Measuring Trauma: Workshop Summary

DETAILS

66 pages | 6 x 9 | PAPERBACK
ISBN 978-0-309-44337-1 | DOI: 10.17226/23526

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Measuring Trauma

Workshop Summary

Krisztina Marton, *Rapporteur*

Committee on National Statistics and
Board on Behavioral, Cognitive, and Sensory Sciences,
Division of Behavioral and Social Sciences and Education

and

Board on Health Sciences Policy
Health and Medicine Division

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THE NATIONAL ACADEMIES PRESS
Washington, DC
www.nap.edu

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This activity was supported by Contract No. HHSP233201400020B/HHSP23337002 between the National Academy of Sciences and the U.S. Department of Health and Human Services. Support of the work of the Committee on National Statistics is provided by a consortium of federal agencies through a grant from the National Science Foundation (No. SES-1024012). Any opinions, findings, conclusions, or recommendations expressed in this publication do not necessarily reflect the views of any organization or agency that provided support for the project.

International Standard Book Number-13:
International Standard Book Number-10:
Digital Object Identifier: 10.17226/23526

Additional copies of this report are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; http://www.nap.edu.

Printed in the United States of America

Suggested citation: National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Trauma: Workshop Summary.* K. Marton, Rapporteur. Committee on National Statistics and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Health and Medicine Division. Washington, DC: The National Academies Press. Washington, DC: The National Academies Press. doi: 10.17226/23526.

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Acknowledgment of Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Academies of Sciences, Engineering, and Medicine. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this report: Margarita Alegria, Disparities Research Unit, Massachusetts General Hospital, Harvard Medical School; Evelyn Bromet, School of Medicine, Stony Brook University; Joel Gelernter, Department of Psychiatry and Department of Genetics and Neuroscience, Yale University School of Medicine; Robert J. Ursano, Department of Psychiatry and Center for the Study of Traumatic Stress, Uniformed Services University of the Health Sciences.

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the report nor did they see the final draft of the report before its release. The review of this report was overseen by Susan A. Murphy, Department of Statistics and Institute for Social Research, University of Michigan. Appointed by the National Academies of Sciences, Engineering, and Medicine, she was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the rapporteur and the institution.

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Introduction

BACKGROUND

This report summarizes the presentations and discussions at the Workshop on Integrating New Measures of Trauma into the Substance Abuse and Mental Health Services Administration's (SAMHSA) Data Collection Programs, which was held in Washington, D.C., in December 2015. The workshop was organized as part of an effort to assist SAMHSA and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services (DHHS) in their responsibilities to expand the collection of behavioral health data in several areas. The workshop was structured to bring together experts in the measurement of exposure to traumatic events, the measurement of posttraumatic stress disorder (PTSD) and health survey methods to facilitate discussion of measures and mechanisms most promising for expanding SAMHSA's data collections in this area.

The overall effort is being overseen by the Standing Committee on Integrating New Behavioral Health Measures into the Substance Abuse and Mental Health Services Administration's Data Collection Programs.[1] In addition to the topics covered by this workshop, SAMHSA and ASPE are interested in expanding data collection on serious emotional disturbance in children, on specific mental illness diagnoses with functional impairment, and on recovery from substance use or mental disorder. Workshops on all four topics were held as part of the overall effort, and reports from the first two workshop have been published.[2,3]

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[1] For a description of the overall study, see http://sites.nationalacademies.org/DBASSE/CNSTAT/Behavioral_Health_Measures_Committee/index.htm [April 2016].

[2] National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Serious Emotional Disturbance in Children: Workshop Summary,* Krisztina Marton, Rapporteur, Committee on National Statistics and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Institute of Medicine. Washington, DC: The National Academies Press.

[3] National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Specific Mental Illness Diagnoses with Functional Impairment: Workshop Summary*. J. C. Rivard and K. Marton, Rapporteurs. Committee on National Statistics, and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Institute of Medicine, Washington, DC: The National Academies Press.

WORKSHOP FOCUS

At the beginning of the workshop, Neil Russell of SAMHSA described the agency's goals in exploring how to best measure and expand SAMHSA's data collection programs to include measures of exposure to traumatic events and PTSD, which can have a profound impact on people's lives. Studies have found associations between exposure to a traumatic event and a wide range of negative outcomes: substance use and dependence; depression, anxiety and conduct problems; schizophrenia and personality disorders; PTSD and acute stress disorder; poorer psychological response to subsequent traumatic event exposure; and suicide. SAMHSA would like to better understand how these outcomes occur in order to connect people who are impacted with treatments that can facilitate recovery.

Russell said that the descriptions of traumatic event exposure first appeared in the third edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-III), when PTSD was added as a mental disorder (trauma-related disorders had previously been listed under other diagnoses). With the introduction of the DSM-IV, emphasis was placed on defining a traumatic event by the event itself rather than through people's reactions to the event and on defining a traumatic event as an event that involved actual or threatened death or serious injury or a threat to the physical integrity of the person or others. A PTSD diagnosis required that the event result in feelings of intense fear, helplessness, or horror and that the person also meet criteria in several other symptom categories, such as re-experiencing the event, avoidance, arousal, duration of at least 1 month, and associated functional impairment.

