Serious Emotional Disturbance (SED) Expert Panel Meetings

Substance Abuse and Mental Health Services Administration (SAMHSA)
Center for Behavioral Health Statistics and Quality (CBHSQ)

September 8 and November 12, 2014

Summary of Panel Discussions and Recommendations

In September and November of 2014, SAMHSA/CBHSQ convened two expert panels to discuss several issues that are relevant to generating national and State estimates of childhood serious emotional disturbance (SED). Childhood SED is defined as the presence of a diagnosable mental, behavioral, or emotional disorder that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities (SAMHSA, 1993).

The September and November 2014 panels brought together experts with critical knowledge around the history of this federal SED definition as well as clinical and measurement expertise in childhood mental disorders and their associated functional impairments. The goals for the two expert panel meetings were to

- operationalize the definition of SED for the production of national and state prevalence estimates (Expert Panel 1, September 8, 2014) and
- discuss instrumentation and measurement issues for estimating national and state prevalence of SED (Expert Panel 2, November 12, 2014).

This document provides an overarching summary of these two expert panel discussions and conclusions. More comprehensive summaries of both individual meetings' discussions and recommendations are found in the appendices to this summary. Appendix A includes a summary of the September meeting and Appendix B includes a summary of the November meeting). The appendices of this document also contain additional information about child, adolescent, and young adult psychiatric diagnostic interviews, functional impairment measures, and shorter mental health measurement tools that may be necessary to predict SED in statistical models. Appendix C summarizes these instruments by age, and Appendix D gives an overview of the various instruments. Appendices E through G describe the individual diagnostic interviews, functional impairment measures, and prediction tools in more detail.

Mental Disorders to Be Included in the Definition of SED

Panel members agreed that an operational definition of SED based on the 1993 *Federal Register* notice should

- exclude all substance use disorders,

- exclude all neurodevelopmental disorders *except* attention deficit-hyperactivity disorder (ADHD),
- exclude medication induced movement disorders, and
- include all other disorder categories.

In considering the measurement of mental disorders within a study designed to generate national and state SED prevalence estimates, panel members commented on several issues:

- Not all diagnoses that form part of the definition of SED should (or can) be measured. For some diagnoses, symptoms may be sufficient and a high priority (i.e., psychotic experiences, mania/hypomania) to measure and include.
- Although the mental disorder to be included or excluded as part of the definition of SED should not differ significantly based upon age, different disorders may be more or less of a measurement priority for various age groups. For example, attachment disorders may be an assessment priority for infants and toddlers.
- Expert panel members also indicated that the transition from the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) to the fifth edition (DSM-5) will likely have little impact on SED estimates. The panel did agree that the two new DSM-5 disorders that are relevant to children (i.e., Social Communication Disorder and Disruptive Mood Dysregulation Disorder) should be included in the definition of SED.

Instrumentation: No specific diagnostic interview is designed to measure the presence of a mental disorder among individuals from birth to 18 years of age (or 22 years if SAMHSA decides to increase the age span covered). There are, however, many different diagnostic tools with diverse characteristics; several of these instruments will be well-suited to measure the presence of a past year mental disorder within a given age range. However, it will need to be determined whether the validation was performed across a national sample, for Spanish language groups, and across modes.

With regard to the measurement of a childhood mental disorder, panel members specifically recommended the following:

- A national study could be designed to estimate SED beginning at the age of 4 years. Beginning at 4 years, there are well-established, developmentally appropriate diagnostic interviews to establish the presence of a mental disorder. There are measures for use with children as young as 2 years; however, the measures are less well established.
- To determine the presence of a mental disorder, both parent and child report on a diagnostic interview is recommended at least up to age 18 years. Child report should

be used once the child is cognitively able to self-report (e.g., 9 years old, as used by many instruments). However, the methodological impact of using a single reporter up to a certain age and then using multiple reporters on SED estimates must be considered.

- Where there are two reporters, the presence of a mental disorder should be estimated by either parent *or* child report. It is not necessary for both reporters to indicate the presence of a mental disorder; one or the other should be considered sufficient.
- Lifetime estimates of mental disorders in children should not be used. They are underestimates because of respondent recall problems.
- Estimates for past 12 month, past 3 month, and last month mental disorders in children will be very similar due to respondent recall problems. SAMHSA should use the time-reference period most consistent with the *Federal Register* definition.

Functional Impairment

Expert panel members noted that adequate research, measurement development, and associated publications surrounding the functional impairment of childhood mental disorders are lacking. They emphasized that any definition of "functional impairment" should be tailored to a child's age and developmentally appropriate expectations. Existing measures of impairment need to be more strongly operationalized with concrete, developmentally grounded, and culturally sensitive anchors to increase the accuracy of their assessment.

Measurement tools are not available to assess impairment from 0 to 22 years. Different impairment measures may be needed across child ages. Impairment can be reliably assessed in school-aged children beginning at age 6; however, cut-offs to determine the level of impairment required to meet the federal definition of SED will also need to be established within existing impairment measures. For example, for an instrument that measures impairment on a scale from 1 to 100, scoring cut-offs would need to be established for SED-relevant levels of functional impairment. Tools to assess functional impairment in very young children are still needed.

Instrumentation: With regard to measurement of functional impairment, panel members specifically recommended the following:

- A stand-alone measure of impairment that is separate from the diagnostic interview should be used to establish the presence of a mental disorder.
- For the purpose of estimating SED, an ideal impairment measure would have indicators across the three domains described in the *Federal Register* (home, school, and community). However, requiring impairment in at least one domain may lead to the noninclusion of children with subthreshold levels of impairment that cross two or more domains.

- A study should not rely exclusively on interviewer ratings of impairment. Parent and/or child report should be used instead of or in addition to interviewer ratings.

Tools to Predict SED in Statistical Models

A short mental health assessment tool may be needed to predict SED in a statistical model. In considering potential tools to be used for statistical prediction, panel members made the following comments:

- This area lacks sufficient research to serve as a basis for recommending one particular measure. Therefore, panel members could not identify one particular screening instrument with strong data indicating its power to predict SED in a statistical model.
- In general, the Strengths and Difficulties Questionnaire (SDQ) could be used in models to predict the possibility of having SED. This is because of its common use in epidemiological surveys worldwide; however, some instrumentation work will be necessary to determine which SDQ items have the greatest power to predict SED.
- An immediate next step might be to leverage any existing datasets with data that could accommodate the testing of various SED predictive models using existing instruments.

Overarching Recommendation

Comparable estimates of SED for individuals from birth to 22 years may not be feasible. A core set of common measures does not exist for children, youths, and young adults. Consequently, SAMHSA should take caution in providing one integrated estimate of SED across this wide age range. Instead, SAMHSA might want to consider providing age-group-specific prevalence estimates (0-5 or 2-5, 6-11, 12-18, or 19-22 years), even though these estimates would not be comparable. Panel members further noted that this may be still be helpful in state service planning because interventions and service sectors frequently differ across these age groups.

Reference

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.

Appendix A: Expert Panel 1
September 8, 2014

Serious Emotional Disturbance (SED) Expert Panel 1 Meeting

Substance Abuse and Mental Health Services Administration (SAMHSA)
Center for Behavioral Health Statistics and Quality (CBHSQ)

September 8, 2014

Meeting Summary

Meeting Goal: Operationalize the definition of serious emotional disturbance (SED) for the production of national and state prevalence estimates (based on the Substance Abuse and Mental Health Services Administration [SAMHSA] definition of SED, as described in the 1993 *Federal Register*)

I. Summary of Panel Background and *Federal Register* Definition of SED

Staff from SAMHSA and RTI provided a description of the *Federal Register* definition of SED, current related SAMHSA initiatives, and currently considered revisions to the definition of SED in the *Federal Register*. A list of panel participants is included at the end of this summary.

II. Presence of a Mental Disorder: What Disorders Should Be Included in National and State Estimates of SED?

Discussion Question 1: Which DSM-5 disorders should be included and excluded?

- **Discussion Summary Points:**
  - Any study to assess national/state prevalence of SED should be careful not to exclude children with developmental disabilities (DD) from the sample. There is high comorbidity between DD and other mental disorders, so excluding these children from the sample would lead to a potential underestimate of SED.
    - Panel cautioned on the operational issues related to including children with pervasive developmental disabilities in any sample. Children with some disorders like autism might require a modified interview/instrument that is responsive to development.
  - Not all diagnoses within the definition of SED should (or can) be measured within a study to estimate national and state SED prevalence (see table of mental disorders starting on page 7 of this summary).
    - For some diagnoses, symptoms may be sufficient and a high priority—priority symptoms might include psychotic symptoms/experiences, mania/hypomania, suicidality, regulatory behaviors.
    - Sleep disorders should be measured. In the National Comorbidity Survey–Adolescent supplement (NCS-A) sleep module, insomnia is one of the most important predictors of SED (high comorbidity in children with bipolar, depression, anxiety).

- Personality disorders should not be measured. Personality disorders are not typically diagnosed in younger children (until a stable identity develops). Personality disorders can be diagnosed in children younger than 18 years of age once a stable identity has developed, but panel members cautioned that the validity of personality disorder categories in the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) are questionable and largely unmeasurable except for antisocial personality.
- In epidemiological studies, sometimes low prevalence conditions are excluded; however, this may not be an appropriate exclusion rationale for a study estimating SED, where severely impairing conditions (even with low prevalence) may be a priority.

- The transition from DSM-IV to DSM-5 will likely have very little impact on SED estimates.
  - The panel recommended caution with somatic disorders. "Psychological factors affecting other medical conditions" is a diagnosis in DSM-5 but it was not in DSM-IV. This is a problematic diagnosis because it is very vague and might produce high prevalence estimates.
- The length of diagnostic interviews to assess the presence of childhood mental disorders will vary by child age (e.g., an hour may be sufficient for a school-aged child, but not for a transition-aged youth).
- Assessing more disorders may not necessarily increase the overall interview length significantly. Many children will "screen out" of the less common disorders.
- As with substance abuse, neurocognitive conditions like traumatic brain injury should be excluded except when co-occurring (e.g., additional diagnosis as a comorbid condition, with primary diagnosis being mental health problem).
  - Panel recommended caution when offering a blanket exclusion of neurodevelopmental disorders from the SED definition as some disorders are associated with later psychosis and present very early in life. Excluded disorders should be named specifically.
- Some children may not meet all of the relevant DSM-5 criteria for a disorder but have significant functional impairment. For SED, children need to meet DSM-5 mental disorder criteria and have significant functional impairment (overall or across domains of SED). Panel members commented that the best predictor of service need is impairment, not psychiatric disorder. This is why it is important to have an additional measure of impairment besides the one embedded within a specific diagnostic tool. Such a separate instrument allows the ability to identify children potentially in need of services who don't meet diagnostic criteria for a disorder. This situation may happen in cases of nonverbal children, young children, or children younger than 12 with internalizing disorders where parents may not be good reporters of children's internal states.
  - Should a study designed to generate national and state prevalence estimates of SED also be able to identify individuals who do not meet DSM-5 diagnostic thresholds but demonstrate substantial functional impairment?

- Panel commented on the need for estimates of SED plus comorbid conditions. States are struggling with providing services to individuals with comorbid conditions (either mental health and substance abuse, or mental health and developmental disabilities). Children with this type of comorbidity are high service priorities and challenges for states that lack resources and training to serve them.

- **Recommendations** (also see Mental Disorder Summary Table):

  The operational definition of SED should:
  - exclude all substance use disorders;
  - exclude all neurodevelopmental disorders except ADHD, and further, should specify and name all excluded neurodevelopmental disorders;
  - exclude medication induced movement disorders (DSM-5 section 709 on "Medication-induced movement disorders and other adverse effects of medication"); and
  - include all other disorder categories, noting a few specific disorders to be excluded within certain categories.

Discussion Question 2: How should new DSM-5 disorders be handled (social [pragmatic] communication disorder [SCD], disruptive mood dysregulation disorder [DMDD])?

- **Recommendations:**
  - SCD should be excluded (consistent with decisions regarding learning disabilities and other communication disorders).
  - DMDD should be included but will likely not need a new, separate diagnostic module to assess within a study to generate national and state estimates. This new disorder pulls from many symptoms included in prior DSM-IV diagnoses.

Discussion Question 3: Should the included/excluded DSM-5 disorders differ across age groups?

- **Discussion Summary Points:**
  - Diagnostic instruments administer various modules with age related cut-points, so the selected instrument will help dictate which disorders are assessed at which age.
  - Different instruments will be necessary to assess mental disorders across such a broad age spectrum (0 to 22 years).
  - There has been tremendous growth in knowledge of how to assess the presence of mental disorders in early childhood. Consequently, there are measures to reliably assess mental disorders in 2 to 6 year olds, maybe even starting at 10 to 12 months of age.
  - Reporter variation (parent only, parent + child) will create differences in the prevalence estimates (seam effects) across child age just by virtue of the number of reporters. Children less than 9 years of age are assessed by parent report only.

Children 9 years or older are assessed by both parent and self-report, yielding more opportunities for symptom endorsement.
- The use of different instruments across the different age groups may also contribute to seam effects.

- **Recommendation:** Mental disorder inclusionary and exclusionary criteria to assess the presence of SED will not differ significantly based upon age; however, different disorders may be more or less of a measurement priority for various age groups. For instance, attachment disorders would be a priority for young children 1 to 3 years old.

III. Impairment: Is the *Federal Register Notice* definition of serious impairment operationalized sufficiently for epidemiological study? What components need to be more measureable or specific?

Discussion Question 4: How might what we have learned about impairment since the 1993* Federal Register *definition of SED change the definition?

- **Discussion Summary Points:**
  - Research, measurement development, and associated publications on functional impairment have not changed much since the 1990s.
  - Measures of impairment need to be more strongly operationalized with concrete criteria organized by developmental periods and age-specific examples. Cut-offs to determine SED need to be established within the available impairment measures.
  - Tools/measures to assess impairment in very young children may be lacking.
  - In a young child, impairment may manifest itself as the impact of a child's symptoms on a parent or family's functioning (e.g., parent's ability to work outside the home).
  - Teachers may be helpful second or third reporters—more so for the presence of certain symptom clusters (e.g., ADHD) than for the measurement of "any mental disorder" and associated impairment.
  - The panel cautioned that for young children, parents might have a difficult time attributing impairment to specific disorders and diagnoses.

