that meets the needs of children with SED. An important step toward this goal involves

estimating the number of Class Members, that is, youth who experience SED in Idaho, so that progress in meeting the needs of this population can be monitored. In order to fulfill this requirement, the Idaho Department of Health and Welfare has proposed an estimation methodology to determine the number of Class Members. The purpose of this report is to evaluate the proposed methodology with respect to its concordance with established scientific principles, methods, and evidence.

The report is organized into five sections. Part 1 presents definitions of

key terms as outlined by the Settlement Agreement. Part 2 describes the Department's proposed estimation methodology. Part 3 presents a review of the scientific literature which provides information and evidence against which to assess the proposed methodology's assumptions and conclusions as well as a description of the scientific consensus regarding measurement of SED among youth. Part 4 provides an evaluation and analysis of the proposed methodology based on the scientific evidence and principles reviewed. Part 5 presents conclusions and recommendations.

Part I: Key Terms and Definitions

The Jeff D. Settlement agreement defines *Class Members* as Idaho residents, under the age of eighteen (18), who experience a Serious Emotional Disturbance. The Settlement Agreement goes on to define Serious Emotional Disturbance in accordance with the definition provided by the US Substance Abuse and Mental Health Services Administration (SAMHSA) pursuant to Public Law 102-321 and as operationalized in Idaho Administrative Code (IDAPA 16.07.37). The SAMHSA and Idaho definitions of SED are presented in Box 1. Based on these

definitions, the two essential criteria for determining class membership involve assessing whether a child experiences a *DSM disorder* and *substantial functional impairment* secondary to that disorder.

Part II: Proposed Estimation Methodology

This section details the methodology proposed by the Idaho Department of Health and Welfare to estimate the number of Class Members in Idaho. Using this methodology, the Department estimates that there were 21,000 total Idaho Class Members in 2016. This

represents 4.8% of Idaho's 2016 youth population under the age of 18. This estimate is based on a multi-step methodology that incorporates data from multiple sources as well as several assumptions. The data and assumptions are described next.

The methodology begins with two pieces of information from the US Census Bureau: (a) the 2016 Idaho population of persons under the age of 18, identified as 434,465, and (b) the rates of Medicaid insured, privately insured, and uninsured Idaho children, identified from Census Bureau data as 48.0%, 47.8% and 4.1%, respectively.

Next, rates of SED were estimated within each of these groups. The number of youth with Medicaid insurance who experienced SED was estimated through an analysis of Medicaid claims data. The criterion to determine SED caseness was based on the number of medical contacts youth received in 2016 for an ICD-9 mental disorder diagnosis. Youth who received 10 or more Medicaid service contacts for an ICD-9 mental disorder diagnosis within the preceding year were determined to have SED.¹ In 2016, a total of 13,301 youth met this caseness criterion, representing 6.4% (13,301 / 208,687) of Idaho's youth Medicaid participants.

The number of uninsured Idaho youth who experienced SED was estimated by assuming that the prevalence of SED in this population was substantially similar to, or equal to, that of the Medicaid insured population. Given the prevalence estimate of 6.4% among Medicaid insured youth, it was assumed that 6.4% of uninsured Idaho youth also experienced SED. In 2016, this yielded an estimated 1,146 (.064 x 17,984) Idaho youths with SED who did not have health insurance.

The prevalence of SED among youth with private insurance was assumed to be half the rate of youth with Medicaid

Box 1. Definitions of Serious Emotional Disturbance

US Substance Abuse and Mental Health Services Administration

Pursuant to section 1912(c) of the Public Health Service Act, as amended by Public Law 102-321 "children with serious emotional disturbance" are persons:

- From birth up to age eighteen (18),
- who currently or at any time during the past year,
- have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual of Mental Disorders (DSM),
- that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities.

Idaho Administrative Code (16.07.37)

To be eligible for children's mental health services through a voluntary application to the Department, the applicant must:

- Be under eighteen (18) years of age,
- reside within the State of Idaho,
- have a DSM-IV-TR Axis I diagnosis (a substance use disorder alone, or a developmental disorder alone, does not constitute an eligible Axis I diagnosis, although one more of these conditions may coexist with an eligible Axis I diagnosis), and
- have a substantial functional impairment as assessed by using the Child and Adolescent Functional Assessment Scale (CAFAS) or the Preschool and Early Child Functional Assessment Scale (PECFAS) with a full eight (CAFAS) or seven (PECFAS) scale score of 80 or higher with "moderate" impairment in at least one of three areas including: Moods/ emotions, Thinking, or Self-harm.

¹ See appendix A for a list of ICD-9 mental health diagnoses included in the analysis. In terms of service contacts, any contact for an ICD principle diagnosis from the specified list was counted, which included: professional outpatient, hospital outpatient (including Emergency Room), and inpatient hospital.

Box 2. Key Assumptions Underlying the Proposed Idaho Department of Health and Welfare SED Prevalence Estimation Methodology

Assumption 1. The prevalence of SED systematically and reliably varies by insurance type such that:

- The prevalence of SED among youth who are uninsured is substantially similar to, or equal to, that of youth who participate in Medicaid, and
- The prevalence of SED among youth who are privately insured is substantially similar to, or equal to, *one half* the rate among youth who participate in Medicaid;

Assumption 2. The prevalence of SED among youth who participate in Medicaid is accurately represented by the proportion of youth who received 10 or more medical service contacts for a DSM disorder over a one year period. This implies:

- Accurate estimates of DSM disorder prevalence can be derived from medical claims data, and
- Receipt of 10 or more mental health service contacts in one year is a valid indicator of SED caseness among youth who participate in medical services.

insurance. Given the estimated rate of SED among Medicaid insured youth was 6.4%, this assumption indicated that 3.2% of privately insured youths experienced SED. Applying this prevalence estimate to the number of Idaho youth who had private insurance in 2016 (.032 x 207,794) yielded an estimated 6,622 Idaho youths with SED who were privately insured.

The total number of Idaho youth who experienced SED in 2016 (and who were therefore Class Members) was determined by summing the three estimates of SED across the three insurance categories (13,301 + 1,146 + 6,622). In 2016, this totaled 21,070 Idaho youth which, when rounded to the nearest thousand equals 21,000 Idaho youth.