The fifth edition of the DSM (DSM-5) brought about several further changes, Russell noted. In this edition, PTSD was moved from the category of anxiety disorders into a new category of trauma and stressor-related disorders. Symptoms were divided into four clusters: intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity. This change involved separating the DSM-IV avoidance and numbing criterion into two criteria: avoidance and negative alterations in cognitions and mood, as well as adding the requirement of at least one avoidance symptom for a PTSD diagnosis. Three new symptoms were also added in the DSM-5: persistent and distorted blame of self or others, persistent negative emotional state, and reckless or destructive behavior. One criterion was removed: fear, helplessness, or horror right after the trauma. The DSM-5 also revised several symptoms to clarify symptom expression.

Russell next turned to discussing the work SAMHSA has done in this area. One of the strategic initiatives on trauma and justice called for the development of a surveillance strategy for trauma and its association with mental and substance use disorders. As part of this initiative, SAMHSA began thinking about ways to obtain national estimates of exposure to trauma and posttraumatic stress symptoms, including subclinical and clinical PTSD, initially still based on the DSM-IV definition. Determining associations between trauma events and PTSD symptoms, as well as mental health and substance use problems, was also part of this initiative.

One of SAMHSA's projects focused on the concept of trauma—including trauma exposure and trauma or posttraumatic stress response components—through three "*E*s":

event, experience of event, and effect. The event is the actual or extreme threat of physical or psychological harm or, for a child, severe, life-threatening neglect that imperils healthy development. The experience of the event is whether the event is traumatic, in other words, how the individual labels, assigns meaning to, and is physically and psychologically disrupted by an event. The effect is the adverse experience resulting from trauma exposure that may occur acutely, immediately after the event, or may have a delayed onset.

Russell briefly described the National Survey on Drug Use and Health (NSDUH), SAMHSA's existing survey on substance use and mental health. The survey has been conducted since 1990, and it involves approximately 67,000 interviews completed annually, with respondents aged 12 and over, sampled from the household (non-institutionalized) population in the United States. The interviews are conducted at respondents' homes by trained lay interviewers and, for the sensitive portions of the survey, through an audio computer-assisted self-interview. In addition to questions about substance use and mental health, the NSDUH collects data on physical health conditions and demographic characteristics, including the respondent’s age, race, and veteran status. The questionnaire is available in English and Spanish, but almost all of the interviews (around 96 percent) are completed in English. The survey is in the field practically every day of the year with approximately 600 interviewers, across all states. Russell underscored that the NSDUH is a very large undertaking.

Because legislation (Public Law No. 102-321) requires the estimation of serious mental illness by state, SAMHSA developed conceptual and operational definitions of serious mental illness and a methodology for producing estimates. The approach for producing the estimates relies on the Mental Health Surveillance Study (MHSS), which was a follow-on to the NSDUH conducted between 2008 and 2012. The MHSS involved a clinical interview administered to a nationally representative subset of the NSDUH respondents (500-700 people annually) a few weeks after they completed the NSDUH interview. This sample was limited to adults and conducted in English, by telephone. The primary goal was to produce overall model-based estimates of serious mental illness, but the survey also enabled SAMHSA to make estimates of specific mental disorders.

Russell said that the MHSS was not designed to measure exposure to potentially traumatic events and PTSD, but the survey contained measures that enabled SAMHSA to produce some estimates on these topics (which will be discussed later in the workshop). Despite its current limitations in terms of data on exposure to potentially traumatic events and PTSD, Russell said that the MHSS design is important to understand because it illustrates one possible approach for collecting data on a focused topic as a follow-on to an existing large-scale survey.

Russell noted that SAMHSA faces a number of challenges as it attempts to expand its data collection in this area. There is a need to differentiate between trauma exposure and the potential outcome of trauma exposure (e.g., PTSD). Responses to traumatic events may differ across the lifespan; by ethnicity, race, and culture; and by a person's role in the event. In addition, individuals have different levels of resiliency, that is, ability to tolerate traumatic events.

Another challenge, said Russell, is that predicting the trajectory of symptom development and potential severity may not be possible on the basis of a simple "yes" or "no" question about traumatic exposure. The type of traumatic event, the intensity of the event, and the setting of the event can all influence the effects of the exposure, and all of them may need to be ascertained as part of the data collection.

Russell discussed several approaches and issues that SAMHSA will need to consider for collecting information on trauma exposure. One option might be to instruct respondents to self-report events in their own words and then analyze those responses after the data are collected. If the questionnaire is to be administered by an interviewer, a decision has to be made about whether to use lay interviewers or clinical interviewers. If lay interviewers are used, a standardized set of questions and answer choices could be administered, and the event would be classified as traumatic depending on the respondent's understanding of what a traumatic event entails. By contrast, a clinical interviewer could ask a series of questions aimed at collecting detailed information and then make a judgment based on that information about whether the event should be classified as traumatic.

