Healthy Minds

LEGISLATORS DEPARTMENT OF HEALTH & HUMAN SERVICES

(healthcare decision makers, state policy decision makers)

40+ years of age educated people

How can DHHS maximize its use of federal grants to fund state mental health services?

1. Clarify and update its definition of SED (and SMI) in NRS and NAC
2. Standardize a method for determining SED
3. Standardize and streamline mental health assessment across all eligibility-based programs

We recommend focusing on the SED population because investing in children will yield the highest return. The consequences of impairment in childhood are much more severe and longer-lasting than those for adults. When children have an SED and drop out of school, they are less likely to become employed and more likely to remain impaired for life.

What is the federal definition of SED?

A child with a "serious emotional disturbance" has had a diagnosable mental disorder within the past year that substantially interfered with or limited the child's role or functioning in family, school, or community activities. Ultimately, SED is not a diagnosis; it is an administrative classification. Doctors have training to diagnose mental illness, not to estimate or determine SED.

How many children have a serious emotional disturbance?

In 1995, SAMSHA estimated an SED prevalence rate in children ages 9-17 ranging from 5-13% depending on the strictness of the cut-off. SAMSHA could not estimate prevalence rates for children under age 9.

What is the origin of SED determination?

In 1992, US Congress decided to incentivize states to give children with the most severe and disabling disorders priority for service. The Community Mental Health Services Block Grant (MHBG) is the largest Federal program to assist States in developing comprehensive, community-based mental health systems of care. The Comprehensive Community Health for Children and Their Families (CMHI) provides funds to public entities to promote the coordination of multiple and often fragmented systems. States looking to use federal dollars to fund state mental health services were forced to estimate the number of children with SED to ensure federal funds were used only to serve children with the most severe and disabling disorders.

1990 Individuals with Disabilities Education Act (IDEA)

- Financially incentivized states to improve and guarantee free access to appropriate public education for children with disabilities
- Established that SED
  - Required educational impairment
  - Must exist "over a long period of time and to a marked degree"
  - Excludes children who are "socially maladjusted" (e.g., Conduct Disorder) unless they meet other SED criteria
  - Be based on 1 of 5 conditions
- Does not describe a standardized method for determining SED

Criticism of IDEA criteria as fuzzy, ambiguous criteria led to proposition of structured guidelines for interpreting these criteria to minimize over- and under-classification of SED.

- The Council for Children with Behavioral Disorders advised SED determination should
- Does not describe a standardized method for determining SED

1992 ADAMHA Reorganization Act amended by Children's Health Act of 2000

- Defined SED
- Sparked the development of a standardized method for estimating the prevalence of SED

How has Nevada approached SED determination?

1993 NRS 433B.045 governs mental health for children

- Differentiated a child with an emotional disturbance from a child with a serious emotional disturbance
- Requires diagnosis of a mental disorder
- Calls for judgment about the child's age-adjusted impairment in accurately perceiving the world, controlling impulses, maintaining satisfactory relationships, or learning
- Does not exclude temporary disorders or expected responses to stressful events

1997 NAC 433.040 governing programs for mental health and mental retardation

- Established that SED
- Does not describe a standardized method for estimating the prevalence of SED

Chapter 400 of the Medicaid Services Manual

- Identifies an SED assessment as "a tool utilized to determine a recipient's eligibility for higher levels of care and Medicaid service categories."
- Does not describe how one can obtain the tool
- Does not offer a standardized method for determining SED

Chapter 2500 of the Medicaid Services Manual

- Defined SED
- Does not offer a standardized method for determining SED

Chapter 3600 of the Medicaid Services Manual

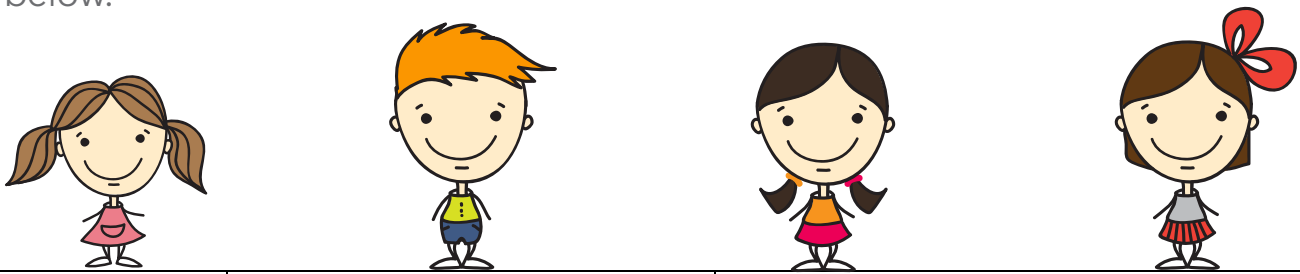
- Uses SED determination to compel MCOs to ensure enrollees receive referrals and adequate services, including case management, lab work, prescriptions, as well as acute and ancillary services
- Authorizes enrollees to disenroll from MCOs on the basis of an SED determination
- Does not offer MCOs a standardized method for determining SED

These differences in SED definition and determination complicate the estimation of the number of children whose mental health services would be eligible for federal reimbursement. Of particular note is the application of SED criteria with children who have a high number of adverse childhood experiences (ACE). How one can rule out the high number of ACEs as an explanation for a child's presentation as opposed to mental illness? Certain problematic behaviors are normal reactions to abnormal circumstances that are temporary and expected responses to stressful events and would likely resolve once external stressors dissipate. Should these considerations be used as a rationale to eliminate children with a high number of ACEs (e.g., child welfare, juvenile justice) from SED estimates or determinations? How many children in Nevada meet the criteria but are excluded from SED estimates? How many federal matching dollars are not being received as a result?