Discussion Question 5: Which impairment measures might be considered for inclusion in a study to generate national and state estimates of SED?

- Discussion Summary Points:
  - Child World Health Organization Disability Assessment Schedule (WHODAS)—developed for the DSM-5 field trials. Panel noted that this instrument was adapted for children aged 6 years or older from the adult WHODAS and not developed from the "ground up" as a "child instrument." Nevertheless, results were reliable in field trials for parent-only report for children aged 6 to 11; parent and youth report for children aged 12 or older. Clinician-rated versions are typically not reliable for assessing

children's impairment. The child WHODAS cannot be used for other purposes at this time (need permission, resolve copyright issues). The panel commented that the American Psychiatric Association (APA) has a large amount of data about the child WHODAS that could be used to test reliability, create a shorter version (currently 36 items), and study psychometric properties.

- Children's Global Assessment Scale (CGAS):
  1. Advantages—it is a global measure (i.e., not associated with individual mental disorders) and panel members commented that it has been used by trained interviewers. Lends itself to specific cut-points.
  2. Disadvantages—the CGAS needs to be more specifically "grounded" to more easily establish cut-points by child age (and developmentally appropriate guidelines). The CGAS is not designed to distinguish impairment specifically across home, school, and community—it offers only 1 overarching score. There was criticism by the panel that the CGAS (1) mixes psychiatric symptoms with impairment, and (2) applies criteria based on everything said about the child and may be limited by a parent's perception of something being or not being problematic.
  3. Panel commented on the need to have C-GAS scores guided by examples with developmental specificity for each cut-point (e.g., behaviors or specific functioning examples of how a given score might look for a young child versus an adolescent). Work that could be done as secondary data analysis of existing data sets using the CGAS. Panel also commented on the availability of a parent version (Parents' Global Assessment Scale, or PGAS) developed for studies in Puerto Rico.
- Brief Impairment Scale—generates one score for each functional domain (home, school, community).

- **Issues in Need of Further Discussion:**
  - Impairment measurement development or refinement work is likely needed. This work is acutely needed for impairment associated with internalizing problems (anxiety, depressive disorders) for children up to 12 years old. The measurement work is also clearly needed to assess impairment in young children.
  - SAMHSA should consider how existing secondary data might be analyzed to help shed light on measurement development or design issues to inform a future study designed to generate national/state estimates of SED.

Discussion Question 6: Should impairment be determined within the context of defining the presence of a "mental disorder," separately in a global fashion, or both?

- **Recommendation**: SAMHSA should consider using a global measure of impairment within a study to generate national and state estimates of SED. This would be the preferred alternative to having an impairment measure that is embedded within disorder-

specific modules of a diagnostic interview. A global measure of impairment could be used as its own separate indicator different from the measure used to assess symptom presence/absence.

IV. Other Considerations for Generating National and State Estimates of SED

- Discussion Summary Points:
  - There is high concern at state and federal levels for transitioning young adults aged 18 to 22 and aged 18 to 25 due to problematic behavior and violence that often generates public attention. Instrumentation is available for young adults, but there has been limited focus on that developmental period. For those in need, services drop to half compared to adolescents. For this group, the prevalence of SED would likely be slightly higher than that of serious mental illness (SMI), and impairment would have additional domains (e.g., marriage, employment, graduation/schooling).
  - There is currently much more literature on the 2 to 6 age range than was available in the 1990s.
  - Children in kindergarten through 8th grade are also a critical population with key transitions during that period that have long-term consequences for future child development.
  - SED estimates should consider the inclusion of children who are in treatment and who without treatment might have seriously impaired functioning.
  - Any study estimating the prevalence of SED will have to consider seam effects that may be due to child age, reporter type, and measurement tool(s).
  - Estimating the presence of SED from birth to 22 years will be a methodological challenge, but there are tools for assessing mental disorders, particularly from 2 to 22 years. Within a large-scale survey context, panel members suggested considering a multimethod assessment, with carefully targeted subpopulations for efficiency and economy (e.g., validity substudies for young children with teacher/day care provider surveys). This issue will have greater focus in Expert Panel 2.

- **Issue for Future Discussion:** SAMHSA might want to consider embedding various validation substudies within any effort to estimate SED within this wide age span. Which types of substudies would be recommended?

SED Expert Panel, September 8th 2014

Summary of Meeting Discussion

Discussion Question: *Which DSM-5 disorders should be excluded and included in national and state estimates of SED?*

DSM-5 Disorder	Recommend for Inclusion in the Operational Definition of SED? (Yes/No)	Recommended to Be Measured Within a Study to Generate National and State Estimates of SED (Yes/No)
Neurodevelopmental Disorders		
Intellectual Disabilities	No	No
Communication Disorders		
Language Disorder	No	No
Speech Sound Disorder	No	No
Childhood Onset Fluency Disorder	No	No
Social Communication Disorder	No	No
Unspecified Communication Disorder	No	No
Autism Spectrum Disorder	No	No
Attention-Deficit/Hyperactivity Disorder	Yes	Yes
Specific Learning Disorder	No	No
Motor Disorders		
Developmental Coordination Disorder	No	No
Tourette's Disorder	No	No
Other Neurodevelopmental Disorders	No	No
Schizophrenia Spectrum and Other Psychotic Disorders	Yes	Yes—psychotic symptoms and experiences, but not specific disorders
Schizotypal Personality Disorder	Yes	No
Delusional Disorder	Yes	No
Brief Psychotic Disorder	Yes	No
Schizophreniform Disorder	Yes	No
Schizophrenia	Yes	No
Schizoaffective Disorder	Yes	No
Substance/Medication-Induced Psychotic Disorder	Yes	No
Psychotic Disorder Due to Another Medical Condition	Yes	No
Catatonia Associated With Another Mental Disorder (Catatonia Specifier)	Yes	No
Catatonic Disorder Due to Another Medical Condition	Yes[1]	No
Unspecified Catatonia	Yes	No
Other Specified Schizophrenia Spectrum and Other Psychotic Disorder	Yes	No
Unspecified Schizophrenia Spectrum and Other Psychotic Disorder	Yes	No
Bipolar and Related Disorders	Yes	Yes—add Mania and Hypomania
Bipolar I Disorder	Yes	Yes

DSM-5 Disorder	Recommend for Inclusion in the Operational Definition of SED? (Yes/No)	Recommended to Be Measured Within a Study to Generate National and State Estimates of SED (Yes/No)
Bipolar II Disorder	Yes	Yes
Cyclothymic Disorder	Yes	No
Bipolar and Related Disorder due to a Medical Condition	Yes	No
Other Unspecified Bipolar and Related Disorder	Yes	No
Unspecified Bipolar and Related Disorder	Yes	No
Depressive Disorders		
Disruptive Mood Dysregulation Disorder	Yes	Yes, will be able to assess without adding specific new module
Major Depressive Disorder, Single and Recurrent Episodes	Yes	Yes
Persistent Depressive Disorder (Dysthymia)	Yes	Yes
Premenstrual Dysphoric Disorder	Yes	No
Substance/Medication-Induced Depressive Disorder	Yes	No
Depressive Disorder Due to Another Medical Condition	Yes	No
Other Specified Depressive Disorder	Yes	No
Unspecified Depressive Disorder	Yes	No
Anxiety Disorders		
Separation Anxiety Disorder	Yes	Yes
Selective Mutism	Yes	Yes
Specific Phobia	Yes	Yes
Social Anxiety Disorder (Social Phobia)	Yes	Yes
Panic Disorder	Yes	Yes
Panic Attack (Specifier)	Yes	Yes
Agoraphobia	Yes	Yes
Generalized Anxiety Disorder	Yes	Yes
Substance/Medication-Induced Anxiety Disorder	Yes	No
Anxiety Disorder Due to Another Medical Condition	Yes	No
Other Specified Anxiety Disorder	Yes	No
Unspecified Anxiety Disorder	Yes	No
Obsessive Compulsive and Related Disorders	Yes	
Obsessive-Compulsive Disorder	Yes	Yes
Body Dysmorphic Disorder	Yes	?[2]
Hoarding Disorder	Yes	?
Trichotillomania (Hair-Pulling Disorder)	Yes	?
Excoriation (Skin-Picking) Disorder	Yes	?
Substance/Medication-Induced Obsessive-Compulsive and Related Disorder	Yes	No
Obsessive-Compulsive and Related Disorder Due to Another Medical Condition	Yes	No
Other Specified Obsessive-Compulsive and Related Disorder	Yes	No
Unspecified Obsessive-Compulsive and Related Disorder	Yes	No
Trauma and Stressor Related Disorders		
Reactive Attachment Disorder[3]	Yes	Yes
Disinhibited Social Engagement Disorder	Yes	No
Posttraumatic Stress Disorder	Yes	Yes
Acute Stress Disorder	Yes	Yes
Adjustment Disorders	Yes	Yes
Other Specified Trauma- and Stressor-Related Disorder	Yes	No
Unspecified Trauma- and Stressor-Related Disorder	Yes	No

DSM-5 Disorder	Recommend for Inclusion in the Operational Definition of SED? (Yes/No)	Recommended to Be Measured Within a Study to Generate National and State Estimates of SED (Yes/No)
Dissociative Disorders		
Dissociative Identity Disorder	Yes	No
Dissociative Amnesia	Yes	No
Depersonalization/Derealization Disorder	Yes	No
Other Specified Dissociative Disorder	Yes	No
Unspecified Dissociative Disorder	Yes	No
Somatic Symptom and Related Disorders		
Somatic Symptom Disorder	Yes	No
Illness Anxiety Disorder	Yes	No
Conversion Disorder (Functional Neurological Symptom Disorder)	Yes	No
Psychological Factors Affecting Other Medical Conditions[4]	Yes	No
Factitious Disorder	Yes	No
Other Specified Somatic Symptom and Related Disorder	Yes	No
Unspecified Somatic Symptom and Related Disorder	Yes	No
Feeding and Eating Disorders		
Pica	Yes	?
Rumination Disorder	Yes	?
Avoidant/Restrictive Food Intake Disorder	Yes	?
Anorexia Nervosa	Yes	Yes
Bulimia Nervosa	Yes	Yes
Binge-Eating Disorder	Yes	Yes
Other Specified Feeding or Eating Disorder	Yes	?
Unspecified Feeding or Eating Disorder	Yes	?
Elimination Disorders		
Enuresis	Yes	?
Encopresis	Yes	?
Other Specified Elimination Disorder	Yes	?
Unspecified Elimination Disorder	Yes	?
Sleep Wake Disorders (e.g., Insomnia Disorder, Narcolepsy)	Yes	Yes
Sexual Dysfunctions (e.g., Substance/Medication-Induced Sexual Dysfunction	Yes	No
Gender Dysphoria	Yes	No
Gender Dysphoria	Yes	No
Other Specified Gender Dysphoria	Yes	No
Unspecified Gender Dysphoria	Yes	No
Disruptive, Impulse-Control and Conduct Disorders		
Oppositional Defiant Disorder	Yes	Yes
Intermittent Explosive Disorder	Yes	?
Conduct Disorder	Yes	Yes
Antisocial Personality Disorder	No Dx < 18 years	?
Pyromania	Yes	?
Kleptomania	Yes	?
Other Specified Disruptive, Impulse-Control, and Conduct Disorder	Yes	?
Unspecified Disruptive, Impulse-Control, and Conduct Disorder	Yes	?
Substance-Related and Addictive Disorders[5]	No	No
Neurocognitive Disorders (e.g., Disorder due to Traumatic Brain Injury)[3]	No	No

DSM-5 Disorder	Recommend for Inclusion in the Operational Definition of SED? (Yes/No)	Recommended to Be Measured Within a Study to Generate National and State Estimates of SED (Yes/No)
Personality Disorders	Yes	No[6]
General Personality Disorder	Yes	No
Cluster A Personality Disorders	Yes	No
Paranoid Personality Disorder	Yes	No
Schizoid Personality Disorder	Yes	No
Schizotypal Personality Disorder	Yes	No
Cluster B Personality Disorders	Yes	No
Antisocial Personality Disorder	Yes	No
Borderline Personality Disorder	Yes	No
Histrionic Personality Disorder	Yes	No
Narcissistic Personality Disorder	Yes	No
Cluster C Personality Disorders	Yes	No
Avoidant Personality Disorder	Yes	No
Dependent Personality Disorder	Yes	No
Obsessive-Compulsive Personality Disorder	Yes	No
Other Personality Disorders	Yes	No
Personality Change Due to Another Medical Condition	Yes	No
Other Specified Personality Disorder	Yes	No
Unspecified Personality Disorder	Yes	No
Paraphilic Disorders (e.g., Sexual Masochism Disorder)	Yes	No
Other Mental Disorders		
Other Specified Mental Disorder Due to Another Medical Condition	Yes	No
Unspecified Mental Disorder Due to Another Medical Condition	Yes	No
Other Specified Mental Disorder	Yes	No
Unspecified Mental Disorder	Yes	No

[1] There was discussion by the expert panel about whether mental disorders that were secondary to medical problems should be included. The group decided yes, they should be included, because a child would need treatment from multiple providers, one of which would be specifically for the mental health problem.

[2] "?" is noted for disorders that were not specifically discussed by the panel. Any disorders that were reported in past epidemiological studies are presumed to be included, because the panel did not indicate that any disorders should be subtracted from the list of disorders reported by other studies.

[3] Reactive attachment and adjustment disorders will be important to report for young children, age 12 months to 3 years.

[4] The expert panel expressed concern that inclusion of this disorder might skew prevalence rates such that somatic disorders will be very prevalent. This was not a diagnosis in DSM-IV.

[5] Substance use disorders and neurocognitive disorders would be included only if co-occurring with a mental health diagnosis.

[6] The panel expressed concerns about the validity and measurability of personality disorders in children and adolescents. If personality disorders are considered for reporting, this category of disorders would only be relevant for 18-22 year olds.

