



# **EXPANDING BEHAVIORAL HEALTH DATA COLLECTION: TRAUMA**

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# Introduction

- U.S. Department of Health and Human Services seeks to expand behavioral health data collection.
- Require guidance on how to best measure and collect these data.
- SAMHSA working through ASPE to engage the Committee on National Statistics (CNSTAT)/National Research Council (NRC).

# Expand Behavioral Health Data

- Guidance needed on how to measure and collect data on these behavioral health topics:
  - Topic 1: Specific adult mental illness including functional impairment
  - Topic 2: Serious Emotional Disturbance (SED) in children
  - **Topic 3: Trauma**
  - Topic 4: Recovery

# SAMHSA Interest in Trauma

- Traumatic event exposure can have profound and lasting cumulative effects on an individual's mental health and is associated with significant social, personal, and economic costs.
- Studies links traumatic event exposure to increased rates of
  - substance abuse and dependence,
  - depression, anxiety, conduct problems,
  - schizophrenia, personality disorders,
  - posttraumatic stress disorder (PTSD), acute stress disorder (ASD),
  - poorer psychological response to subsequent traumatic event exposure, and
  - Suicide.
- SAMHSA recognizes the critical importance to link recovery to those individuals and families affected by trauma.

# History of Defining Trauma

- Descriptions of traumatic event exposure first appeared in the *Diagnostic and Statistical Manual of Mental Disorders*, third edition (DSM-III), when PTSD was added as a mental disorder.
- A shift toward defining a traumatic event by the event itself rather than upon reactions to the event occurred with the introduction of DSM-IV:
  - Traumatic event was defined as an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of themselves or others.
  - PTSD diagnosis required
    - that the event result in feelings of intense fear, helplessness, or horror and
    - then meet criteria in a number of other symptom categories (e.g., re-experiencing, avoidance, arousal, duration of at least 1 month, associated functional impairment).

# History of Defining Trauma: DSM-5

DSM-5 had several changes including:

- PTSD moved from the class of anxiety disorders into a new class of "trauma and stressor-related disorders."
- The three clusters of DSM-IV symptoms are divided into four clusters in DSM-5: intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity.
- DSM-IV Criterion C, avoidance and numbing, was separated into two criteria: Criteria C (avoidance) and Criteria D (negative alterations in cognitions and mood) and now requires at least one avoidance symptom for PTSD diagnosis.
- Three new symptoms were added: persistent and distorted blame of self or others, persistent negative emotional state, and reckless or destructive behavior.
- Other symptoms were revised to clarify symptom expression.
- Criterion A2 (requiring fear, helplessness, or horror happen right after the trauma) was removed in DSM-5.

# SAMHSA's "Trauma and Justice" Strategic Initiative

Objective 2.1.1 of SAMHSA's "Trauma and Justice" strategic initiative: creation of a surveillance strategy for trauma and its association with mental and substance use disorders.

SAMHSA has been charged with the following:

- finding a way to define and measure trauma (e.g., obtain national estimates of exposure to trauma and post-traumatic stress symptoms, including subclinical and clinical post-traumatic stress disorder [PTSD]\*); and
- determine associations between trauma/post-traumatic stress symptoms and mental health/substance use problems.

\* Started before DSM changed from IV to 5 and the new chapter on Trauma- and Stressor-Related Disorders

# SAMHSA's Past Work - Definition of Trauma: The 3 E's

The 3 E's of Trauma (includes trauma exposure and "trauma" or post-traumatic stress response components):

- 1. Events:** actual or extreme threat of physical or psychological harm or severe, life-threatening neglect for a child that imperils healthy development (consistent with DSM-5 definition of trauma exposure)
- 2. Experience of Event:** determines whether the event is traumatic—how the individual labels, assigns meaning to, and is disrupted physically and psychologically by an event
- 3. Effect:** adverse experiences resulting from trauma exposure that may occur acutely or have a delayed-onset (duration may be short or long term)



# Overview of National Survey on Drug Use and Health (NSDUH)

- NSDUH:
  - Structured interview conducted in respondents' homes by trained lay interviewers
  - Administered to respondents aged 12 and older
  - Primarily administered as an ACASI interview
  - Collects demographic information, including age, race, and veteran status, as well as substance use, mental health indicators, and physical health conditions
  - An annual survey since 1990
  - Questionnaire completed each year by approximately 44,000 adults, 96 percent in English

ACASI = audio computer-assisted self-interviewing.

# Legal Background

- Legislation (Public Law No. 102-321) required the estimation of serious mental illness (SMI) by state
- In accordance with the 1992 Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Reorganization Act, SAMHSA developed conceptual and operational definitions of serious mental illness (SMI) and developed a methodology for producing estimates of SMI.