Assuming US Census Bureau estimates of Idaho's youth population and the percentages of youth covered by different insurance types are correct; this analysis is based on two key assumptions that have implications for the validity of the methodology. These assumptions are presented in Box 2. The following section reviews scientific literature pertaining to these assumptions as well as literature addressing the prevalence of SED as derived via alternative estimation methodologies.

Part III: Review of Scientific Literature

Scientific Literature Related to Key Assumptions

- **There is evidence that rates of SED vary systematically by insurance type.**

Converging evidence from multiple methodologically rigorous, population representative studies supports the assumption that SED prevalence varies systematically across insurance type (see Figure 1). In the first study to use gold-standard methodological approaches to examine this issue, Burns and colleagues (1997) conducted in-person, structured diagnostic interviews using standardized measures to assess youth for DSM diagnoses, level of functional impairment, cross-sector mental health service use, and insurance coverage among a representative sample of 1,015 youth and their caregivers in the Great Smoky Mountains region of North Carolina. Results indicated that 8% of youth experienced SED, defined as the presence of a DSM disorder plus substantial functional impairment in one or more functional domains (e.g., school, family, peers). Most importantly, this study showed that rates of SED varied significantly across insurance types such that 22.2% of Medicaid insured youth experienced SED, 8.1% of uninsured youth experienced SED, and 4.3% of privately insured youth experienced SED (see Figure 1).

A more recent study using nationally representative data from 11,182 children ages 6 to 11 who participated in the 2010-2012 National Health Interview Survey also provided evidence that rates

of SED vary by insurance type (Simon et al., 2015). The National Health Interview Survey is an annual, population representative, in-person, household interview survey of the civilian noninstitutionalized population in the United States (National Center for Health Statistics, 2017). The survey is sponsored by the US Centers for Disease Control and Prevention. As part of the survey, information is obtained about a sample child's health in each household. Information is provided by an adult who is knowledgeable about the child; in over 90% of cases the respondent is the child's parent. During the years 2010 through 2012, parents reported on their child's mental health using the empirically validated Strengths and Difficulties Questionnaire (National Center for Health Statistics, 2017b), a standardized measure of child behavior problems and functional impairment that has high concordance with standardized diagnostic interviews of DSM mental disorders with impairment (Bourdon et al., 2005; Goodman, 2001).

Results from this study indicated that the national prevalence of SED based on the Strengths and Difficulties Questionnaire was 5.8% which is consistent with estimates of the most severe levels of SED produced by SAMHSA and a recent meta-analysis (Friedman et al., 1996; Williams et al., 2017). Most importantly, rates of SED varied significantly across insurance types such that 8.6% of Medicaid insured youth experienced SED, 4.5% of uninsured youth experienced SED, and

3.5% of privately insured youth experienced SED (Simon et al., 2015; see Figure 1).

Findings from Simon et al.'s (2015) study are substantively similar to an analysis of 2001 National Health Interview Survey data conducted by Mark and Buck (2006) which also relied on the Strengths and Difficulties Questionnaire. Mark and Buck (2006) assumed that children above the 90th percentile on the Total Problems Score from the Strengths and Difficulties Questionnaire experienced SED and examined how rates of SED varied across insurance coverage. Their sample included 10,376 youth, ages 4 to 17, who participated in the 2001 National Health Interview Survey. The overall prevalence of SED in this sample was 10% which is consistent with the most inclusive estimates of SED prevalence based on SAMHSA's expert recommendations and a recent meta-analysis of population representative studies in the US (Friedman et al., 1996; Williams et al., 2017). This study found that 22% of youth with Medicaid insurance experienced SED, 15% of youth who were uninsured experienced SED, and 7% of youth with private insurance experienced SED. Together, these studies confirm that rates of SED vary systematically across youth based on their insurance status.

- Evidence is mixed regarding the equivalence of SED prevalence rates

among Medicaid insured youth relative to uninsured youth.

Across the studies reviewed for this report, rates of SED were consistently lower among youth who were not insured relative to youth who participated in Medicaid; however, the specific ratio of SED prevalence between these two groups varied across studies. In the Burns et al. (1997) study, the prevalence of SED among uninsured youth was one-third the prevalence of SED among Medicaid insured youth (see Figure 1). In the much larger, nationally representative Simon et al. (2015) study, the prevalence of SED among uninsured youth was one-half the prevalence of SED among Medicaid insured youth. In the Mark and Buck (2006) study, which also relied on national data, but included a less-impaired population of youth with SED, the SED prevalence among uninsured youth was two-thirds the prevalence of SED among Medicaid insured youth.

- Evidence is mixed regarding the ratio of SED prevalence among Medicaid insured youth relative to privately insured youth.

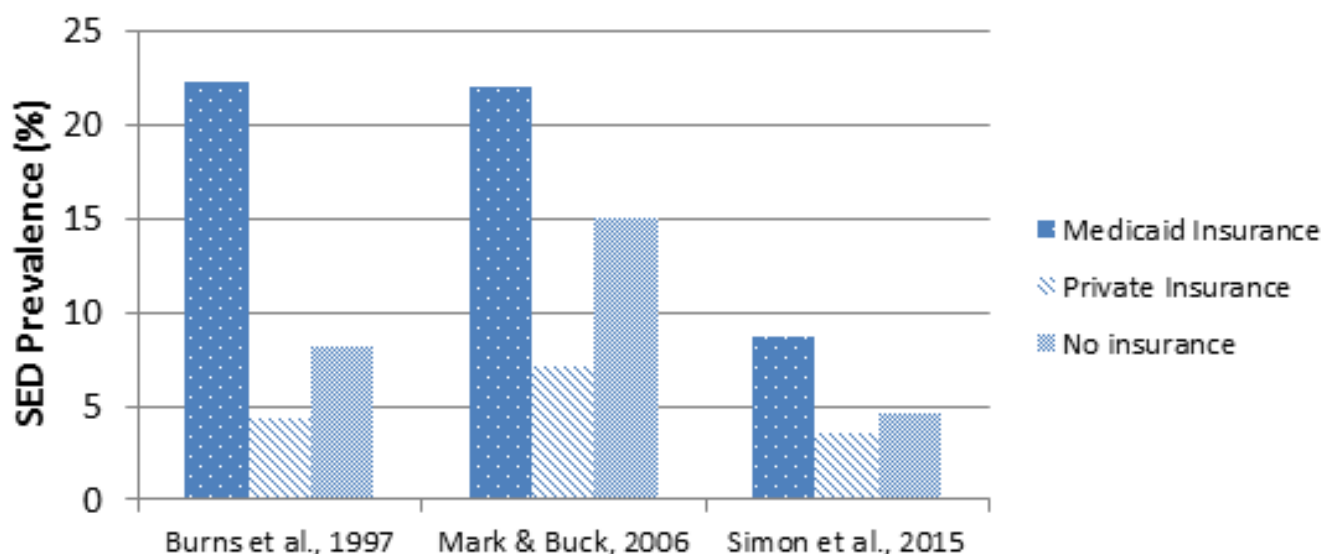
Across the studies reviewed for this report, rates of SED among youth who had private insurance never exceeded 50% of the rate of SED among youth who were insured by Medicaid; however, in no cases was the ratio exactly 50% as is suggested by the Department's methodology. In the Burns et al. (1997) study, the ratio of SED prevalence among