Serious Emotional Disturbance (SED) Expert Panel 1 Meeting Participants

September 8, 2014

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Appendix B: Expert Panel 2
November 12, 2014

Serious Emotional Disturbance (SED) Expert Panel 2 Meeting

Substance Abuse and Mental Health Services Administration (SAMHSA)
Center for Behavioral Health Statistics and Quality (CBHSQ)

November 12, 2014

Meeting Summary

Meeting Goal: Discuss instrumentation and measurement issues when estimating national and state prevalence of childhood serious emotional disturbance (SED) (based on the Substance Abuse and Mental Health Services Administration [SAMHSA] definition of SED as described in the 1993 *Federal Register*)

I. Summary of Panel Background

Staff from SAMHSA provided an overview of how this task originated; the SAMHSA mission regarding SED; a description of the *Federal Register* definition of SED; current SAMHSA related initiatives, including the Institute of Medicine (IOM) report and the SED workgroup; and a description of Panel 1 recommendations. Also, staff discussed two potential survey structures to generate national/state estimates of SED: (1) creating a new, separate study, or (2) using an existing, national survey platform. A list of panel participants is included at the end of this summary.

II. Establishing the Presence of a Past Year DSM-5 Mental Disorder among Children Aged 0 to 22 Years

Discussion Question 1: Which diagnostic instruments are best suited to measure the presence of a past year DSM-5 mental disorder among children aged 0 to 22 years for the purpose of estimating SED?

- **Discussion Summary Points:**
  - No one diagnostic interview will measure the presence of a mental disorder among individuals aged 0 to 22 years.
  - There are many different well-validated diagnostic tools with diverse characteristics. Several will be well suited to measure the presence of a past year mental disorder within a specific age range; the question is which one will best meet all of SAMHSA's priorities (target age range, Spanish language availability, desired survey mode administration, availability of a DSM-5 update, etc.).
  - Children with intellectual and developmental disabilities should be included in a study sample due to comorbidity with other mental disorders, but these children will require a modified interview/instrument that is responsive to their development.

- **Recommendation:** Create a checklist table that compares and contrasts candidate measures across priority issues (e.g., age range, Spanish language version availability, survey modes tested, interviewer type required, DSM-5 update) that are key to deciding which measures are best suited for generating national and state estimates of SED.

Discussion Question 2: Where might instrument development work be necessary to meet the different* Federal Register *criteria?

- **Discussion Summary Points:**
  - Instrument development work might be necessary related to the translation and testing of key instruments from English to Spanish
    - Given the increasingly large population of Spanish-speaking people in the United States, the panel noted that administering a survey in Spanish might be an important issue to consider
    - Many instruments are available in Spanish; however, they may not be appropriately validated for the U.S. Spanish-speaking population or for specific Hispanic subpopulations.
    - Time reference period and duration questions are particularly complicated in language translations.
  - Linguistic as well as pediatric validation may be necessary. Pediatric validation would be necessary for changing the administration age for a particular instrument beyond its originally developed purpose (adaptation for a younger or older target population).
  - Panel members noted that the Diagnostic Interview Schedule for Children (DISC) has been translated, adapted, and tested for validity and reliability in both English and Spanish. The Mini International Neuro-psychiatric Interview for Children and Adolescents (MINI-KID) was also provided as an example of an instrument translated and validated for other languages with an age range from preschool to young adulthood.

- **Recommendations:** If Spanish-language administration is a priority, SAMHSA should evaluate the linguistic validation of existing diagnostic interviews. Linguistic validation substudies may be necessary. If diagnostic instruments need to be extended beyond their originally intended administration age, SAMHSA may need to consider conducting some pediatric validation substudies to ensure that children of various ages comprehend diagnostic items as intended.

Discussion Question 3: Past 12 month duration period: Should another time reference period be used along with past year (particularly since the* Federal Register Notice *revisions may no longer include a specific time reference period)? What are the implications of having more than one time frame?

- **Discussion Summary Points:**
  - Specific time reference periods may not matter as much one might imagine. Respondents generally report on their recent experiences and memories.
  - Estimates for past 12 month, past 3 month and past month mental disorders will be very similar due to respondent recall problems. The recall bias will most typically lead to disorder underestimates for longer time reference periods. False positives are not a large concern; however, with shorter time reference periods, false negatives may be a problem. Certain cases may have met diagnostic criteria in the past but no longer meet those criteria.
  - There are feasibility issues when trying to get truly accurate estimates of past 12 month disorders. To get accurate estimates, a study would need to conduct interviews 4-6 times during the past 12 month reference period (likely not feasible).
  - Data sets are available to analyze issues related to recall bias and varying time reference periods. These data could be examined to understand how estimates of different mental disorders vary depending on the time reference period used.

        - Analyses based on instruments like the DISC have shown that comparisons of rates based on current state and 1-year timeframe produce almost identical rates.
        - Similar findings were reported for the Child and Adolescent Psychiatric Assessment (CAPA) when comparing current, 1 month, and past 3 month estimates.
    - Panel members noted that some individual mental disorders have symptom duration criteria that are necessary to establish the presence of a mental disorder. Disorder-specific duration criteria are separate from an instrument's overarching time reference period distinctions.
    - Many, but not all, panel members thought that questions asking about symptoms in the past 3 months would generate the most accurate responses from respondents; however, this may not be what SAMHSA needs.
    - Because states need funding estimates for children and adolescents meeting the *Federal Register* criteria in the past year, then the past 12 month criteria seem important.

- **Recommendation:** Conduct secondary data analysis to understand variation in disorder estimates based upon past year versus past 3 month versus current reporting periods.

Discussion Question 4: What do we know about the recall accuracy for reports of "lifetime" childhood mental disorders? Past year?

- **Discussion Points Summary:** Panel commented that lifetime estimates not good measures of mental disorders in children. They produce underestimates of disorder prevalence rates.

- **Recommendation:** Do not use lifetime estimate of childhood mental disorders.

Discussion Question 5: Who should be the reporter of this information? Do parent and child report differ by the specific diagnosis assessed?

- **Discussion Points Summary:**
    - For a large-scale epidemiological study (e.g., household survey), both parent and child report is recommended at least up to age of 18 years (to the extent that is feasible).
    - Child report should not be used until a child is cognitively able to self-report (e.g., 9 years old—used by many instruments).
    - If study resources are limited, parents should report on children up to 11 years old, and children alone could be reporters beginning at the age of 12 years.
    - Disorder status should then be estimated using the "or" rule—by either parent *or* child report. Parent and child reports will often disagree.
    - For very young children, parent reports on diagnostic interviews may not be the best method. Instead, direct assessments are sometimes recommended. Direct assessments of young children by lay assessors are feasible using puppet interviews for children aged 4 to 6 years old. There are also recommended assessment tools for young children where an interviewer list attributes for other children and then asks a respondent if the target child shares the trait.
    - For certain diagnoses, parent report may be more accurate than child report (e.g., attention-deficit/hyperactivity disorder). Meanwhile, youth report alone may be sufficient for other diagnoses (e.g., substance use, conduct disorder). However, even with these

disorders, there will be cases in which a parent will report on substance use or suicide that the youth did not disclose.
    - Validation studies of the MINI-KID with the Kiddie-Schedule of Affective Disorders and Schizophrenia (K-SADS) showed higher accuracy in general for information provided by children due to parental underreporting of hallucinations, suicidal ideation, and substance use.
  - Unfortunately, the evidence base is not strong enough to confidently guide recommendations to collect diagnosis-specific information from only one informant.
  - Due to the discordance between reporters, panel members indicated that the use of a second reporter (e.g., roommate) for young adults might be useful but potentially not feasible.

- **Recommendation:** It would be ideal to use both parent and child report on diagnostic interviews for children aged 9 to 18 years. Direct assessments could be used for children younger than the age of 9 years. If not feasible, there are parent report diagnostic tools to assess symptoms in children younger than 9 that can stand alone (without a child reporter).

III. Measuring Whether a Childhood Mental Disorder "Substantially Interferes with or Limits" Functioning

Discussion Question 1: What are the best measures of global impairment for persons aged 0 to 22?

- **Discussion Summary Points:**
  - There should be an impairment measure that is separate from the diagnostic interview used to estimate SED. Certain cases will have high functional impairment without meeting diagnostic criteria for a mental disorder.
  - Many young children may not yet reach all symptomatology required by the DSM for a particular mental disorder but still have considerable impairment, putting them at high risk and in need of treatment.
  - From the perspective of the World Health Organization, disability is considered from the perspective of the whole individual (including but not relying exclusively on a specific diagnosis or set of symptoms).
  - There are very few tools are available to assess impairment from 0 to 22 years. Different impairment measures may be needed across child ages.
    - Seam effects that result from using different measures at different ages could be statistically examined by using both measures at the point of the seam (e.g., giving two instruments to the parents of 6-year-old children).
  - Impairment can be reliably assessed in school-aged children beginning at age 6.
  - The Children's Global Assessment Scale (CGAS) is still a commonly used, strong global measure of impairment. Panel members commented that it was easy to train interviewers to administer the CGAS with reliability (2 hours or less of training).
    - One disadvantage of the CGAS is that most cases will be classified within a narrow range of scores. Interviewers typically use a compressed range of scores between 40 to 70 points instead of using the full scale range from 0 to 100. This limits the usefulness of the scale.

        - Another disadvantage of the CGAS may be that it does not provide new information about impairment beyond information gathered during the diagnostic interview. The interviewer uses information collected during the interview process to provide a CGAS score. Meanwhile, functional impairment for SED does not necessarily need to be tied to specific symptoms or disorders.
        - One advantage of the CGAS is that it adds no burden to the interviewee (when completed by interviewer).
        - The CGAS can be based on parent, child, or interviewer report, with parents being the best reporter and children being the worst in terms of reliability.

    - **Recommendation:** If SAMHSA wishes to use a global measure of functional impairment, the CGAS would be recommended (with caveats noted). The CGAS does need to have behavior-specific and developmentally appropriate anchors created to guide respondents and increase the degree to which the full range of possible CGAS scores are used.

Discussion Question 2: Do these measures assess impairment in home, school, and community? What type of impairment score would be helpful to estimate SED (one total score, separate scores by impairment domain)?

- **Discussion Summary Points:**
    - For the purpose of estimating SED, an "ideal" impairment measure would have indicators across the three domains described in the *Federal Register* (home, school, and community). Global measures like the CGAS have only one summary score. Meanwhile, the Brief Impairment Scale and the Columbia Impairment Scale each provide separate scores for each of these domains.
    - If a measure with three separate domain scores is used, a decision will have to be made about how to consolidate information across the separate scores to create a cut-point for SED.
        - For example, the SED definition requires having significant impairment in at least one specific domain. What about a child who has moderate impairment across all three domains but does not have significant impairment in any one domain?
        - Some scales (e.g., Sheehan Disability Scale) have a summary score in addition to domain-specific scores, but not all instruments have this overarching summary score.

- **Recommendation:** SAMHSA should seek out consensus around what specific, well-operationalized behaviors (or defined level of functional impairment) meet the *Federal Register* definition of significant impairment for SED. Then, a developmentally appropriate cut-point on the various measures of functional impairment can be determined.

Discussion Question 3: How do impairment measures need to differ to accommodate child age?

- **Discussion Summary Points:**
    - There are fewer impairment instruments for younger children. Most epidemiological studies have not assessed mental health younger than the age of 2 years. So, there is less data available for very young children.
    - A definition of serious functional impairment in young children should consider including impairment in family life (e.g., burden of illness on the family).
    - Impairment measures sometimes ask parents to rate a child's behavior when "compared to other children." Parents of young children may not perform well in these types of assessments because they do not have good references for what "other children" may be like. As a solution, some other impairment measures look at specific functional domains (how child is eating, feeding, sleeping).
    - Panel members also noted more generally that perceptions of impairment vary widely by cultural background.

- **Recommendation:** The impairment component to the SED definition should be operationalized in a way that is developmentally grounded and culturally sensitive.
- **Recommendation:** Instrument development work is likely necessary to create an impairment tool to help define SED in very young children.

Discussion Question 4: Are impairment measures available for children and young adults ages 0 to 22 years? How can they be made most compatible with each other?

- **Discussion Summary Points:**
    - Child instrument adapted from the World Health Organization Disability Assessment Schedule (WHODAS):
        - This instrument (underdevelopment) will cover this age spectrum; however, the instrument does not currently have specific anchors. Consequently, it is difficult to interpret the meaning of a given score. Some panel members commented that the Columbia Impairment Scale (CIS; for ages 7 to 17) does a better job with well-operationalized anchors to individual items.
    - CIS:
        - The CIS is now included in the Medical Expenditures Panel Survey (MEPS). Results on the CIS in MEPS are expected to be published soon based on 6,000 children annually. Panel members suggest that preliminary examination of the MEPS data suggest that the CIS is performing well.
        - The CIS has good psychometric properties for administration in both English and Spanish. The CIS is short (when compared to the Brief Impairment Scale) and has also been used in large epidemiological studies across Puerto Rico. The CIS was developed for administration to both parents and children.

        - The CIS surfaced as a recommended measure in a meeting sponsored by the National Institute of Mental Health (NIMH) to define common data elements for use in studies of mental health.
        - The CIS is copyrighted but free.
    - Brief Impairment Scale (BIS):
        - Panel members commented that the BIS may be even better than the CIS for SAMHSA's purpose. The BIS only takes 4 to 5 minutes to administer. The BIS is based on the CIS—many items are the same and it was developed by the same author. The BIS just has more items per domain. The BIS parent version goes as young as 4 years of age; it has been tested with children as young as age 6.
    - For young children, panel members indicated that the Preschool-Age Psychiatric Assessment (PAPA) and its impairment module is the gold standard for assessing impairment in young children aged 2 to 5 years old. One disadvantage of the PAPA for SAMHSA's purpose may be that the impairment module in the PAPA is embedded in the diagnostic tool.
    - It is especially important that definitions of impairment be tailored to a child's age and developmentally appropriate expectations. Even within the same DSM mental disorder diagnosis, impairment (and symptom manifestation) may be defined very differently.

Discussion Question 5: Who should be the reporter of this information? Parent only, child only, or both? How does this vary by child age?