# 2008-2012 Mental Health Surveillance Study (MHSS)

- The original intent of the 2008-2012 MHSS was to administer a clinical interview to assist in the development of a model and methods for the NSDUH to yield model-based estimates of SMI among adults in the United States.
- As a secondary goal, data from the MHSS were also used to make estimates of specific mental disorders for years 2008-2012.

# 2008-12 MHSS (con't)

- The MHSS comprised:
  - short scales measuring psychological distress and functional impairment included in the main NSDUH interview;
  - clinical psychiatric diagnostic data collected from a nationally representative subset of NSDUH respondents each year from 2008 to 2012; and
  - had measures that would allow for an estimation methodology for SMI and AMI among adults based on a weighted, statistical model.

# 2008-12 MHSS (con't)

- For respondents, a two-part process:
  - National Survey on Drug Use and Health (NSDUH)
  - Mental Health Surveillance Study (MHSS)
- Following completion of the NSDUH main interview, a sample of respondents who met certain criteria were recruited for the MHSS clinical interview study (e.g., aged 18 or older, English was first language).
- The MHSS diagnostic interview was completed within 4 weeks of the NSDUH interview.

# 2008-12 MHSS (con't)

- The MHSS is a subsample from the NSDUH in which a diagnostic interview was administered by telephone by trained clinicians.
- The MHSS used a semi-structured clinical interview that demonstrated good agreement between face-to-face and telephone administration (Structured Clinical Interview for DSM-IV-TR Axis I Disorders [SCID]; First et al., 2002).

# 2008-12 MHSS (con't)

- All aspects of data collection were adapted for clinical interviewers (CIs) to work remotely.
- CIs were trained on the nuances of conducting assessments by telephone.
- Protocols were developed and refined for handling unusual, difficult, and/or risky situations remotely.
  - A safety protocol was developed for handling distressed\* respondents.

\* A total of 201 respondents were classified as distressed during the 2008-2012 MHSS administration.

# Challenges: Trauma Definition

- There is a need to differentiate between trauma *exposure* and "trauma" used to refer to a potential outcome of trauma exposure (e.g., post-traumatic stress response).
  - The tautological issue of defining an event as traumatic by its outcome (i.e., by the trauma produced) is an ongoing debate in the field of trauma assessment and contributes to the ambiguity of measuring traumatic event exposure.
- There are varying definitions of what constitutes a traumatic event. What constitutes a traumatic event is “subjective”.
- Traumatic events and responses to trauma may differ across the lifespan (i.e., age and developmental stage), by ethnicity/race/culture, and by the person's role in the event.
- Individuals have different levels of resiliency, or ability to tolerate traumatic events.



# Challenges: Variation by Traumatic Event

- Simple assessment of trauma exposure (yes vs. no) may not yield enough information to predict trajectory of symptom development and potential severity.
- Type of traumatic event, intensity of the event, and setting of the event all affect the impact that a traumatic event may have.

# Challenges: Assessment Mode

- Mode of assessment may affect “measuring” trauma:
  - Self-report versus interview
  - Respondent-based interview conducted by a lay interviewer (where an event is classified as traumatic depending on the respondent's understanding of what a traumatic event entails)
  - Interviewer-based interview (where clinical interviewer uses all information collected during interview to make judgment about whether an event is traumatic)
- Less expensive assessment methods such as screening instruments vary greatly in types of traumatic events assessed and quantification of resulting post-traumatic stress symptoms.

# Challenges: Large-Scale Surveys

- It is difficult to obtain nationally representative estimates of trauma exposure and effects because some populations most affected by trauma and resulting condition are not easily captured in large-scale studies:
  - Active-duty military personnel
  - Institutionalized individuals
  - People in jails or prisons
  - Homeless people
  - Youth living in foster care
- Some traumatic events are sensitive and difficult to assess via an interview; special consent procedures may be required (especially among children and adolescents).

# Parameter for Collecting Trauma Data

- Goal/Definitions: The goal of this effort is to understand the association between trauma and mental health and substance use. Trauma is not just defined as PTSD, but in broader terms.
  - Uses the definitions listed on the previous two slides
- Level of geography: National
- Periodicity: Every to 3 to 5 years
- Key covariates: mental health/substance use problems, language spoken, race/ethnicity, gender, age, education, income, medical conditions, health insurance status.

# Collect Trauma Data

Possible means of collecting the data:

- Use the National Survey on Drug Use and Health (NSDUH) ,
- Reinstate the Mental Health Surveillance Study (MHSS),
- Develop a new data collection program,
- Use existing data, and/or

Guidance needed on estimation method (which may effect design options and vice versa):

- Construct model-based estimation procedures using existing data sources.

# Trauma Workshop Charge

- Provide guidance on how to measure Trauma
- Consider survey and questionnaire design tradeoffs
- Assess mechanisms for collecting the data and provide suggestions
- Provide suggestions for measuring these data and assess potential impact of changes to NSDUH
- Discuss or present commissioned papers