privately insured youth relative to Medicaid insured youth was .19 (4.3% / 22.2%). In the Mark and Buck (2006) study the ratio of SED prevalence among privately insured youth relative to Medicaid insured youth was .32 (7% / 22%) and in the Simon et al. (2015) study the ratio was .41 (3.5% / 8.6%).

- Estimates of SED prevalence that rely exclusively on medical claims data are likely to be inaccurate because approximately 40% to 50% of youth with SED do not participate in billable mental health services.

Several community-based, population representative epidemiological studies have examined mental health service use among youth in the United States. Results of these studies are consistent in showing that only about half of all youth who experience SED (based on gold-standard structured DSM diagnostic interviews and standardized measures of functional impairment) participate in *any* type of mental health service over a 12 month period (see Figure 2); furthermore, many youth who do participate in services do not receive billable mental health care that would be captured in claims data. Estimates of past year mental health service use across *any* service sector for youth with SED ranged from a low of 40.3% in the Great Smoky Mountains Study (GSMS) (Burns et al., 1995) to 56% in the 2001 NIMH-sponsored National Health Interview Survey (Bourdon et al., 2005). Data from

Figure 1. Prevalence of SED by Insurance Type across Studies



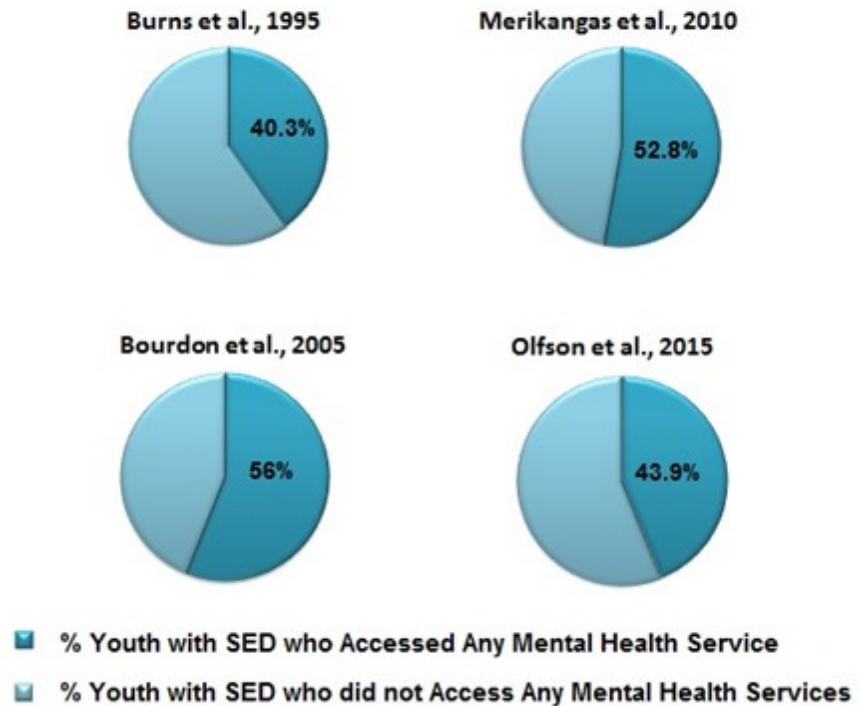
the nationally-representative National Health and Nutrition Examination Survey, collected in collaboration with the National Institute of Mental Health, indicated only 52.8% of youth with a psychiatric disorder and severe impairment had participated in mental health services from *any* sector in the last year (Merikangas et al., 2010). Data from the 2010-2012 Medical Expenditure Panel Survey, a nationally-representative survey of the noninstitutionalized US population sponsored by the US Agency for Health Research and Quality, indicated that 43.9% of youth with severe mental health impairment participated in services during a 12-month period (Olfson et al., 2015). These converging data points from multiple methodologically rigorous and population representative studies confirm that many youth who experience SED do not participate in billable mental health services and therefore will not be counted by methodologies that rely on medical claims data.

- **There is evidence that youth with SED have more medical service contacts for mental health disorders than their less impaired peers and that among youth with SED who *do* receive mental health services, a cut point of 10 or more service contacts per year is useful for estimating caseness.**

Research on 12-month mental health service contacts by youth with and without SED indicates that youth who have SED are over 9 times more likely than their unimpaired peers to receive mental health services and on average participate in over 4 times the number of service contacts (Burns et al., 1997). Leaf (1996) et al. found that youths with SED were 6.8 times more likely to have seen a mental health specialist than youths without a psychiatric disorder and with no impairment.

These studies suggest that a cut-point of 10 or more service contacts per year is a useful proxy indicator for identifying youth with SED from among those who participate in mental health services. In the Great Smoky Mountains Study (Burns et al., 1997), Medicaid insured youth with SED had an average of 13.3 service contacts per year, including outpatient and inpatient mental health services (see Figure 3). Walter et al.

Figure 2. Percent of Youth with SED who received Any Mental Health Services during the Previous 12 Months



(2017) reported similar levels of service use among a sample of 2,159,019 privately insured youth, ages 3 to 17 years, who experienced a primary mental health diagnosis. This study, based on a large commercial claims database that incorporated youth covered by employer-sponsored health plans from 2007 to 2013, showed that youth with mental disorders participated in an average of 11.84 mental health related service contacts per year with mental health professionals and physicians.