- **Discussion Summary Points:**
    - For global scales that require the interviewer to determine a score based on information shared during an intervention (e.g., CGAS), there is some utility in asking parents to rate the degree of functional impairment. A parent may consider information about the child beyond specific areas that were covered by the interview (and consequently unknown by the interviewer).
        - Some studies using the CGAS have the measure completed by both interviewers and parents. The parents' CGAS is typically better than interviewer's CGAS because the parent knows the level of impairment related to disorders excluded from the study or impairment due to behaviors not discussed during the interview.
    - Panel members cautioned that high impairment could be related to issues excluded from the SED definition (e.g., substance use disorder, developmental delay).
    - In young preschool children, teachers may be better reporters than parents as teachers have superior knowledge of the normative comparison group.
    - Youth reports of impairment would also be useful, but this would require instrument development work. Impairment measures are currently most often designed to be completed by parent or interviewer.
        - The child instrument adapted from the WHODAS has a version to be completed by children aged 11 years or older. Panel members indicated parent report

improves reliability over child report alone for this instrument; however, child report alone has sufficient reliability.

- **Recommendation:** Parent report of child impairment would be helpful (either in addition to interviewer ratings or instead of interviewer ratings).

Discussion Question 6: Where might instrument development work be necessary to meet the* Federal Register *criteria for SED?

- **Recommendations:**
  - Secondary data analysis is needed to compare CGAS ratings to those derived from multidimensional impairment scales (e.g., CIS/BIS).
    - There are analyses conducted from the Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) multisite study data that compare the CIS to the CGAS; but these use the CGAS as the gold standard. The data can to be re-analyzed using the CIS as the gold standard.
  - There are Puerto Rican data sets that include different impairment and diagnostic measures. In these datasets, the BIS has been shown to predict mental health service need and use better than diagnostic interviews (i.e., DISC).
  - The child instrument adapted from the WHODAS is still under development, but it could possibly be ready for an SED survey (that would begin later). One limitation would be that the Child WHODAS is longer than the CIS; however, its length is comparable to the BIS. Work is needed to analyze the data available on the child instrument adapted from the WHODAS to reduce the length and determine its psychometric properties.
  - Large datasets using the BIS could be used to identify "best performing" items to produce a shorter version and then test its validity.
  - Work is needed to operationalize "burden of illness" for preschoolers, because impairment would mostly be expressed through parent report.
  - Research is needed to better understand the cross cultural applicability of impairment measures. Even a well-translated instrument will have difficulties understanding impairment as it is understood so differently from one culture to the next.

IV. Screening Tools to Estimate National and State SED

Discussion Questions: Are there a set of screening items that have good predictive SED power? Can they be shortened for inclusion in a national large-scale epidemiological study or must they be maintained at the original length? If screening items have not been tested for their ability to predict SED, which screening tools are best suited to estimate SED within a national survey? Where might instrument development work be necessary?

- **Discussion Summary Points:**
  - Panel members suggested that the term "screening tool" may be a misleading here. The purpose of a scale here is not to identify specific children or cases but to identify a scale that can best predict SED for use in a statistical model.
  - This area lacks sufficient research to suggest one particular measure is "best" at predicting SED within a statistical model.
  - Panel members could not identify one particular screening instrument with strong data indicating its predictive SED power.
    - However, datasets exist to examine how well some of the screening instruments predict SED.
    - The Duke team has a data set with multiple diagnostic interviews and multiple screening measures that is well-suited for data mining. This dataset would allow identification of an optimal number of Strengths and Difficulties Questionnaire (SDQ) items or other instrument screening items (e.g., Child Behavior Checklist, Multidimensional Anxiety Scale for Children items) to predict SED as measured by a diagnostic interview. This dataset also includes younger children who have both SDQ and PAPA scores.
    - Other panel members also have data sets that can be used for analysis with the DISC and CAPA.
    - Studies similar to these have been completed with adults seen within Kaiser Permanente medical clinics. This research identified three items from the Sheehan Disability Scale that had the best predictive capacity for mental disorders (published by Andrew Leon).
  - For the youngest age groups, screening instruments usually measure social functioning, not psychopathology; however, the Brief Infant Toddler Social Emotional Assessment (BITSEA) may be a candidate screener for very young children.
  - Other possible screening instruments (e.g., Achenbach screener, DISC Predictive Scales) would be too long for integration into an existing, large-scale national survey.

- **Recommendation:** In general, panel members seemed to think the SDQ could be used in models to predict the possibility of having SED. This was due to its common use in epidemiological surveys worldwide; however, some instrumentation work will be necessary to determine which SDQ items have the greatest predictive SED power.

V. Mode of Administration

Discussion Questions: Which diagnostic interviews and impairment measures have been studied to understand the impact of administration mode (computer assisted personal interviewing (CAPI), computer-assisted telephone interviewing (CATI), audio computer-assisted self-interviewing (ACASI), paper and pencil/self-report)? Are certain modes not validated or recommended?

Can diagnostic tools and impairment measures be reliably administered by telephone? Are some more easily administered by telephone than others?

- **Discussion Summary Points:**
    - Although the substance abuse field has some research on the impact of mode of data collection on prevalence estimates; relatively less work has been done in the field of mental health.
        - One review by Myrna Weisman of Columbia University compared telephone interviews with paper-and-pencil interviews. Another study conducted by Lewinsohn with adolescents compared in person to telephone interviews.
    - There is not enough information in the field to provide clear answers to determine the "best" administration mode for diagnostic interviews, impairment measures, and screening instruments.
    - Audio computer-assisted self-interview (ACASI) versions of the DISC have been widely used with juvenile justice populations (aged 11 to 18 years). In the juvenile justice setting, ACASI versions are preferred by juveniles over an in-person interview.
    - There is research to suggest that people admit to more socially undesirable behaviors with ACASI than in person interviews.
    - The DISC, a respondent-based instrument, might be easier to administer phone; however interview length might be an issue for telephone administration. Many diagnostic interviews in their current forms may take too long.
    - Panel members suggested that it may be difficult to determine at what age a child can be interviewed successfully by telephone versus in person. It will not be feasible to interview younger children by phone.
    - Some scales will be easily administered by phone. Others, particularly those with multiple response options, will be highly challenging to administer by phone.
        - Panel suggested sending a packet ahead of telephone interviews that have cards with response categories printed.

- **Recommendation:** Panel members did not feel comfortable making a recommendation around administration mode.

Discussion Question 3: What are the implications of administration mode (telephone versus in-person) for prevalence estimates?

- **Discussion Summary Points:**
    - In some juvenile subpopulations, ACASI administration actually takes a longer time than with in-person interviews. Some panel members have observed that youths appear to be thinking more about individual questions on the computer rather than rushing through questions during an in-person interview.
    - ACASI administration has the advantage of using a platform (online, computer) within which youths are accustomed to disclosing personal issues.

        - Panel commented on youth preferences to communicate via text, Facebook, and other online platforms instead of in person, as well as the challenge of locating youths when they are changing cell phone cards monthly.
    - Panel members suggested that ACASI administration could be feasible once children have learned to read.
    - Panel members expressed caution on the use of telephone interviews due to the potential underrepresentation of high-risk, low-income minority populations that do not have stable telephones or cell phones.
    - Privacy issues were also a concern for panel members considering telephone administration of diagnostic interviews.

- **Recommendation:** Panel members stressed the need to look beyond survey administration mode to consider more broad study design issues. What type of design will assure that the public (and state administrators) will accept SED estimates as useful and valid? This will require a representative study with the highest possible response rates. Panel members questioned whether an adequately representative sample with high response rates could be obtained from a telephone instead of a household survey.

VI. Issues Related to Measuring SED among Children Aged 0 to 22 Years

Discussion Question 1: What are the developmental and methodological implications of possibly extending the age range for SED to 18 to 22 year olds?

- **Discussion Summary Points:**
    - A 0 to 22 year old age range will require the use different instruments across the age span due to differences in which questions are the most appropriate for different ages. For example, questions designed for young adults will not work for children (and vice versa).
    - The number of reporters across this age span will also vary—likely parent report only for children under 9 or 11 years old, both parent and youth reports for children 11 to 17, and only young adult reports for those 18 or older.
    - Meta-analysis could determine expected variations in prevalence estimates of mental health disorders by age group and number of reporters, but even so, most of the studies are not nationally representative.
    - Natural progressions in the prevalence of mental disorders exist across different age groups. For instance, there are dramatic increases in depression from 6 to 18 years old. These types of estimate changes should be expected and not assumed to be exclusively due to methodological differences in study design for different age groups. However, sudden, nontrendable differences at the "seam" (i.e., at the age where a different instrument was being used) are likely to be related to the difference in instrument and other methodological differences.

- **Recommendation:** SAMHSA might want to consider conducting sub-studies to examine how estimates change based on the availability of one versus two reporters.
- **Recommendation:** SAMHSA should take caution in providing one central, integrated estimate of SED across this wide age range (where estimation methodologies will differ).

Discussion Question 2: What is the youngest age at which SED can be validly and reliably assessed?

- **Discussion Summary Points:**
    - SED can be measured beginning at 2 years old; however, the measurement of mental disorders and impairment is still emerging in very young children. Psychometric studies are in the midst of being conducted.
    - Beginning at 4 years, there are child report instruments that are developmentally appropriate for reporting psychiatric symptoms. The PAPA parent diagnostic interview also begins at the age of 4 years.

Discussion Question 3: If complementary instruments do not exist to cover this entire age range, how can comparable prevalence estimates be best generated?

- **Discussion Summary and Recommendations:**

    - Completely comparable estimates of SED may not be feasible. One common set of measures and one common survey method will not exist for children, youths, and young adults from 0 to 22 years old.
    - Panel members suggested an alternative to providing one central estimate of SED from 0 to 22 years old. SAMHSA might want to consider providing age group-specific prevalence estimates (0 to 5 or 2 to 5, 6 to 11, 12 to 18, 19 to 22 years), even though they would not be comparable. This may be especially helpful in state service planning as interventions and service sectors differ across these age groups.

Serious Emotional Disturbance (SED) Expert Panel 2 Meeting Participants

November 12, 2014

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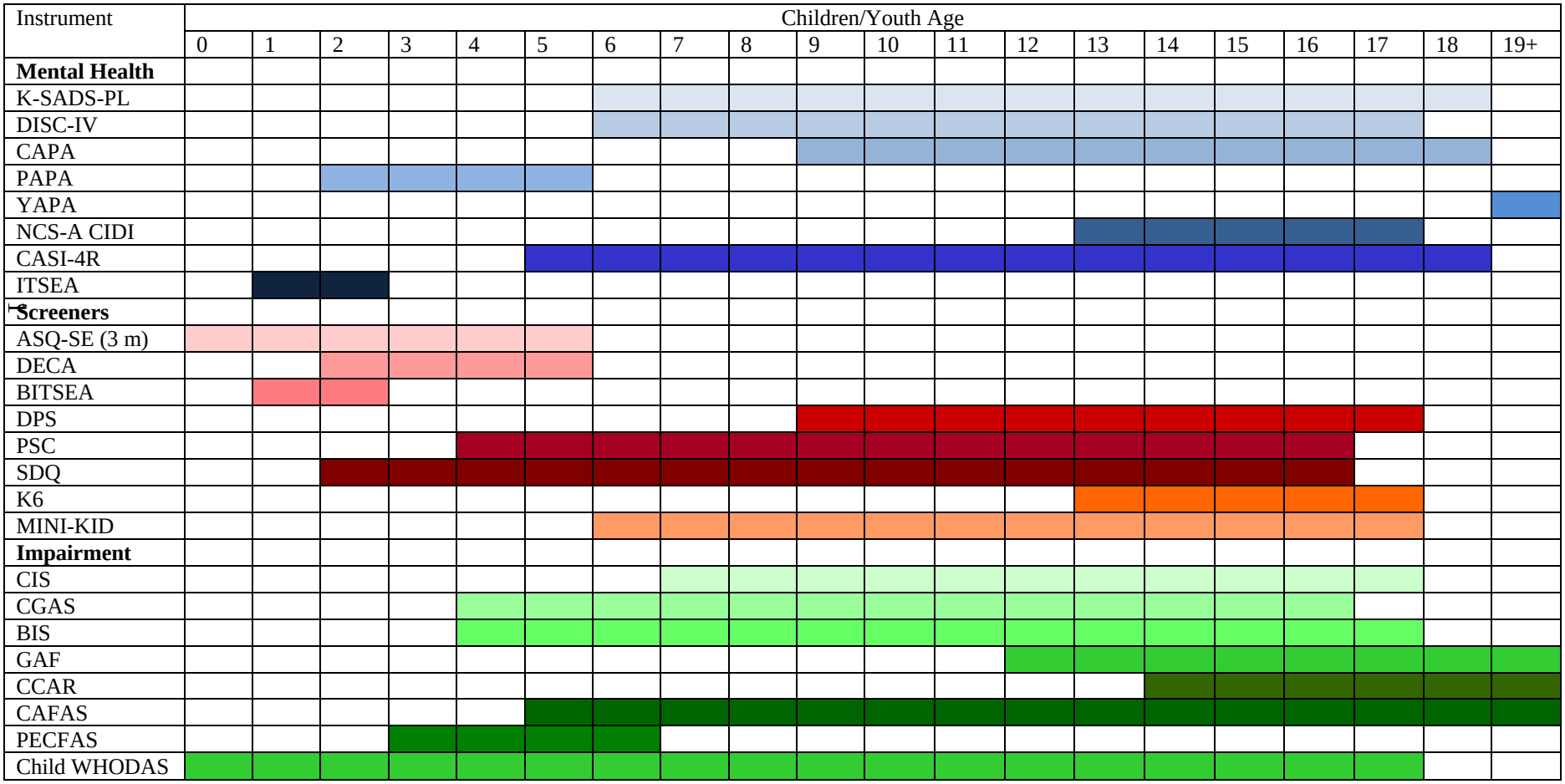
Appendix C: Summary Age Coverage by Instrument

Summary Age Coverage by Instrument

Diagnostic Instruments/Interviews for Child Mental Health Assessment: Blue

Screeners: Red

Impairment: Green



Diagnostic Mental Health: CAPA = Child and Adolescent Psychiatric Assessment; CGAS = Children's Global Assessment Scale; CIDI = Composite International Diagnostic Interview; CIS = Columbia Impairment Scale; DISC-IV = Diagnostic Interview Schedule for Children Version IV; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders IV; GSMS = Great Smoky Mountain Study; ICD-10 = International Classification of Diseases 10; ITSEA = Infant Toddler Social Emotional Assessment; K-SADS = Kiddie-Schedule of Affective Disorders and Schizophrenia; MECA = Methods for the Epidemiology of Child and Adolescent Mental Disorders; MEPS = Medical Expenditures Panel Survey; MH = mental health; NCS-A = National Comorbidity Survey Replication Adolescent Supplement; NHANES = National Health and Nutrition Examination Survey; NHIS = National Health Interview Survey; PAPA = Preschool Age Psychiatric Assessment; SDQ = Strength and Difficulties Questionnaire.