How should Nevada standardize its method for determining SED?

The best solution will allocate greater resources to children with the most severe and disabling disorders while maximizing federal reimbursement and still providing adequate services for the remaining population. To achieve this, it helps to differentiate between a process for determining if a child has SED versus estimating the number of children with SED in Nevada. Inclusive estimates of children with SED would maximize federal reimbursement. Restrictive determination would allocate resources to children with the most severe and disabling disorders.

Some experts believe there should independent assessment of diagnosis and impairment because SAMSHA's definition of SED identifies them in separate bullet points. Their distinction is evident in fact that 2 people with the same diagnosis can have different levels of impairment, just as 2 people with the same level of functioning do not necessarily have the same diagnosis. But the use of different diagnostic systems in the United States and other countries complicates separate assessment of diagnosis and impairment. We discuss the implications for estimating and determining SED below.



	United States	Other countries	
	DSM5	ICD10	ICF
Diagnostic system	classifies diagnoses, which requires significant distress or impairment	classifies diagnoses	classifies impairment

SED estimation

The difference between a diagnosed disorder and a diagnosable disorder becomes meaningful when producing population estimates. Using actually diagnosed disorders will severely underestimate Nevada's SED prevalence rates given Nevada's low access to care. Children already have the lowest rates of service utilization. With very limited access to care, it becomes more difficult for children to receive a diagnosis. In Health Professional Shortage Areas, it becomes even more important to identify reliable ways of estimating the number of children with diagnosable DSM5 disorders instead of counting the number of children with a DSM5 diagnosis.

The presence of a diagnosable DSM5 disorder would be a simple method for estimating SED. It could involve a single assessment because DSM5 diagnosis is, by definition, both a diagnosis and an indication of significant distress or impairment. Paradoxically, using existing data sources that indicate impairment may provide the best estimate of diagnosable DSM5 disorders. Impairment precedes diagnosis in the first place and is the most common reason parents take their children to treatment where diagnosis occurs. The ultimate goal in treatment is to reduce impairment and thus improve a child's functioning. As an indicator of a diagnosable DSM5 disorder, impairment data would not have to be limited to children with diagnosed disorders. Research has demonstrated that the presence of multiple family stressors (e.g., physical abuse, parental psychiatric illness) is very common in children classified as SED. These data could be incorporated to ensure no children with a diagnosable disorder are excluded from SED estimates.

The best method for estimating SED prevalence and maximizing federal reimbursement may be a combination of a DSM5 assessment and use of existing data sources that indicate impairment. The biggest challenge will be deciding on cut-offs for impairment. Experts agree that what constitutes substantial impairment is arbitrary and depends on the rater and measurement instrument. This may lead to an over-estimation of SED prevalence because a DSM5 diagnosis can be made on the basis of significant distress, not impairment. However, over-estimation may be justified given Nevada's ranking of 49th in the nation in mental health by Mental Health America on the basis of its high prevalence rates and low access to care.

Children with the most severe and disabling disorders frequently require and receive services from multiple agencies that apply different disability or eligibility criteria. These children will benefit significantly from a standardized, streamlined process for estimating and determining disability, eligibility, and SED. Currently, determinations under one program's definition does not lead to eligibility under another program, but these determinations could be used as a proxy for estimating SED. Interdepartmental coordination and collaboration would simplify a process that is often too complex for this high-need population to navigate. SED estimations could presume eligibility based on existing eligibility- (or disability-) based programs' determinations rather than spending money on screenings and assessments to detect diagnosis and impairment that other programs have already detected. More versatile eligibility decisions and SED estimates could be achieved using records from the following entities:

- Desert Regional Center
- Bureau of Disability Adjudication
- Bureau of Vocational Rehabilitation
- County School Districts
- Inpatient psychiatric hospital records
- DHCFP cost reports

SED estimation

Even with maximized federal reimbursement, optimization of still limited funds will be important to ensure services are ultimately provided to children with the most severe and disabling disorders. Restrictive SED determination would more effectively conform to SAMSHA's intent to allocate resources to children with the most severe and disabling disorders.

Use of just a DSM5 diagnosis does not acknowledge varying levels of severity within the population of children with a diagnosable disorder. Allocating federal resources to the entire population of children with a diagnosable disorder would spread thin the resources intended to serve the children with the most severe and disabling disorders, likely resulting in poorer outcomes for the most disadvantaged children.

Thus, SED determination should involve an additional assessment of functioning. Independent assessment of diagnosis and impairment in SED determination acknowledges that 2 people with the same diagnosis can have different levels of impairment and enables resources to be targeted to children whose diagnosis involves or results in substantial impairment—children with the most severe and disabling disorders. Although there are no valid cut-off scores for measures of impairment, the need to allocate limited funds may justify added effort to direct services to children with the most severe and disabling disorders.

Other existing instruments and data sources for estimating and determining SED are listed below. Experts suggest that the best instruments for measuring SED:

- have scores for severity or impairment
- assess functioning in different contexts, such as school, family, and friends (multidimensional)
- can be used with a wide range of ages
- incorporate both parent and child reports
- have good psychometric properties for the U.S. population in English and Spanish
- do not require the assessor to have prior knowledge of the child

Each of these requirements increases cost and complexity, and no existing measure meets all of these requirements. Some states have customized instruments or developed original assessments that suit their needs.