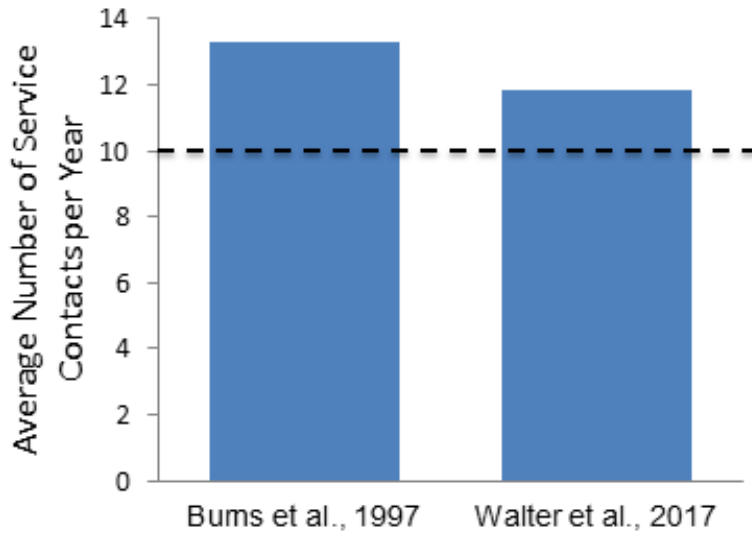
Additional evidence supporting the cut point of 10 service contacts per year is provided by data on lifetime mental health service use from the 2002-2004 National Comorbidity Survey, Adolescent Supplement (Merikangas et al., 2011). In a nationally representative US survey of 6,483 adolescents, ages 13 to 17, Merikangas et al. (2011) found that only 15.5% of all youth with mental health disorders received more than 20 specialty mental health service visits in their *lifetime*. This suggests that a cut-point of 10 services *per year* is highly likely to identify the most impaired and highest need youth with SED who participate in services.

Scientific Literature Addressing the Prevalence of SED

Methods for estimating the prevalence of mental disorders (with and without functional impairment) among children and adolescents have developed rapidly over the last 30 years (Costello, Egger, and Angold, 2005; Kessler et al., 2012; Merikangas et al., 2010; National Academies of Sciences, Engineering, and Medicine, 2016). These developments have resulted in a strong scientific consensus regarding gold-standard methodological practices for estimating SED prevalence as well as the completion of several population representative studies that estimate SED prevalence in the US (Costello, Egger, & Angold, 2005; Friedman et al., 1996; SAMHSA, 2014). This section provides an overview of this literature.

The first major scientific consensus regarding the estimation of SED prevalence was established by an expert workgroup of leading epidemiologists and technical experts assembled by SAMHSA in 1996. This group was charged with operationalizing key concepts contained in the 1993 federal definition of SED (e.g., “substantial functional impairment”) and recommending estimation methodologies

Figure 3. Average Number of Mental Health Service Contacts per Year for Youth with SED



Note: Dashed line indicates proposed service contact cut-score to indicate SED caseness.

for establishing the prevalence of children with SED (Friedman et al., 1996). The group published their findings in the landmark monograph *Prevalence of Serious Emotional Disturbance in Children and Adolescents* (Friedman et al., 1996) contained in the SAMHSA report, *Mental Health, United States, 1996*. Several of their contributions have had a lasting impact on the field.

First, noting the lack of a true gold-standard against which to define “substantial functional impairment,” the group recommended that SED be operationalized at two levels of functional impairment in order to permit flexibility in service planning and to encourage further research on this topic. The more inclusive or less conservative cut-off point for functional impairment, which was deemed to still meet federal criteria for SED, was labeled “substantial functional impairment” and corresponded to impaired youth functioning in at least one domain of family, peers, or community (Friedman et al., 1996). This level of impairment yields a higher prevalence estimate of SED that corresponds to a Children’s Global Assessment Scale (CGAS) score of 60 or lower (Shaffer et al., 1983). The less inclusive or more conservative cut-off point for impairment, which yields a lower prevalence of SED, was labeled “extreme functional impairment.” This

cut point signified impaired functioning across two or more functional domains and corresponded to a CGAS score of 50 or lower. The workgroup noted that these two levels of impairment have also been labeled “domain-specific” (i.e., the more inclusive definition) and “global” (i.e., the less inclusive definition) (Costello et al., 1998). The workgroup noted that both of these populations of youth meet the federal definition of SED and therefore likely need mental health services; however, the “extreme functional impairment” population (which represents a subset of the total SED population) is likely to have much higher needs with regard to service intensity.

Second, this group defined a range of SED prevalence for both levels of impairment based on a review of published and unpublished community studies conducted prior to 1996 (Friedman et al., 1996). For substantial functional impairment, the group established official federal SED prevalence estimates of 9% to 13%. For extreme functional impairment, the group established official federal SED prevalence estimates of 5% to 9%. Notably, these ranges (9-13% and 5-9%) are still used by SAMHSA today, in combination with information on poverty rates across the States, to develop synthetic State-level estimates of SED prevalence as reported in SAMHSA’s

Uniform Reporting System (URS) output tables (<https://www.dasis.samhsa.gov/dasis2/urs.htm>).

Third, this group established gold-standard methodological guidelines for assessing SED prevalence which continue to be used to this day. According to this group, gold-standard methods for assessing SED prevalence incorporate the following: (a) selection of a population representative community sample of youth that incorporates a wide range of ages up to 17 years, (b) use of in-person structured diagnostic interviews to establish youth DSM (or ICD) diagnoses on the basis of combined parent or youth report, and (c) use of standalone, age-appropriate, standardized measures of functional impairment (which in some cases have consensus cut scores to determine various levels of SED and norms for scoring) (Friedman et al., 1996).