Screeners: ASQ:SE = Ages and Stages Questionnaires: Social-Emotional; BITSEA = Brief Infant Toddler Social Emotional Assessment; DECA = Devereux Early Childhood Assessment Program; DPS = DISC Predictive Scales; MINI-KID = Mini International Neuro-psychiatric Interview for Children and Adolescents; PSC = Pediatric Symptom Checklist; SDQ = Strength and Difficulties Questionnaire.

Impairment: BIS = Brief Impairment Scale; CAFAS and PECFAS = Child and Adolescent Functional Assessment Scale or Preschool and Early Childhood Functional Assessment Scale; CGAS = Children's Global Assessment Scale; CIS = Columbia Impairment Scale; CCAR = Colorado Client Assessment Record; GAF = Global Assessment of Functioning; ICF-CY International Classification of Functioning, Disability and Health-Children and Youth version; Child WHODAS = World Health Organization Disability Assessment Schedule; LOF = Level of Functioning Scale.

Appendix D: Measurement Tools Checklist

		Time	Validation			Mode		Interviewer Training		Terms of Use				
	DSM-5	Less than 50 Minutes	Independent Validation	Validity in National Population	Spanish Version Validated	CATI	ACASI	Lay Interviewers	Clinical Interviewers	Cost to Use	Items Proprietary—Can't Be Included in the Files	Need Permission to Modify	Requires Certification	Cost of Certification
Diagnostic Instruments														
DISC			√	√	√	√		√		√	√	√		
CAPA			√		√	√		√			√	√	√	
PAPA			√		√	√		√			√	√	√	
YAPA								√			√	√	√	
K-SADS	√			√		√			√		√	√	√	
CIDI-A			√	√		√		√			√	√	√	√
ITSEA			√	√						√	√	√		
Impairment Measures														
Columbia Impairment Scale		√	√	√				√				√		
CGAS		√	√		√			√			√	√		
Brief Impairment Scale		√	√					√			√	√		
WHODAS Child	√	√						√			√	√		
SED Predicting Items														
Pediatric Symptom Checklist		√	√		√	√		√			√	√		
DISC Predictive Scales		√	√		√			√		√	√	√		
SDQ – 25 items		√	√			√		√			√	√		
K6 for SED		√	√			√	√	√			√	√	√	√
MINI-KID		√	√						√	√	√	√	√	√
BITSEA		√	√					√		√	√	√		

ACASI = audio computer-assisted self-interviewing; BITSEA = Brief Infant Toddler Social Emotional Assessment; CAPA = Child and Adolescent Psychiatric Assessment; CATI = computer-assisted telephone interviewing; CGAS = Children's Global Assessment Scale; Child WHODAS = World Health Organization Disability Assessment Schedule; CIDI-A = Composite International Diagnostic Interview–Adolescent; DISC = Diagnostic Interview Schedule for Children; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition; ITSEA = Infant Toddler Social Emotional Assessment; K6 = Kessler 6-item Psychological Distress Scale; K-SADS = Kiddie-Schedule of Affective Disorders and Schizophrenia; MINI-KID = Mini International Neuro-psychiatric Interview for Children and Adolescents; PAPA = Preschool Age Psychiatric Assessment; SDQ = Strength and Difficulties Questionnaire; SED = serious emotional disturbance; YAPA = Young Adults Psychiatric Assessment.

Appendix E: Diagnostic Instruments/Interviews for Child Mental Health Assessment

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded That Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
K-SADS-PL 2009 Joan Kaufman, David Axelson, Boris Birmaher, Jamie Zelazny, and Mary Kay Gill	6–18 years	• Child (6–18) • Parent • One study used parent report for children 2–5 (good validity compared to PAPA) (Birmaher et al., 2009)	• Clinician • validated mode: in-person semi-structured interview (Kaufman et al., 1997) • Trainer: http://www.psychiatry.pitt.edu/node/8233	For in-person interview: • 1.5 hours child • 1.5 hours parent	• Semi-structured interview • (82-item screener available) Items scored 0 = no information, 1 = symptom not present, 2 = subthreshold symptomatology, 3 = threshold criteria • PAPI in-person validation. • Spanish version not updated. No validation in Spanish • CAPI version available but not validated.	• Affective • Anxiety • Behavioral • Eating • Psychotic • Substance abuse	• DMDD • Selected mutism • Reactive attachment disorder	• Lifetime • Past year (worst episode) • Considered current if not symptom-free for past 2 months	• DSM-IV • Update: Interview is DSM-5 compatible. • Computer version under construction.	• NCS-A–assessed K-SADS convergent validity with CIDI • Oregon Adolescent Depression Project • Note: K-SADS has been administered by phone (Kessler et al., 2009)	• This instrument is copyrighted. • Needs written permission from Dr. Kaufman. • Instrument can be downloaded free (2009 and 1996 versions).	• Children's Global Assessment Scale (CGAS available at the end of the instrument). • An alternative measure of impairment could be used in addition to the CGAS.

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded That Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
DISC-IV Fisher, L. Lucas, C. Lucas, Sarsfield, and Shaffer	6–17 years	Child (9–17) Parent (of child 6–17)	• In-person, respondent-based interview • Trained lay interviewer (paper or computerized • ACASI version for youth 9–17 (except schizophrenia) • Validity: study of in-person interview included in MECA (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000) • Time: 1–2 hours for computer-assisted version, 4–5 hours for paper-and-pencil version	• In-person CAPI: 70 min. community samples, 90–120 min. clinical samples • ACASI youth 9–17: 90 min. clinical, 63 min. community	• Structured interview • Spanish version available for computerized version IV (Bauermeister et al., 2007) • CAPI validation in English and Spanish. • CATI validation in English. • ACASI validation in English. • No PAPI in-person validation. • No PAPI phone validation.	• Anxiety • Mood • Disruptive, • Schizophrenia • Behavior, • Substance use • Miscellaneous disorders • 30 disorders total	• DMDD • Reactive attachment disorder • Acute stress • Adjustment disorder • Binge eating • Sleep/wake disorders (symptoms only)	• Past year • Current (past 4 weeks) • Lifetime • Age at onset	• DSM-IV • ICD-10 • Update: Not DSM-5 compatible. • No updates planned, but it would be easy to do with some funding.	• MECA • NHANES • Puerto Rico island-wide probability • Household sample (N=1,886) (Bauermeister et al., 2007). • More than 30 different studies (including 8 large epi studies carried out in the United States and Puerto Rico).	• Computerized C-DISC-IV versions are copyrighted Columbia University. • There is a charge for the paper version of the NIMH-DISC-IV that covers copying and mailing expenses. • There is also a charge for the computerized version but it can be installed on multiple computers.	• Series of impairment questions after each diagnostic module. • Reliability and validity of the impairment ratings has generally not been examined independently (Rapee, Bogels, van der Sluis, Craske, & Ollendick, 2012)

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded That Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
CAPA Version 4.2 A. Angold, A. Cox, M. Prendergast, M. Rutter, and E. Simonoff	9–18 years	Child (9–18) Parent	• In-person, interviewer-based interview • Trained lay interviewer (at least bachelor degree) • Validity study with in-person interview (Angold & Costello, 2000) • emeasures@psych.duhs.duke.edu to arrange a training session and discuss the fee schedule	• In-person interview: 1+ hour parent • 1 + hour child	• Semi-structured interview • Spanish version 4.1 • PAPI in-person validation (forwards & backwards). • ACASI validation for parts of the interview.	• Anxiety • Obsessive compulsive • Mood • Somatization, • Food related disorders; • Sleep problems; • Elimination disorders, • Tic disorders, • Disruptive behaviors • psychotic • PTSD • adjustment • substance	none	• Lifetime • Current (past 3 months) • Age at onset	• DSM-IV • DC:0–3 • Update: Scoring algorithms will be updated.	• GSMS • SDQ Pilot study	• Requires collaboration with instrument developer (Duke University staff) and letter of copyright approval from Dr. Angold. • No charge for use of pencil paper version. • All CAPA scoring algorithms proprietary to Duke University.	Impairment module is done at the end of the interview, and could be swapped out for a different impairment instrument.

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded That Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
PAPA Helen Egger, MD; Barbara Ascher, MA; and Adrian Angold	2–5 years	Parent	• In-person, interviewer-based interview. • Mode reliability: in-person interview • Trained lay interviewer (at least bachelor degree) • Training: 1–2 weeks classroom, 1–2 weeks practice • Request: emeasures@psych.duhs.duke.edu to arrange a training session and discuss the fee schedule	• 1 hour parent • 2 hours child	• Semi-structured interview. • Spanish version. • PAPI in-person validation English version. • CAPI and ACASI are not typical for small children. • CATI not validated.	• Anxiety • OCD • Sleep behaviors • Elimination problems • Somatization • Accidents • ODD/CD • ADHD • Separation anxiety • Anxious affect • Worries; • Rituals and repetitions • Tics; • Stereotypes • Reactive Attachment • Depression • Mania • Dysregulation • PTSD	None	• Current (past 3 months) • Lifetime for some symptoms • Age at onset	• DSM-IV • DC:0–3 • Update: Scoring algorithms will be updated.	• Birth cohorts Norway (N=995) (Wichstrom, Belsky, Jozefiak, Sourander, & Berg-Nielsen, 2014)	• Requires collaboration with instrument developer (Duke University staff) and letter of copyright approval from Dr. Egger. • No charge for use of pencil paper version. • Certification required to use in field. • All PAPA scoring algorithms (diagnoses for DSM-IV, DC:0–3, ICD-10) are proprietary to Duke University.	• Impairment component for young children settings (family, day care). • Impairment module could be switched out for a different impairment measure.

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded that Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using this Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
YAPA Version 2.0.3 (2009) A. Angold, A. Cox, M. Prendergast, M. Rutter, and E. Simonoff	19–21 years	Young adult	• In-person, interviewer-based interview (Copeland, Shanahan, Costello, & Angold, 2011) • Trained lay interviewer (at least bachelor degree) • emeasures@psych.duhs.duke.edu to arrange a training session and discuss fee	• In-person interview: 1 hour parent • 1 hour child	• Semi-structured interview. • No Spanish version. • No independent validations for any modes. • YAPA is the only young adult scale extended up from validated child instruments.	• ADHD • Agoraphobia • Substance disorders • CD • Depression • Generalized anxiety • ODD • Panic disorder • PTSD • Separation anxiety • Social phobia • Specific phobia	• Same as CAPA – all the child disorders are included. • No adult disorders are included.	• Lifetime • Current (past 3 months) • Age at onset	• DSM-IV • Update: Scoring algorithms will be updated.	GSMS	• Requires collaboration with instrument developer (Duke University staff) and letter of copyright approval from Dr. Angold. • No charge for use of pencil paper version. All CAPA scoring algorithms are proprietary to Duke University.	• Extensive impairment module tailored to the young adult age group. • Could not be swapped out for any other existing impairment scale, because it is specific to young adults.

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded that Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using this Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
NCS-A CIDI R.C. Kessler, S. Avenevoli, J. Green, M.J. Gruber, M. Guyer, Y. He, R. Jin, J. Kaufman, N.A. Sampson, A.M. Zaslavsky, and K.R. Merikangas	13–17 years	Child (13–17) Parent	• In-person interview by trained lay interviewer • Validated via PAPI, CIDI compared to K-SADS, N= 347), with K-SADS administered by phone (Kessler et al., 2009). • NCS-A CIDI conducted in English only. • Training: on-site at Univ. Mich. • Contact http://www.hcp.med.harvard.edu/ncs/summerTraining.php	• 2–3 hours child • Also available: • Shorter parent instrument • CIDI short form stem questions require about 45 minutes	• Structured interview • Short version of 159 symptom questions. • Paper-and-pencil and computer-administered forms. • Spanish version has not been validated. • CATI was validated against the K-SADS.	• Mood • Anxiety • Disruptive behavior • Substance use • Anorexia/ bulimia/ • Binge eating disorders • Neurasthenia • Suicidality • 19 total	• Additional instrument needed for psychosis: WMH SCID 2000 • Excluded: • DMDD • Selective mutism • Panic attack • Obsessive compulsive • Reactive attachment • Acute stress • Adjustment disorder • Sleep wake disorders • Elimination disorders	• Lifetime • Past year	• DSM-IV • ICD-10 • Update: None planned.	• NCS-A • In-person interview (N=10,148) (Kessler et al., 2009)	• All instruments posted but training is required by WHO CIDI. • Contact: • Training and Reference Center University of Michigan, Beth Pennell bpennell@umich.edu • Training for PAPI, CAPI (plus Blaise program). Both include SAS programs for DSM-IV and ICD-10 diagnoses.	• Expanded version of the Sheehan Disability Scale after each diagnostic module to assess overall level of impairment associated with a disorder.