Since the publication of Friedman et al.’s (1996) seminal report, several population representative epidemiological studies have been conducted among community samples of youth in the US using the recommended gold-standard methods (Costello et al., 2005; Williams et al., 2017). These studies include several population representative regional samples as well as two US national samples (National Academies of Sciences, Engineering, and Medicine, 2016). However, because of differences in instrumentation, sampling, age ranges covered, and other study and sample characteristics, these studies produced a range of SED prevalence estimates varying from 4% to 17% (Costello et al., 1998). Williams et al. (2017) synthesized this research by conducting a systematic review and meta-analysis of all population representative epidemiological studies conducted in the US which assessed the prevalence of SED at either level of functional impairment. Their review identified a total of 12 population representative studies, including 4 US national studies and 8 regional studies, conducted between 1980 and 2015 that estimated the prevalence of SED among youth ages 2 to 18 years old. Among studies that used structured diagnostic interviews and standardized measures of impairment, their results indicated that 10% of US

youths experienced SED with substantial impairment (i.e., domain-specific) and 5.96% of US youths experienced SED with extreme impairment (i.e., global). These population point estimates of SED are consistent with the published SAMHSA estimates of 9 to 13% for substantial impairment and 5 to 9% for extreme impairment, respectively.

In addition to the scientific work completed on estimating SED prevalence since the 1996 SAMHSA report, SAMHSA has continued to convene working groups of technical experts to advance the goals of operationalizing the measurement of SED and recommending methods for estimating SED prevalence. Most recently, a workgroup convened in 2014 made several recommendations with respect to estimating the prevalence of SED (SAMHSA, 2014). Among the recommendations made by this group was the suggestion to use short, standardized, and well-validated mental health assessment tools to predict SED prevalence at the population level through statistical modeling.

Specifically, this group singled out the Strengths and Difficulties Questionnaire (Goodman, 2001) as a potentially valuable tool for estimating the prevalence of SED given its common use in epidemiological surveys of youth psychopathology worldwide, including in national surveys conducted regularly in the US. The panel also recommended that psychometric work be conducted to evaluate the validity of the Strengths and Difficulties Questionnaire for predicting SED prevalence against gold-standard diagnostic interviews. Since the writing of that report, validation work has been completed showing that the Strengths and Difficulties Questionnaire has high concordance with structured DSM interviews and can be used to statistically model SED prevalence in large population areas (Ringeisen et al., 2015). These findings have important implications for developing model-based estimates of SED at the State level based on existing survey data collected by the Centers for Disease Control and Prevention.

Part IV: Evaluation of the Proposed Methodology

This section evaluates the strengths and weaknesses of the prevalence estimation methodology proposed by the Department with respect to the scientific literature reviewed above. Two approaches are taken to evaluating the methodology. The first approach evaluates the validity of the methodology's assumptions based on the scientific literature. The second approach examines the congruence of the overall prevalence estimate derived via the proposed methodology with estimates based on studies incorporating gold-standard approaches to SED prevalence estimation.

Evaluation of Assumption 1: The prevalence of SED varies by insurance type

This review found strong evidence to support the assumption that the prevalence of SED varies systematically across youth based on their insurance status (i.e., Medicaid insurance, private insurance, no insurance). The evidence for this assumption was strong based on converging and consistent evidence from multiple methodologically sound studies that examined the association between SED and insurance coverage in representative community samples of youth using gold-standard methods for the assessment of DSM disorders and functional impairment.

This review found mixed evidence to support the specific rates of SED determined for each insurance group by the proposed methodology (see Figure 4). The modal prevalence of SED among Medicaid insured youth in the studies reviewed was 22% with a range from 8% to 22% (see Figure 4, Panel A). In contrast, the proposed methodology estimates that 6.4% of youth with Medicaid insurance experience SED in Idaho. An estimate of 6.4% is consistent with population-representative studies of SED in the general population. However, in all the studies reviewed here, youth with Medicaid insurance were at increased risk for SED; consequently, the estimated SED prevalence of 6.4% among Medicaid insured youth is likely

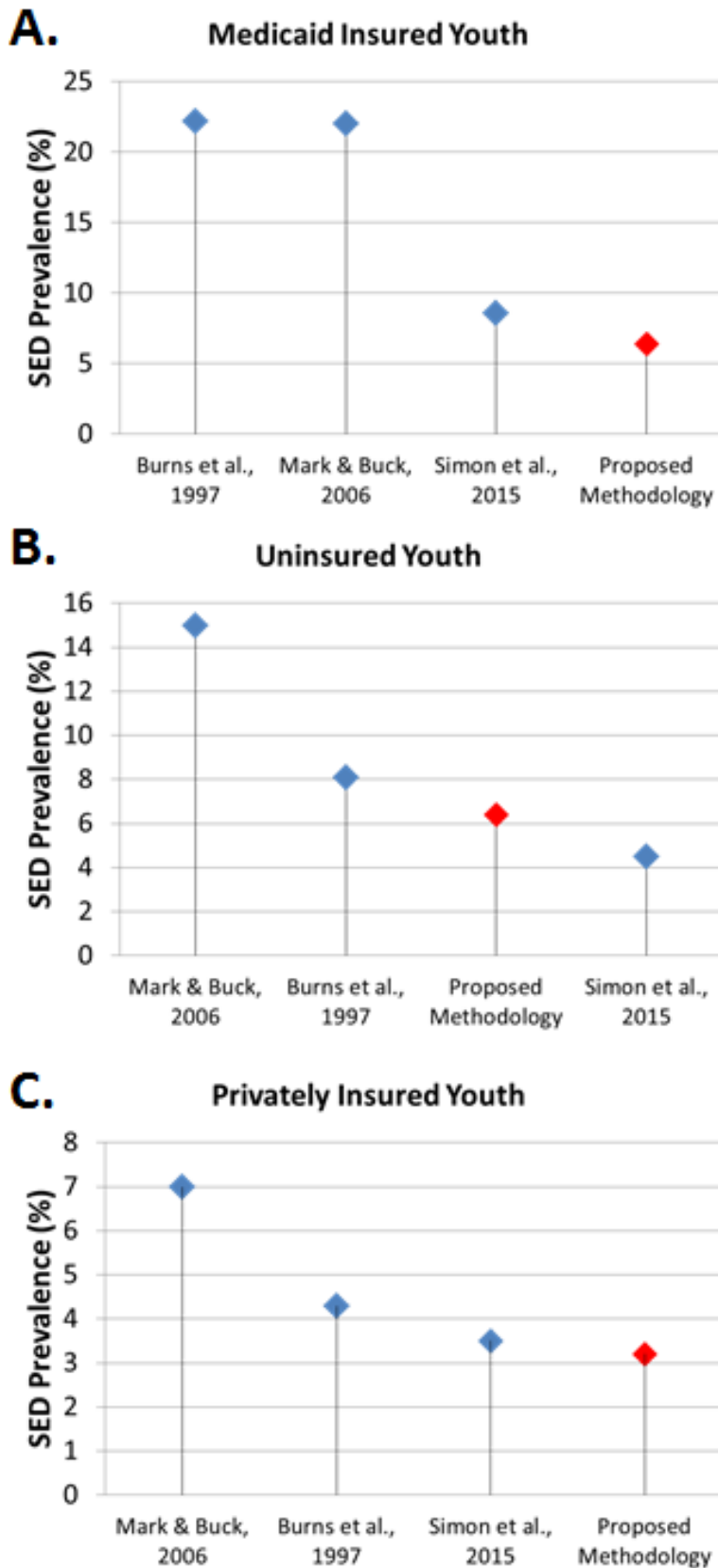
downwardly biased (see Figure 4, Panel A). The estimated SED prevalence of 6.4% among uninsured youth was more consistent with the studies reviewed here which exhibited a range of SED prevalence among uninsured youth from 4.5% to 15% (see Figure 4, Panel B). The estimate of 3.2% SED prevalence among privately insured youth was somewhat lower than estimated by the studies reviewed here which ranged from 3.5% to 7% (see Figure 4, Panel C). In general, the specific rates of SED prevalence among each of the insurance groups as proposed by the Department's methodology were somewhat consistent with the lowest estimates found in the literature.

This review did not find strong evidence to support the proposed *ratios* of SED prevalence across insurance groups. Whereas the proposed methodology assumes that rates of SED are equivalent between Medicaid insured youth and uninsured youth, the available evidence suggests that rates of SED are typically 32% to 64% lower among uninsured youth relative to Medicaid insured youth (see Figure 1). If the estimated rate of SED among Medicaid insured youth is correct (which may or may not be the case) this implies that the proposed methodology is over-estimating SED prevalence among uninsured youth.

The proposed methodology assumes that the rate of SED among privately insured youth is one-half the rate among Medicaid insured youth; however, evidence gathered here suggests the SED rate among privately insured youth is 19% to 41% as high as the rate among Medicaid youth. To the extent that the estimated prevalence among Medicaid youth is accurately determined, these discrepancies suggest that the estimated prevalence of SED among privately insured youth is likely to be too high. However, because the prevalence estimate among Medicaid youth was generally lower than the prevalence estimates reported in prior research, it is unclear whether the estimated prevalence among privately insured youth is too high or too low.

Evaluation of Assumption 2: SED prevalence is accurately estimated through the analysis of medical claims data

Figure 4. Proposed versus Observed SED Prevalence Estimates by Insurance Type



This review found strong evidence that SED prevalence estimates based on claims data are likely to underestimate the overall prevalence of SED even as they successfully identify service users who are most likely to experience SED. Numerous methodologically rigorous and population representative studies of youth mental health service use in the United States confirm that no more than 56% of youth with SED receive mental health services from *any* source in a one year period and an even lower percentage participate in mental health services detectable through medical claims data. This is because many youth receive mental health services through the educational system, social services, and juvenile justice sectors which may or may not bill Medicaid for mental health services provided. Given this evidence, it is questionable whether SED prevalence estimates based on Medicaid claims data will accurately estimate the prevalence of SED among this population.

However, the studies reviewed here also consistently showed that youth with SED are more likely than their peers to receive mental health services and that the most impaired youth with SED receive more intensive levels of medical services. Most importantly, the average number of medical service contacts by youth with SED ranged from 11.84 to 13.3 in the studies reviewed here which is consistent with the threshold of 10 service contacts proposed by the Department’s methodology. Indeed, the cut point of 10 service contacts is slightly below the annual average number of service contacts for youth with SED documented in these studies and therefore represents an inclusive threshold for caseness. Based on this evidence, it is likely that the proposed methodology is accurately identifying Medicaid service users who experience SED even as it misses some Medicaid insured youth who experience SED but do not participate in medical services for their condition. In addition, it should be noted that some expert panels have cited specific diagnoses or symptoms (e.g., psychosis) as indicative of SED regardless of the level of specific impairment or service use given their prognostic implications (SAMHSA, 2014).

Evaluation of the Proposed Total Prevalence Estimate

This review found mixed evidence regarding the concordance between the Department’s proposed SED prevalence estimate of 4.8% and synthetic estimates based on gold-standard methods (see Figure 5). First, it should be noted that this estimate is well below the point estimate of 10% for SED with substantial impairment based on meta-analytic evidence from population representative studies conducted in the US and also outside of SAMHSA’s range of 9 to 13% for SED with substantial impairment (see Figure 5). The Substance Abuse and Mental Health Services Administration has been consistent in noting that its official definition of SED includes the entire population of youth who experience impairment secondary to a mental illness, including those within the 9% to 13% range. However, SAMHSA has also noted that a more impaired level of SED can be delineated that includes 5% to 9% of the US youth population. Based on this definition, a recent meta-analysis estimated that 5.96% of US youths experience SED (see Figure 5).

Factors supporting the 4.8% prevalence estimate include (a) epidemiological studies conducted in the 1980s and early 1990s that identified rates of SED as low as 4.4% (Costello et

al., 1998), and (b) Idaho’s ranking as one of the least impoverished States for youth which suggests that its rate of SED will be at the lower end of the spectrum. Factors that reduce confidence in this estimate include the fact that its absolute value is below SAMHSA’s smallest estimate of SED and that it is not based on methodologically rigorous gold-standard methods that incorporate a community sample.