Table 1. Diagnostic Instruments/Interviews for Child Mental Health Assessment (continued)

Instrument	Age	Informant	Administered by	Time	Format	Diagnostic Coverage	Disorders Excluded That Are Part of SED	Diagnostic Time Frame	Diagnostic Criteria/ DSM-5 Update Plans	Studies Using this Instrument	Data Dissemination Issues/ Proprietary	Impairment Component
ITSEA A.S. Carter and M.J. Briggs-Gowan	12–36 mo.	Parent/child-care Provider	• Self-administered • Validity of self-administered ITSEA compared to CBCL and PSI in U.S. birth cohort (Carter, Briggs-Gowan, Jones, & Little, 2003), The Netherlands (clinical sample) (Visser et al., 2010), China (Urban sample N=5,323) (Jianduan et al., 2009)	• Parent and child care provider: 25–30 minutes	• 166 items • 3-point scale: 0 = Not true/rarely, 1 = Somewhat true/ sometimes, 2 = Very true/often • Standardized scores (range 0–100)	4 broad domains, 17 specific subscales, and 3 index scores: • Externalizing (Impulsivity, aggression, defiance) • Internalizing (depression, general anxiety, separation distress, inhibition) • Dysregulation (sleep, eating, sensory) • Competence	• ADHD • Psychotic disorders • Bipolar • OCD • Trauma disorders • Elimination disorders	Last month	• Items reflect symptoms included in diagnostic criteria of DC:0–3 • DSM-IV	• Birth Cohort Study (Yale, N=1,235, children 12–36 months) (Carter et al., 2003) • Clinical studies: outpatient university clinic, The Netherlands (N=85). (Visser et al., 2010)	• Copyrighted • Cost: ITSEA kit $182 • http://www.harcourtassessment.com/ • http://www.pearsonclinical.com/education/products/100000652/infant-toddler-social-emotional-assessment-itsea.html	

ACASI = audio computer-assisted self-interviewing; ADHD = attention-deficit/hyperactivity disorder; CAPA = Child and Adolescent Psychiatric Assessment; CAPI = computer-assisted personal interviewing; CATI = computer-assisted telephone interviewing; CBCL = Child Behavior Checklist; CD = conduct disorder; CGAS = Children's Global Assessment Scale; CIDI = Composite International Diagnostic Interview; CIS = Columbia Impairment Scale; DISC-IV = Diagnostic Interview Schedule for Children Version IV; DMDD = disruptive mood dysregulation disorder; DSM-IV = *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition; DSM-5 = *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition; GSMS = Great Smoky Mountain Study; ICD-10 = International Classification of Diseases 10; ITSEA = Infant Toddler Social Emotional Assessment; K-SADS = Kiddie-Schedule of Affective Disorders and Schizophrenia; MECA = Methods for the Epidemiology of Child and Adolescent Mental Disorders; MEPS = Medical Expenditures Panel Survey; MH = mental health; NCS-A = National Comorbidity Survey Replication Adolescent Supplement; NHANES = National Health and Nutrition Examination Survey; NHIS = National Health Interview Survey; OCD = obsessive-compulsive disorder; ODD = oppositional defiant disorder; PAPA = Preschool Age Psychiatric Assessment; PAPI = paper-and-pencil interviewing; PSI = Parenting Stress Index; PTSD = posttraumatic stress disorder; SDQ = Strength and Difficulties Questionnaire; WHO = World Health Organization; WMH SCID = World Mental Health Structured Clinical Interview for DSM-IV Axis I Disorders; YAPA = Young Adults Psychiatric Assessment.

References

Angold, A., & Costello, E. J. (2000). The Child and Adolescent Psychiatric Assessment (CAPA). *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(1), 39-48. doi: 10.1097/00004583-200001000-00015

Bauermeister, J. J., Shrout, P. E., Ramirez, R., Bravo, M., Alegria, M., Martinez-Taboas, A., . . . Canino, G. (2007). ADHD correlates, comorbidity, and impairment in community and treated samples of children and adolescents. *Journal of Abnormal Child Psychology, 35*(6), 883-898. doi: 10.1007/s10802-007-9141-4

Birmaher, B., Ehmann, M., Axelson, D. A., Goldstein, B. L., Monk, K., Kalas, C., . . . Brent, D. A. (2009). Schedule for affective disorders and schizophrenia for school-age children (K-SADS-PL) for the assessment of preschool children - A preliminary psychometric study. *Journal of Psychiatric Research, 43*(7), 680-686. doi: 10.1016/j.jpsychires.2008.10.003

Carter, A. S., Briggs-Gowan, M. J., Jones, S. M., & Little, T. D. (2003). The Infant-Toddler Social and Emotional Assessment (ITSEA): Factor structure, reliability, and validity. *Journal of Abnormal Child Psychology, 31*(5), 495-514. doi: 10.1023/a:1025449031360

Copeland, W., Shanahan, L., Costello, E. J., & Angold, A. (2011). Cumulative Prevalence of Psychiatric Disorders by Young Adulthood: A Prospective Cohort Analysis From the Great Smoky Mountains Study. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(3), 252-261. doi: 10.1016/j.jaac.2010.12.014

Jianduan, Z., Huishan, W., Shuhua, S., Xiaonan, H., Guoyan, L., Guangli, L., & Junxin, S. (2009). Reliability and validity of standardized Chinese version of Urban Infant-Toddler Social and Emotional Assessment. *Early human development, 85*(5), 331-336. doi: 10.1016/j.earlhumdev.2008.12.012

Kaufman, J., Birmaher, B., Brent, D., Rao, U., Flynn, C., Moreci, P., . . . Ryan, N. (1997). Schedule for Affective Disorders and Schizophrenia for School-Age Children Present and Lifetime version (K-SADS-PL): Initial reliability and validity data. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*(7), 980-988. doi: 10.1097/00004583-199707000-00021

Kessler, R. C., Avenevoli, S., Green, J., Gruber, M. J., Guyer, M., He, Y., . . . Merikangas, K. R. (2009). National Comorbidity Survey Replication Adolescent Supplement (NCS-A): III. Concordance of DSM-IV/CIDI Diagnoses With Clinical Reassessments. *Journal of the American Academy of Child and Adolescent Psychiatry, 48*(4), 386-399. doi: 10.1097/CHI.0b013e31819a1cbc

Rapee, R. M., Bogels, S. M., van der Sluis, C. M., Craske, M. G., & Ollendick, T. (2012). Annual Research Review: Conceptualising functional impairment in children and adolescents. *Journal of Child Psychology and Psychiatry, 53*(5), 454-468. doi: 10.1111/j.1469-7610.2011.02479.x

Shaffer, D., Fisher, P., Lucas, C. P., Dulcan, M. K., & Schwab-Stone, M. E. (2000). NIMH Diagnostic Interview Schedule for Children Version IV (NIMH DISC-IV): Description, differences from previous versions, and reliability of some common diagnoses. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*(1), 28-38. doi: 10.1097/00004583-200001000-00014

Visser, J. C., Smeekens, S., Rommelse, N., Verkes, R. J., Van der Gaag, R. J., & Buitelaar, J. K. (2010). Assessment of psychopathology in 2- to 5-year-olds: applying the Infant-Toddler Social Emotional Assessment. *Infant Mental Health Journal, 31*(6), 611-629. doi: 10.1002/imhj.20273

Wichstrom, L., Belsky, J., Jozefiak, T., Sourander, A., & Berg-Nielsen, T. S. (2014). Predicting Service Use for Mental Health Problems Among Young Children. *Pediatrics, 133*(6), 1054-1060. doi: 10.1542/peds.2013-3184

Appendix F: Mental Health Tools to Predict SED in Statistical Models

Table 2. Mental Health Tools to Predict SED in Statistical Models

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
ASQ:SE Jane Squires Dianne Bricker Elizabeth Twombly	•Parent-completed questionnaire that is designed to identify children in need of additional assessment. Personal-social areas assessed include self-regulation, communication, autonomy, coping, and relationships. •Items: Varies from 21–32 items, depending on age.	Empirically derived cut-off scores that indicate whether a child needs additional evaluation	3–66 months (5.5 years)	Paper and pencil 10–15 minutes	Parent	•Self-administered paper and pencil •Web-based screening options •http://www.brookespublishing.com/resource-center/screening-and-assessment/asq/asq-online/	Available through publisher http://www.brookespublishing.com/resource-center/screening-and-assessment/ asq/asq-se/	•Copyrighted •Kit of 8 age-related questionnaires •Starter Kit cost: English $225, Spanish $225 •Practice DVD: $50	Unknown	NA
DECA Paul A. LeBuffe Jack A. Naglieri	•Screening instrument designed to assess 27 positive behaviors and 10 problem behaviors. Behaviors are rated as occurring “never,” “rarely,” “occasionally,” “frequently,” or “very frequently.” •Items: 37	Standardized scores are norm referenced.	2–5 years	Paper and pencil 10 minutes	Parent	Self-administered paper and pencil	Videos and technical manual for training available through publisher http://www.kaplanco.com/product/41009/the-devereux-early-childhood-assessment-deca-kit?c=17%7CEA1000	•Copyrighted •Kit cost: $199	Unknown	NA

Table 2. Mental Health Tools to Predict SED in Statistical Models (continued)

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
BITSEA Margaret Briggs-Gowan Alice S. Carter (Briggs-Gowan et al., 2013)	•Two scales: Problem Total Score and Competence Total Score •Items: 42	Standardized scores are norm referenced.	12–36 months	Self-administered: 7–10 minutes	Parent or child care provider	Self-administered	NA	•Copyrighted •BITSEA Kit cost: $166 •http://www.pearsonclinical.com/childhood/products/100000150/brief-infant-toddler-social-emotional-assessment-bitsea.html?Pid=015-8007-352	Unknown	NA
DISC Predictive Scales (DPS) David Shaffer Christopher Lucas Prudence Fisher (Lucas et al., 2001)	•Scales that screen for the presence of 18 DSM-IV diagnoses (including substance use disorders). Scales and related items are derived from a secondary analysis of a large epidemiological dataset containing responses to the full Diagnostic Interview Schedule for Children (DISC 2.3). •Items: 56	Screens for all the major mood and behavioral disorders as well as substance abuse.	9–17 years	10–20 minutes	•Parent •Youths	Self-administered paper and pencil, computer-assisted	Available through http://www.promotementalhealth.org/downloads/DISC%20Brochure.pdf	•Copyrighted •Use requires permission of test developer. •Software version cost: $250 per installation	The full DPS can be used to screen accurately for cases of specific DSM-III-R disorders (Lucas et al., 2001).	7 items for impairment that inquire about parent and teacher reactions to, and limitations resulting from, youths' feelings and behavior

Table 2. Mental Health Tools to Predict SED in Statistical Models (continued)

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
PSC Michael Jellinek Michael Murphy Sandra Bishop Maria Pagano	• Checklist that screens for mental health problems. It has been validated in other forms and translated into a number of languages. It is currently recommended for use in pediatric practices by the Bright Futures program. • Items: 35 • PBHS: comprises PSC-17, plus items on impairment (Blucker et al., 2014).	• Items on this tool are rated as "Never," "Sometimes," or "Often" and are scored as 0, 1, and 2, respectively. • Cut-off scores indicate further evaluation by mental health professional.	4–16 years	10–15 minutes	• Parent (of children 4 or older) • Youths (11 or older)	Self-administered paper and pencil	No information on training but authors can be contacted. http://psc.partners.org/psc_order.htm	Can be downloaded for free in English and Spanish.	Unknown	PBHS: 6 items on impairment for difficulties reported on PSC-17: • (1) upset or distress your child • (2) place a burden on you and your family • (3) interfere • with your child's home life • (4) interfere with your child's friendships • (5) interfere with your child's activities • (6) interfere with school or learning

Table 2. Mental Health Tools to Predict SED in Statistical Models (continued)

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
SDQ R. Goodman	•Brief questionnaire with versions for parent, youth, and teacher reports. Designed to identify the need for more in-depth assessment. •Items: 25 (parents and teachers child 4–16), 22 (parents and teachers 3–4), 25 youth. •A 5-item version of the SDQ was created specifically for use within the NHIS but does not have psychometric validation. •25-item version: published norms for nonclinical samples. strong psychometric properties (Goodman, 2001) •5-item version: no published studies of its psychometric properties	The 25 items are divided among 5 scales of 5 items each: •Emotional Symptoms Scale •Conduct Problems Scale •Hyperactivity Scale •Peer Problems Scale •Prosocial Scale	•3–16 years •Early years: 2–4 (as of June 2014)	•Paper and pencil •5 minutes (25-item) •2 minutes (5-item)	•Parent (3–16) •Youth (11–16) •Teacher (3–16) •5-item by parent report only	Self-administered paper and pencil	Manuals available through developer's Web site but no training available or contact information. http://www.sdqinfo.com/	Copyrighted All versions can be downloaded for free.	SDQ pilot calibration study	Impact supplement sets of additional questions to parents: problems on emotions, concentration, behavior, or being able to get on with other people. Total impact score by aggregating the distress scale and the four impairment scales. Includes burden rating based on item on child problems that are a burden to families. (Fuchs, Klein, Otto, & von Klitzing, 2013; Wille, Bettge, Wittchen, Ravens-Sieberer, & Grp, 2008)

Table 2. Mental Health Tools to Predict SED in Statistical Models (continued)

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
K6 Augmented for SED Ronald C. Kessler Alan Zaslavsky (Green, Gruber, Sampson, Zaslavsky, & Kessler, 2010; Kessler et al., 2010; Wittchen, 2010)	•K6 consists of 11 items that ask respondents how frequently they experienced symptoms of major depression, generalized anxiety disorder, ADHD, intermittent explosive disorder, and ODD along with two personality disorder items. •Items: 11	•Questions use the response options "never,""a little of the time," "some of the time," "most of the time," and "all of the time." •Responses are scored in the range 0–4, generating a scale with a range of 0–24.	13–17 years	Paper and pencil, computer assisted, or interview 5 minutes	Youth (13–17)	Face-to-face interview, paper and pencil, computer-assisted https://www.omh.ny.gov/omhweb/resources/providers/co_occurring/adult_services/screening.html	Contact: Harvard Medical School, Health Care Policy http://www.hcp.med.harvard.edu/publications/estimating-prevalence-of-serious-emotional-disturbance-in-schools-using-a-brief	•All instruments posted but training is required by WHO CIDI. •Contact: Training and Reference Center University of Michigan, Beth Pennell bpennell@umich.edu •Training for PAPI, CAPI (plus Blaise program) Both include SAS programs.	SED prevalence strongly correlated with aggregate K6 scores (rho = 0.70) and K6 augmented (Green et al., 2010; Li, Green, Kessler, & Zaslavsky, 2010)	NA

Table 2. Mental Health Tools to Predict SED in Statistical Models (continued)