Part V: Conclusion & Recommendations

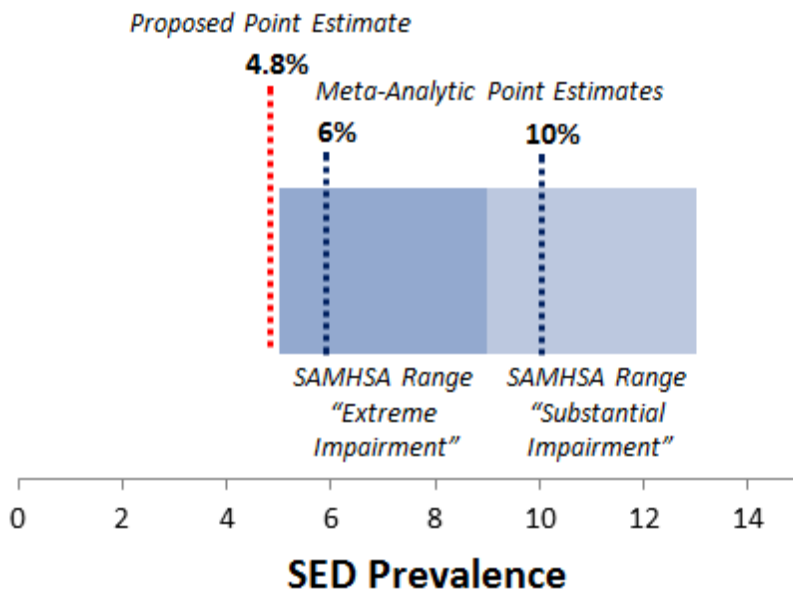
Despite significant progress in the development of methods to diagnose, measure, and estimate the prevalence of mental disorders and associated functional impairments among youth (i.e., SED), significant challenges remain in determining SED prevalence rates within targeted population areas such as at the State level (SAMHSA, 2014). Gold-standard estimation methods provide a useful benchmark for evaluating alternative methodologies; however, gold-standard methods themselves are not cost-effective for use in estimating SED prevalence in targeted areas. Synthetic estimates of SED prevalence that extrapolate from national

or regional studies to the targeted population area are also imperfect, given that States and samples vary in youth characteristics such as poverty and insurance status which have been shown to correspond with variation in SED. As was highlighted in a recent technical report by a SAMHSA sponsored workgroup of technical experts, Idaho is not alone in struggling to address the challenge of estimating SED prevalence. Indeed, many State and federal agencies are involved in efforts to estimate the prevalence of SED among youth (Washington State Department of Social and Health Services, 2003; SAMHSA, 2014). These efforts serve as a reminder of the complexity of estimating SED prevalence in a cost-effective, sustainable, and pragmatic way.

Keeping these complexities in mind, the present evaluation found mixed evidence in support of the Department’s proposed methodology for estimating the prevalence of SED among youth in Idaho. Strengths of the proposed methodology included empirically supported assumptions regarding the systematic covariation between SED prevalence and youth insurance coverage as well as the use of a service contact cut score (i.e., 10 or more service contacts) that is likely to differentiate between youth with and without SED among those who participate in mental health services. Weaknesses included incongruence between the proposed method and available evidence with regard to the specific rates of SED across insurance types and the method’s reliance on medical claims data which likely undercounts youth with SED who do not participate in billable mental health services. The overall prevalence rate of 4.8% was outside the range of estimates published by SAMHSA and supported by meta-analyses of population representative US studies; however, synthetic estimates based on these studies are not gold-standard and there is at least one published study reporting a lower SED prevalence estimate of 4.4% (Costello et al., 1998).

Given these mixed findings it is not possible to place a high level of confidence in the proposed methodology as a procedure for estimating the true population prevalence of SED in Idaho; however, features of the estimation

Figure 5. Comparison of Proposed Overall SED Prevalence Estimate to Meta-Analytic Point Estimates and SAMHSA Ranges



methodology do suggest that it is a useful method for estimating the number of Idaho youth with SED who are likely to access services provided under provisions of the Settlement Agreement. In this sense, the method is viewed as a useful starting point for monitoring progress towards the fulfillment of the Settlement's overarching purpose, which includes the provision of services to youth and families who most need them and who choose to access them. In order to advance the development of methodologies to estimate the prevalence of SED in Idaho, this report makes the following recommendations:

Recommendation 1: The Department should use the proposed estimation methodology as an interim benchmark for monitoring progress toward serving Class Members. In light of the need to establish a benchmark for monitoring progress toward meeting the needs of Class Members, and given that the proposed estimation methodology is likely to identify youths with SED who currently access mental health services and who have the highest levels of need, it is recommended that the Department use its current estimation methodology as an interim benchmark for monitoring progress toward meeting the needs of youth who experience SED in Idaho even as it works to develop a more robust approach to estimating SED prevalence statewide.

Recommendation 2: The Department should leverage population health survey data collected annually by the Centers for Disease Control and Prevention and other federal agencies to develop model-based estimates of SED prevalence in Idaho. Recently completed research has demonstrated the validity of predictive algorithms that generate SED prevalence estimates based on statistical models that incorporate routinely collected, standardized data available from population representative surveys conducted by the Centers for Disease Control and Prevention (Ringeisen et al., 2015). Since 2001, the CDC has collected data on youth psychopathology and functional impairment using the Strengths and Difficulties Questionnaire (Bourdon et al., 2005) as part of the National Health

Interview Survey. The Strengths and Difficulties Questionnaire is a well-established measure of youth psychopathology and functional impairment that has been validated and used in several population representative studies across the globe (Bourdon et al., 2005; Panos, 2006; SAMHSA, 2014). In 2015, Ringeisen et al. showed that scores on the Strengths and Difficulties Questionnaire could be used to develop prevalence estimates of SED. Their study demonstrated strong concordance between scores on the Strengths and Difficulties Questionnaire and youth SED as measured through gold-standard methods of in-person, structured diagnostic interviews and standardized measures of impairment (Ringeisen et al., 2015). In combination with other research showing the validity of the Strengths and Difficulties Questionnaire for estimating SED prevalence (Bourdon et al., 2005; Panos, 2006; SAMHSA, 2014), this research indicates that predictive statistical models can be used to generate SED prevalence estimates based on Strengths and Difficulties Questionnaire scores.

Studies published to date from National Health Interview Survey data provide national prevalence estimates of SED that could be used to develop a synthetic estimate of SED for Idaho; however, a superior approach is to access Idaho specific data from the NHIS database and develop an Idaho-specific SED prevalence estimate based on Idaho State data. This is possible because the NHIS database includes State-level data which is available through the NHIS restricted release data files. Access to this database requires an application process and approval from the Research Data Center of the National Center for Health Statistics (<https://www.cdc.gov/rdc/>). In order to access the data, investigators must submit a rationale for the proposed project along with a research and analysis plan. It is recommended that the Department partner with investigators at Boise State University (or another institution) to develop and submit an application for the use of this data to generate an Idaho State specific estimate of SED prevalence based on NHIS data. This process is replicable, low cost, and will produce scientifically defensible estimates of SED at the State level. ■

References

- Bourdon KH, Goodman R, Rae DS, et al. (2005). The Strengths and Difficulties Questionnaire: U.S. normative data and psychometric properties. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 557-564.
- Burns BJ, Costello EJ, Angold A, et al. (1995). Children's mental health service use across service sectors. *Health Affairs*, 14, 147-159.
- Burns BJ, Costello EJ, Erkanli A, et al. (1997). Insurance coverage and mental health service use by adolescents with serious emotional disturbance. *Journal of Child and Family Studies*, 6, 89-111.
- Costello EJ, Egger H, Angold A. (2005). 10-year research update review: The epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 972-986.
- Costello EJ, Messer SC, Bird HR, et al. (1998). The prevalence of serious emotional disturbance: A re-analysis of community studies. *Journal of Child and Family Studies*, 7, 411-432.
- Friedman RM, Katz-Leavy JW, Manderscheid RW, & Sondheimer DL. (1996). Prevalence of serious emotional disturbance in children and adolescents. In RW Manderscheid & MA Sonnenschein (Eds.), *Mental health, United States, 1996* (pp. 71-89). Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.
- Goodman R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337-1345.
- Kessler RC, Avenevoli S, Costello J, et al. (2012). Severity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication Adolescent Supplement. *Archives of General Psychiatry*, 69, 381-389.
- Leaf PJ, Alegria M, Cohen P, et al. (1996). Mental health service use in the community and schools: Results from the four-community MECA study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 889-897.
- Mark TL, Buck JA. (2006). Characteristics of U.S. youths with serious emotional

- disturbance: Data from the National Health Interview Survey. *Psychiatric Services*, 57, 1573-1578.
- Merikangas KR, He JP, Brody D, et al. (2010). Prevalence and treatment of mental disorders among US children in the 2001-2004 NHANES. *Pediatrics*, 125, 75-81.
- Merikangas KR, He J, Burstein M, et al. (2011). Service utilization for lifetime mental disorders in U.S. adolescents: Results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child and Adolescent Psychiatry*, 50, 32-45.
- National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Serious Emotional Disturbance in Children: Workshop Summary*. K. Marton, Rapporteur. Institute of Medicine. Washington, DC: The National Academies Press.
- National Center for Health Statistics, Centers for Disease Control and Prevention. (October 1, 2017a). *National Health Interview Survey*. Available at: <https://www.cdc.gov/nchs/nhis/index.htm>.
- National Center for Health Statistics, Centers for Disease Control and Prevention. (October 1, 2017b). *National Health Interview Survey: Questionnaires, Datasets, and Related Documentation*. Available at: https://www.cdc.gov/nchs/nhis/nhis_questionnaires.htm
- Olfson M, Druss BG, Marcus SC. (2015). Trends in mental health care among children and adolescents. *New England Journal of Medicine*, 372, 2029-2038.
- Panos, V. (2006). Strengths and Difficulties Questionnaire: Research and clinical applications. *Current Opinion in Psychiatry*, 19, 367-372.
- Ringeisen H, Aldworth J, Colpe JL, et al. (2015). Estimating the prevalence of any impairing childhood mental disorder in the national health interview survey. *International Journal of Methods in Psychiatric Research*, 24, 266-274.
- Shaffer D, Gould MS, Brasic J, et al. (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry*, 40, 1228-1231.
- Simon AE, Pastor PN, Reuben CA, et al. (2015). Use of mental health services by children ages six to 11 with emotional or behavioral difficulties. *Psychiatric Services*, 66, 930-937.
- Substance Abuse and Mental Health Services Administration. (2014). *Serious Emotional Disturbance (SED) Expert Panel Meetings: Summary of panel discussion and recommendations*. Available at: <https://www.samhsa.gov/data/sites/default/files/SED%20Expert%20Panels%20Summary%20Report.pdf>
- Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (1993, May 20). Definition of children with a serious emotional disturbance. *Federal Register*, 58(96), 29425.
- Substance Abuse and Mental Health Services Administration, Drug and Alcohol Services Information System. (2016). *Uniform Reporting System (URS) Table 1: Number of Children with Serious Emotional Disturbances, age 9 to 17, by State, 2016*. Available at https://www.dasis.samhsa.gov/dasis2/urs/adult_smi_child_sed_prev_2016.pdf
- Walter AW, Yuan Y, Cabral HJ. (2017). Mental health services utilization and expenditures among children enrolled in employer-sponsored health plans. *Pediatrics*, 139(s2), s127-s135.
- Washington State Department of Social and Health Services. (2003). *Report to the legislature: The prevalence of serious mental illness in Washington State*. Available at: <https://www.dshs.wa.gov/sites/default/files/BHSIA/dbh/documents/2003Prevalence.pdf>
- Williams NJ, Scott L, Aarons GA. (2017). Prevalence of serious emotional disturbance among US children: A meta-analysis. *Psychiatric Services*. Available online ahead of print at: <https://doi.org/10.1176/appi.ps.201700145>

Appendix A

The following are ICD-9 codes used in the Department's estimation methodology to identify youth who received medical services for a mental health disorder.

ICD-9 Diagnostic Code	Disorder Type
295-295.5	Schizophrenic disorders
296.-296.99	Episodic mood disorders
297.00- 297.9	Delusional disorders
298.0-298.9	Other nonorganic psychoses
300.00-300.4	Anxiety, dissociative and somatoform disorders
301.0-301.9	Personality disorders
307.1	Anorexia nervosa
307.20-307.3	Tics
307.50-307.7	Other unspecified disorders of eating
309.21	Separation anxiety
309.81	Posttraumatic stress disorder
311.	Depressive disorder, not elsewhere classified
312.30-312.9	Disorders of conduct, not elsewhere specified
313.0-313.9	Disturbance of emotions specific to childhood and adolescence
314.00-314.9	Hyperkinetic syndrome of childhood