Instrument	Description/Items	Scoring	Age Range	Time	Informant	Administered by/Mode	Interviewer Training	Data Dissemination Issues/Proprietary	Predictive Power for SED	Impairment Component
MINI-KID D.V. Sheehan K.H. Sheehan R.D. Shytle J. Janavs Y. Bannon J.E. Rogers K.M. Milo S.L. Stock B. Wilkinson (Sheehan et al., 1998; Sheehan et al., 2010)	• Short structured clinical diagnostic interview for DSM-IV and ICD-10 psychiatric disorders in children and adolescents. Organized in sections, each with 2–4 screening questions for each disorder. • Diagnostic criteria summarized for each disorder (24 psychiatric disorders and suicidality).	All questions yes/no.	6–17 years	In-person interview: 30 minutes	Children and youths accompanied by parent. (It can be used with child alone or with parent alone MINI-KID-P).	Face-to-face interview	• Requires limited training. • Medical Outcomes Systems 2560 Benjamin Road, Jacksonville, FL 32223 • Contact: Christopher Gray, President, Medical Outcomes Systems cgray@medical-outcomes.com	• Copyrighted. • Copyright holder: Dr. David Sheehan • In international clinical trial there was a charge of $5 per single administration. • Contact: Medical Outcomes Systems 2560 Benjamin Road, Jacksonville, FL 32223 • Contact: Christopher Gray, President, Medical Outcomes Systems cgray@medical-outcomes.com	Unknown	CGAS and Sheehan Disability Scale (SDS) used in study of concurrent validity and reliability of the MINI-KID, using as gold standard the K-SADS-PL (Sheehan et al., 2010)

ADHD = attention-deficit/hyperactivity disorder; ASQ:SE = Ages and Stages Questionnaires: Social-Emotional; BITSEA = Brief Infant Toddler Social Emotional Assessment; CAPI = computer-assisted personal interviewing; CIDI = Composite International Diagnostic Interview; DECA = Devereux Early Childhood Assessment Program; DISC = Diagnostic Interview Schedule for Children; DPS = DISC Predictive Scales; DSM-III-R = Diagnostic and Statistical Manual of Mental Disorders, 3rd Text Revision; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, 4th edition; ICD-10 = International Classification of Diseases 10; K6 = Kessler 6-item Psychological Distress Scale; K-SADS = Kiddie-Schedule of Affective Disorders and Schizophrenia; MECA MINI-KID = Mini International Neuro-psychiatric Interview for Children and Adolescents; NA = not applicable; NHIS = National Health Interview Survey; ODD = oppositional defiant disorder; PAPI = paper-and-pencil interview; PBHS = Pediatric Behavioral Health Screen; PSC = Pediatric Symptom Checklist; PSC-17 = Pediatric Symptom Checklist Brief Version; SED = serious emotional disturbance; SDQ = Strength and Difficulties Questionnaire; WHO = World Health Organization.

References

Blucker, R. T., Jackson, D., Gillaspy, J. A., Hale, J., Wolraich, M., & Gillaspy, S. R. (2014). Pediatric behavioral health screening in primary care: A preliminary analysis of the Pediatric Symptom Checklist-17 With Functional Impairment Items. *Clinical Pediatrics, 53*(5), 449-455. doi: 10.1177/0009922814527498

Briggs-Gowan, M. J., Carter, A. S., McCarthy, K., Augustyn, M., Caronna, E., & Clark, R. (2013). Clinical Validity of a Brief Measure of Early Childhood Social-Emotional/Behavioral Problems. *Journal of Pediatric Psychology, 38*(5), 577-587. doi: 10.1093/jpepsy/jst014

Fuchs, S., Klein, A. M., Otto, Y., & von Klitzing, K. (2013). Prevalence of Emotional and Behavioral Symptoms and their Impact on Daily Life Activities in a Community Sample of 3 to 5-Year-Old Children. *Child Psychiatry & Human Development, 44*(4), 493-503. doi: 10.1007/s10578-012-0343-9

Green, J. G., Gruber, M. J., Sampson, N. A., Zaslavsky, A. M., & Kessler, R. C. (2010). Improving the K6 short scale to predict serious emotional disturbance in adolescents in the USA. *International Journal of Methods in Psychiatric Research, 19,* 23-35. doi: 10.1002/mpr.314

Kessler, R. C., Green, J. G., Gruber, M. J., Sampson, N. A., Bromet, E., Cuitan, M., . . . Zaslavsky, A. M. (2010). Screening for serious mental illness in the general population with the K6 screening scale: results from the WHO World Mental Health (WMH) survey initiative. *International Journal of Methods in Psychiatric Research, 19,* 4-22. doi: 10.1002/mpr.310

Li, F., Green, J. G., Kessler, R. C., & Zaslavsky, A. M. (2010). Estimating prevalence of serious emotional disturbance in schools using a brief screening scale. *International Journal of Methods in Psychiatric Research, 19,* 88-98. doi: 10.1002/mpr.315

Lucas, C. P., Zhang, H. Y., Fisher, P. W., Shaffer, D., Regier, D. A., Narrow, W. E., . . . Friman, P. (2001). The DISC Predictive Scales (DPS): Efficiently screening for diagnoses. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(4), 443-449. doi: 10.1097/00004583-200104000-00013

Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., . . . Dunbar, G. C. (1998). The Mini-International Neuropsychiatric Interview (MINI): The development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *Journal of Clinical Psychiatry, 59,* 22-33.

Sheehan, D. V., Sheehan, K. H., Shytle, R. D., Janavs, J., Bannon, Y., Rogers, J. E., . . . Wilkinson, B. (2010). Reliability and Validity of the Mini International Neuropsychiatric Interview for Children and Adolescents (MINI-KID). *Journal of Clinical Psychiatry, 71*(3), 313-326. doi: 10.4088/JCP.09m05305whi

Wille, N., Bettge, S., Wittchen, H. U., Ravens-Sieberer, U., & Grp, B. S. (2008). How impaired are children and adolescents by mental health problems? Results of the BELLA study. *European Child & Adolescent Psychiatry, 17,* 42-51. doi: 10.1007/s00787-008-1005-0

Wittchen, H. U. (2010). Screening for serious mental illness: methodological studies of the K6 screening scale. *International Journal of Methods in Psychiatric Research, 19,* 1-3. doi: 10.1002/mpr.316

Appendix G: Impairment Instruments

Table 3. Impairment Instruments

Instrument	Description/ Items	Age Range	Time	Informant	Impairment Domains	Diagnostic Time Frame	Administered by/Mode	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Measure Psychometrics
CIS Bird, H. Shaffer, D. Fisher, P. Gould, M. Staghezza, B. Chen, J. Hoven, C.	• Structured question-naire. • 13-item scale. Items on a 0 (no problem) to 4 (very bad prob) scale. • Range: 0–52	7–17 years	Mode self-report: 5 minutes	• Child • Parent	Global impairment on four dimensions: interpersonal relationships, psychopathological domains, functioning in job or school, and use of leisure time	Not specified	• Trained lay interviewers • Self-report (in large population-based surveys)	• Used in several mental health surveillance efforts and MEPS (Bell, Johnson, Myers, & Patrick, 2010; Fiks et al., 2012; Nagar, Sherer, Chen, & Aparasu, 2010; Saloner, Carson, & Le Cook, 2014) • Community-based studies: San Francisco Bay area (Hinshaw et al., 2012) • Case Control Study: suicidal adolescents (N=198, from Adolescent Health Study-Northwest, N=2,291) (McCarty et al., 2011) • Clinic-based studies: 2 inpatient and 5 outpatient centers in Arkansas and Texas (N=258) (Kramer et al., 2004)	Free for download	• Strong psychometric properties parent version reported by author (Bird et al., 1993). • Child version factor analysis: three-factor model of functional impairment (at school/work, in socializing, at home) (Singer, Eack, & Greeno, 2011).
CGAS Shaffer, D. Gould, M. Brasic, J. Ambrosini, P. Fisher, P. Bird, H. Aluwahlia, S. (Parent) (PIC-GAS) in Spanish (Bauermeister et al., 2007; Chavez et al., 2014)	• Single scale with a range of 1–100. • 10 anchor points with simplified descriptions for lay interviewer	4–16 years	No administration time because it is based on prior clinical assessment; 5 minutes to generate score	Clinician-trained lay inter-viewer	Unidimensional global measure of social and psychiatric functioning	Not specified (e.g., past 2 weeks) (Mendenhall et al., 2011)	Clinician-trained lay interviewer	• Not used by any of the large child epidemiological studies reviewed • Community-based studies: Brook University, families N=462) (Dougherty et al., 2014) • Clinic-based studies: mental health clinics (N=106) (Brammer & Lee, 2012); outpatient clinics (LAMS Study, N=621) (Mendenhall et al., 2011); meta-analysis (435 RCT; review study: CGAS most common (Becker, Chorpita, & Daleiden, 2011) • Case-control studies: child psychiatry outpatient compared to general pediatric clinic on ODD DSM-IV to DSM-5 changes (N=223) (Keenan, 2012); Adolescents with early onset schizophrenia and healthy control (N=52) (Cervellione, Burdick, Cottone, Rhinewine, & Kumra, 2007) • International: Ireland (case/control, N=106) (Wigman et al., 2014), Newcastle-England random schools sample (N= 1051) (McArdle, Prosser, & Kolvin, 2004)	Free for download	• Validity: significant correlations with CBCL and other instruments • One study reported high reliability between raters and discriminant and concurrent validity (Shaffer et al., 1983)

Table 3. Impairment Instruments (continued)

Instrument	Description/ Items	Age Range	Time	Informant	Impairment Domains	Diagnostic Time Frame	Administered by/Mode	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Measure Psychometrics
BIS Bird, H. Canino, G. Davies, M. Ramirez, R. Chavez, L. Duarte, C. (Bird et al., 2005)	23 items	4-17 years		Parents	• Global measure with three domains: • Interpersonal relations (parents, siblings, peers) • School/work (attendance, performance) • Self-fulfillment (sport, hobbies, enjoyment) (Rapee, Bogels, van der Sluis, Craske, & Ollendick, 2012)	Last 12 months	Clinician	• Puerto Rico island-wide probability • Household sample (N=1,886) (Bauermeister et al., 2007)	• Copyrighted • Free for download	The BIS has high internal consistency (0.81–0.88) and test-retest reliability (0.70) as measured by the intraclass correlation coefficient (ICC) as reported by author. The scale has also shown good concurrent and convergent validity (Bird et al., 2005).
GAF (used for SED impairment in Kentucky, Idaho, North Dakota, Texas) (Hodges & Gust, 1995)	• 10 items • Range: 1–100 • 10 anchor descriptions • GAF is the research equivalent of CGAS	Primarily adults, with some examples for children		Clinician	• Unidimensional, Global impairment (DSM-IV Axis V). • Single score describing the overall functioning of the individual across psychological, social, and occupational (school) domains.	Not specified	Clinician	• 1997 CPSS administered by CMHS (nationally representative survey N=296,755. Subsample Adolescents 12–17, N=2,412) (Warner, 2006) • Community Studies: Clinical sample in Manoa, Hawaii (N=617) (Francis, Ebesutani, & Chorpita, 2012) • CAFAS/GAF comparisons suggest that CAFAS scores show that children with externalizing symptoms have significantly higher levels of functional impairment and higher rates of SED	Free for download	• Moderate internal consistency (Hall, 1995)(Hall, 1995) • Concurrent validity: correlations with measures of support needs (Jones et al., 1995)(Jones, Thornicroft, Coffey, & Dunn, 1995) and severity of depression (Hall, 1995)(Hall, 1995); moderate levels of interrater agreement, cited by Francis et al. (2012)

Table 3. Impairment Instruments (continued)

Instrument	Description/ Items	Age Range	Time	Informant	Impairment Domains	Diagnostic Time Frame	Administered by/Mode	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Measure Psychometrics
CCAR (used for SED impairment in Colorado and other states) (Hodges & Gust, 1995)	• Checklist of 77 items for personal problems profile • Functioning scores from 1 to 50 (extreme dysfunction) • Examples for adults and children	• Adults and children • Better suited for age 14 or older		Clinician	• Multidimensional • No global score, each content domain receives a functional score • Nine content domains: mood, thinking, physical, substance use, family, role performance, socio/legal, and self-care	Prior 3 weeks	Clinician	From official website: "The Colorado client assessment record—CCAR was developed over 25 years ago, and is used in Arizona, Delaware, Florida, Wyoming, and Canada. As a result of its extensive use over time, it is a well-tested instrument, with high inter-rater reliability. In Colorado, the CCAR has been required on all Admissions and Discharges to the Colorado Public Mental Health System since 1978."	Contact: http://www.colorado.gov/cs/Satellite/CDHS-BehavioralHealth/CBON/1251581450335	
CAFAS and PECFAS Functional Assessment Systems (used for SED impairment in Arizona, New Hampshire, North Carolina, Wisconsin) (Hodges & Gust, 1995) By 2001, more than 20 states were using it (Bates, 2001)	• 97 items over 8 scales. Item categories 0 (average) to 30 (severe) • Range 0–240 • 2 subscales on caregiver to assess degree of impairment due to child problems	• CAFAS: 5–19 years • PECFAS: 3–7 years	10 minutes	Parents	• Multidimensional (domain specific) • CAFAS: 8 subscales child: school/work, home, community, behavior toward others, moods/emotions, substance use, self-harm, and thinking • PECFAS: 7 subscales (all minus substance abuse) • 2 subscales: caregiver: basic needs and family/social support.	Varies, typically ranging from previous 1–3 months	• Clinician/lay interviewer (agencies state staff) • Web-based instrument • Telephone interview available	• Clinic-based studies: Clinical sample in Manoa, Hawaii (N=617) (Francis et al., 2012); clinical sample in Idaho (N=135) (Williams, 2009) • As reported by Bates et al. (2006): "The CAFAS has been and continues to be used in federal and local programs, such as the Fort Bragg Evaluation Project (FBEP) (Bickman, 1996; Lambert, Salzer, & Bickman, 1998) and the CMHS children's mental health system of care initiative (Center for Mental Health Services 1999; Friesen, Giliberti, Katz-Leavy, Osher, & Pullmann, 2003), and has been adopted by the Ministry of Children and Youth Services in the Canadian province of Ontario (Boydell, Barwick, Ferguson, & Haines, 2005)." (Bates, Furlong, & Green, 2006)	• Copyrighted • Contact: http://www2.fasoutcomes.com/Content.aspx?ContentID=12	• Validity reported by Francis et al. (2012): correlated with CGAS, CBCL, CAS • Good internal consistency (ranging from .63 to .78) and high interrater reliability Hodges & Wong (1996), cited by Francis et al. (2012)

Table 3. Impairment Instruments (continued)

Instrument	Description/ Items	Age Range	Time	Informant	Impairment Domains	Diagnostic Time Frame	Administered by/Mode	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Measure Psychometrics
Child WHODAS (based on ICF-CY) (Canino, Fisher, Alegria, & Bird, 2013)	• 34 items based on ICF-CY • Scores range from 0 to 100 (full disability) • Scoring followed a weighting system previously used with the adult version • At the end, participant provides overall rating interfere	• 0–17 years (Parents version) • • 12–17 years (Youth version)	20 minutes	• Parents • Youths • Clinician	• Domain specific and overall functioning (global disability score) • Domains: understanding and communicating, getting around (mobility), self-care, getting along, life activities, participating in society	Past 30 days	Self- or informant-administered	• WHODAS-Child currently undergoing field tests • For example: Rwanda trial (N=367) (Scorza et al., 2013)	• "Not yet available, but has been initiated in light of the growing importance of child and youth populations worldwide." • Contact: http://www.who.int/classifications/icf/whodasii/en/index6.html	The test-retest reliability of the new instrument and its acceptability and usefulness for clinical planning is presently being tested as part of the DSM-5 field trial in the United States (Canino et al., 2013).

Table 3. Impairment Instruments (continued)

Instrument	Description/ Items	Age Range	Time	Informant	Impairment Domains	Diagnostic Time Frame	Administered by/Mode	Studies Using This Instrument	Data Dissemination Issues/ Proprietary	Impairment Measure Psychometrics
ICF-CY	• The ICF-CY has 1,400 categories of functioning. • ICF Core Sets are shortlists of ICF categories.	Children and youths 0–19 years			Functional areas: learning and applying knowledge; general tasks and demands; communication, mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community/ social/civic life			Several ongoing WHO studies on ICF core sets of functioning/impairment for different diagnoses (e.g., ASD; see (Bolte et al., 2014); functional areas (meta-analysis multiple countries, children 3–19 years) (Adolfsson, 2013)		
Carter-Newman LOF (used for SED impairment in Montana, Nevada) (Hodges & Gust, 1995)	Nine brief definitions of level of functioning	Adults but used with children		Clinician	Global impairment based on relative contribution of four criteria: personal self-care, social, vocational or educational, emotional stability/stress tolerance levels of functioning	• Previous 24 hours for impatient • Previous week	• Clinician • No known training materials (Hodges & Gust, 1995)			None known

BIS = Brief Impairment Scale; CAFAS = Child and Adolescent Functional Assessment Scale; CAS = Cognitive Assessment System; CBCL = Child Behavior Checklist; CGAS = Children's Global Assessment Scale; Child WHODAS = World Health Organization Disability Assessment Schedule; CIS = Columbia Impairment Scale; CCAR = Colorado Client Assessment Record; CMHS = Center for Mental Health Services; CPSS = Client/Patient Sample Survey; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, 4th edition; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th edition; GAF = Global Assessment of Functioning; ICF-CY International Classification of Functioning, Disability and Health-Children and Youth version; LOF = Level of Functioning Scale; MEPS = Medical Expenditure Panel Survey; ODD = oppositional defiant disorder; PECFAS = Preschool and Early Childhood Functional Assessment Scale; RCT = randomized controlled trial; SED = serious emotional disturbance; WHO = World Health Organization.

References

Adolfsson, M. (2013). Applying the ICF-CY to identify children's everyday life situations: A step towards participation-focused code sets. *International Journal of Social Welfare, 22*(2), 195-206. doi: 10.1111/j.1468-2397.2012.00876.x

Bates, M. P. (2001). The Child and Adolescent Functional Assessment Scale (CAFAS): Review and current status. *Clinical Child and Family Psychology Review, 4*(1), 63-84. doi: 10.1023/a:1009528727345

Bates, M. P., Furlong, M. J., & Green, J. G. (2006). Are CAFAS subscales and item weights valid? A preliminary investigation of the Child and Adolescent Functional Assessment Scale. *Administration and Policy in Mental Health and Mental Health Services Research, 33*(6), 682-695. doi: 10.1007/s10488-006-0052-4

Bauermeister, J. J., Shrout, P. E., Ramirez, R., Bravo, M., Alegria, M., Martinez-Taboas, A., . . . Canino, G. (2007). ADHD correlates, comorbidity, and impairment in community and treated samples of children and adolescents. *Journal of Abnormal Child Psychology, 35*(6), 883-898. doi: 10.1007/s10802-007-9141-4

Becker, K. D., Chorpita, B. F., & Daleiden, E. L. (2011). Improvement in Symptoms Versus Functioning: How Do Our Best Treatments Measure Up? *Administration and Policy in Mental Health and Mental Health Services Research, 38*(6), 440-458. doi: 10.1007/s10488-010-0332-x

Bell, J. F., Johnson, M. L., Myers, K., & Patrick, D. L. (2010). Primary Health Care Quality in a National Sample of Children and Youth with Mental Health Impairment. *Journal of Developmental and Behavioral Pediatrics, 31*(9), 694-704. doi: 10.1097/DBP.0b013e3181f17b09

Bickman, L. (1996). A continuum of care - More is not always better. *American Psychologist, 51*(7), 689-701. doi: 10.1037//0003-066x.51.7.689

Bird, H. R., Canino, G. J., Davies, M., Ramirez, R., Chavez, L., & Duarte, C. (2005). The brief impairment scale (BIS): A multidimensional scale of functional impairment for children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 44*(7), 699-707. doi: 10.1097/01.chi.0000163281.41383.94

Bird, H. R., Shaffer, D., Fisher, P., Gould, M. S., Staghezza, B., Chen, J. Y., & Hoven, C. (1993). THE COLUMBIA-IMPAIRMENT-SCALE (CIS) - PILOT FINDINGS ON A MEASURE OF GLOBAL IMPAIRMENT FOR CHILDREN AND ADOLESCENTS. *International Journal of Methods in Psychiatric Research, 3*(3), 167-176.

Bolte, S., de Schipper, E., Robison, J. E., Wong, V. C. N., Selb, M., Singhal, N., . . . Zwaigenbaum, L. (2014). Classification of Functioning and Impairment: The Development of ICF Core Sets for Autism Spectrum Disorder. *Autism Research, 7*(1), 167-172. doi: 10.1002/aur.1335

Boydell, K. M., Barwick, M., Ferguson, H. B., & Haines, R. (2005). A feasibility study to assess service providers' perspectives regarding the use of the Child and Adolescent Functional Assessment Scale in Ontario. *Journal of Behavioral Health Services & Research, 32*(1), 105-109. doi: 10.1007/bf02287332

Brammer, W. A., & Lee, S. S. (2012). Impairment in Children With and Without ADHD: Contributions From Oppositional Defiant Disorder and Callous-Unemotional Traits. *Journal of Attention Disorders, 16*(7), 535-543. doi: 10.1177/1087054711403709

Canino, G. J., Fisher, P. W., Alegria, M., & Bird, H. R. (2013). Assessing Child Impairment in Functioning in Different Contexts: Implications for Use of Services and the Classification of Psychiatric Disorders. *Open Journal of Medical Psychology, 2*, 29-34.

Center for Mental Health Services (1999). Annual report to congress on the evaluation of the comprehensive community mental health services for children and their families program.

Cervellione, K. L., Burdick, K. E., Cottone, J. G., Rhinewine, J. P., & Kumra, S. (2007). Neurocognitive deficits in adolescents with schizophrenia: Longitudinal stability and predictive utility for short-term functional outcome. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(7), 867-878. doi: 10.1097/chi.0b013e318054678d

Chavez, L. M., Ramirez, R., Garcia, P., Canino, G., Mir, K., Ortiz, N., & Morales, L. S. (2014). Measurement properties of the Adolescent Quality of Life Mental Health Scale (AQOL-MHS). *Quality of Life Research, 23*(4), 1327-1335. doi: 10.1007/s11136-013-0579-2

Dougherty, L. R., Smith, V. C., Bufferd, S. J., Carlson, G. A., Stringaris, A., Leibenluft, E., & Klein, D. N. (2014). DSM-5 disruptive mood dysregulation disorder: correlates and predictors in young children. *Psychological Medicine, 44*(11), 2339-2350. doi: 10.1017/s0033291713003115

Fiks, A. G., Mayne, S., Localio, A. R., Feudtner, C., Alessandrini, E. A., & Guevara, J. P. (2012). Shared decision making and behavioral impairment: a national study among children with special health care needs. *Bmc Pediatrics, 12*. doi: 10.1186/1471-2431-12-153

Francis, S. E., Ebesutani, C., & Chorpita, B. F. (2012). Differences in Levels of Functional Impairment and Rates of Serious Emotional Disturbance Between Youth With Internalizing and Externalizing Disorders When Using the CAFAS or GAF to Assess Functional Impairment. *Journal of Emotional and Behavioral Disorders, 20*(4), 226-240. doi: 10.1177/1063426610387607

Friesen, B. J., Giliberti, M., Katz-Leavy, J., Osher, T., & Pullmann, M. D. (2003). Research in the service of policy change: The "custody problem". *Journal of Emotional and Behavioral Disorders, 11*(1), 39-47. doi: 10.1177/106342660301100106

Hall, R. C. W. (1995). GLOBAL ASSESSMENT OF FUNCTIONING - A MODIFIED SCALE. *Psychosomatics, 36*(3), 267-275.

Hinshaw, S. P., Owens, E. B., Zalecki, C., Huggins, S. P., Montenegro-Nevado, A. J., Schrodek, E., & Swanson, E. N. (2012). Prospective Follow-Up of Girls With Attention-Deficit/Hyperactivity Disorder Into Early Adulthood: Continuing Impairment Includes Elevated Risk for Suicide Attempts and Self-Injury. *Journal of Consulting and Clinical Psychology, 80*(6), 1041-1051. doi: 10.1037/a0029451

Hodges, K., & Gust, J. (1995). Measures of impairment for children and adolescents. *The Journal of Mental Health Admistration, 22*(4), 403-413.

Jones, S. H., Thornicroft, G., Coffey, M., & Dunn, G. (1995). A BRIEF MENTAL-HEALTH OUTCOME SCALE - RELIABILITY AND VALIDITY OF THE GLOBAL ASSESSMENT OF FUNCTIONING (GAF). *British Journal of Psychiatry, 166*, 654-659. doi: 10.1192/bjp.166.5.654

Keenan, K. (2012). Mind the Gap: Assessing Impairment Among Children Affected by Proposed Revisions to the Diagnostic Criteria for Oppositional Defiant Disorder. *Journal of Abnormal Psychology, 121*(2), 352-359. doi: 10.1037/a0024340

Kramer, T. L., Phillips, S. D., Hargis, M. B., Miller, T. L., Burns, B. J., & Robbins, J. M. (2004). Disagreement between parent and adolescent reports of functional impairment. *Journal of Child Psychology and Psychiatry, 45*(2), 248-259. doi: 10.1111/j.1469-7610.2004.00217.x

Lambert, W., Salzer, M. S., & Bickman, L. (1998). Clinical outcome, consumer satisfaction, and ad hoc ratings of improvement in children's mental health. *Journal of Consulting and Clinical Psychology, 66*(2), 270-279. doi: 10.1037/0022-006x.66.2.270

McArdle, P., Prosser, J., & Kolvin, I. (2004). Prevalence of psychiatric disorder: with and without psychosocial impairment. *European Child & Adolescent Psychiatry, 13*(6), 347-353. doi: 10.1007/s00787-004-0367-1

McCarty, C. A., Russo, J., Grossman, D. C., Katon, W., Rockhill, C., McCauley, E., . . . Richardson, L. (2011). Adolescents With Suicidal Ideation: Health Care Use and Functioning. *Academic Pediatrics, 11*(5), 422-426.

Mendenhall, A. N., Demeter, C., Findling, R. L., Frazier, T. W., Fristad, M. A., Youngstrom, E. A., . . . Horwitz, S. M. (2011). Mental Health Service Use by Children With Serious Emotional and Behavioral Disturbance: Results From the LAMS Study. *Psychiatric Services, 62*(6), 650-658.

Nagar, S., Sherer, J. T., Chen, H., & Aparasu, R. R. (2010). Extent of functional impairment in children and adolescents with depression. *Current Medical Research and Opinion, 26*(9), 2057-2064. doi: 10.1185/03007995.2010.496688

Rapee, R. M., Bogels, S. M., van der Sluis, C. M., Craske, M. G., & Ollendick, T. (2012). Annual Research Review: Conceptualising functional impairment in children and adolescents. *Journal of Child Psychology and Psychiatry, 53*(5), 454-468. doi: 10.1111/j.1469-7610.2011.02479.x

Saloner, B., Carson, N., & Le Cook, B. (2014). Episodes of Mental Health Treatment Among a Nationally Representative Sample of Children and Adolescents. *Medical Care Research and Review, 71*(3), 261-279. doi: 10.1177/1077558713518347

Scorza, P., Stevenson, A., Canino, G., Mushashi, C., Kanyanganzi, F., Munyanah, M., & Betancourt, T. (2013). Validation of the "World Health Organization Disability Assessment Schedule for Children, WHODAS-Child" in Rwanda. *Plos One, 8*(3). doi: 10.1371/journal.pone.0057725

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., & Aluwahlia, S. (1983). A CHILDRENS GLOBAL ASSESSMENT SCALE (CGAS). *Archives of General Psychiatry, 40*(11), 1228-1231.

Singer, J. B., Eack, S. M., & Greeno, C. M. (2011). The Columbia Impairment Scale: Factor Analysis Using a Community Mental Health Sample. *Research on Social Work Practice, 21*(4), 458-468. doi: 10.1177/1049731510394464

Warner, L. A. (2006). Medical problems among adolescents in US mental health services: Relationship to functional impairment. *Journal of Behavioral Health Services & Research, 33*(3), 366-379. doi: 10.1007/s11414-006-9022-6

Wigman, J. T. W., Devlin, N., Kelleher, I., Murtagh, A., Harley, M., Kehoe, A., . . . Cannon, M. (2014). Psychotic symptoms, functioning and coping in adolescents with mental illness. *Bmc Psychiatry, 14*. doi: 10.1186/1471-244x-14-97

Williams, N. J. (2009). Dose-Effect of Children's Psychosocial Rehabilitation on the Daily Functioning of Youth with Serious Emotional Disturbance. *Child & Youth Care Forum, 38*(6), 273-286. doi: 10.1007/s10566-009-9080-z