Russell said that less expensive, brief screening methods could also be considered. The existing screening instruments vary greatly in how they assess traumatic events and the resulting posttraumatic stress symptoms, and SAMHSA would be interested to know if any of them are suitable to meet the agency's goals.

Another challenge associated with producing nationally representative estimates of exposure to trauma and its effects is that some of the populations most affected are not easily captured in typical household surveys, such as the NSDUH. These populations include active-duty military personnel (regardless of where they reside), people in jails or prisons, homeless people, youth living in foster care, and people in institutionalized settings.

SAMHSA would face additional challenges if the estimates are to include children. Some traumatic events are sensitive and difficult to assess in an interview, even with adult respondents. Asking children and adolescents about these issues would be particularly difficult, and special consent procedures might be required if including children is deemed important.

Russell said that SAMHSA is looking for input on the issues and challenges described. From the perspective of the Center for Behavioral Health Statistics and Quality, the center at SAMHSA that commissioned the study, the goal for expanding data collections on these topics is to understand the association between outcomes of exposure to trauma, mental health, and substance use. The agency would like to think more broadly than just PTSD and include other outcomes of trauma exposure. Other key covariates of interest for this research include: language spoken, race and ethnicity, gender, age, education, income, medical conditions, and health insurance status. SAMHSA would like to be able to produce national estimates approximately every 3-5 years. This schedule means that it would be possible to consider a design similar to that of the MHSS, which involves pooling data from several years' worth of interviews in order to produce some of the estimates.

Russell described several data collection strategies that SAMHSA has considered for producing estimates of trauma exposure and outcomes. One option would be to add questions directly to the NSDUH, but he emphasized that it would be important to maintain the average NSDUH administration time at around 60 minutes, primarily because a longer survey could adversely affect response rates. In other words, if new questions are added to the NSDUH, some of the existing questions would likely have to be dropped. Another approach would be to reinstate the MHSS or develop a similar survey to collect data from a subsample of the NSDUH respondents in a follow-on interview.

A third option would be to develop a new, stand-alone data collection. This approach would be expensive, but it might be necessary if neither the NSDUH nor a follow-on to the NSDUH are deemed to be a suitable mechanism for collecting the data of interest. A fourth possibility would be to identify an existing source of national data that could be used to produce estimates of trauma. Russell said that SAMHSA has conducted some research to identify existing data sources, and none seems suitable for the agency's current goal, but they are looking for further input on potential sources of data.

Russell concluded by saying that input from the workshop participants would be particularly useful on several key issues: how to measure exposure to potentially traumatic events and the outcomes of these events; survey and questionnaire design tradeoffs; mechanisms for collecting data; and the impact of potential changes to NSDUH. Since some of the possible approaches discussed could involve model-based estimation procedures, the agency would also appreciate guidance on these types of methods.

Larke Huang, who leads SAMHSA's strategic initiative on trauma and justice, provided additional background on the agency's interest in trauma. She said that trauma was one of the areas that the previous SAMHSA administrator wanted the agency to focus on from a programmatic and policy perspective. SAMHSA would like to have a solid foundation in this area, grounded in research and data. As a first step, the agency needs to crystalize its thinking about the concept of trauma outcomes, beyond just PTSD, and determine how to gain a better understanding of the connections between exposure to traumatic events and areas that SAMHSA is mandated to address, including mental health, substance use disorders, and other conditions, such as HIV. One of the challenges associated with measuring these concepts is that different studies show different prevalence rates, depending on the definitions used, and Huang noted that SAMHSA also wrestles internally with definitional issues. SAMHSA wants to focus on work that has the potential of translating research into policy. The agency would like guidance on how different research methodologies can be used to inform and advance critical programs.

WORKSHOP CHARGE

The specific statement of task for the workshop (shown in Box 1-1) was developed on the basis of the charge for the overall project, which was to expand data collections on several behavioral health topics. The main goals of the workshop were to discuss options for collecting data and producing estimates on exposure to traumatic events and PTSD, including available measures and associated possible data collection mechanisms.

BOX 1-1

STATEMENT OF TASK

A steering committee will organize a public workshop that will feature invited presentations and discussions on options for expanding SAMHSA's behavioral health data collections to include measures of trauma. The discussion will explore new measures and efficient mechanisms for collecting the data. Possibilities include adding new measures to existing surveys, initiating new data collections, or implementing model-based estimation procedures that take advantage of existing data sources, in the event that primary data collection methods are cost-prohibitive or not necessary. Survey and questionnaire design tradeoffs, as well as the potential impact of any changes to existing surveys, will also be discussed. An individually authored summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

ORGANIZATION OF THE REPORT

This summary describes the workshop presentations and the discussions that followed each topic: see the workshop agenda in Appendix A. Biographical sketches of the presenters and of the steering committee members are in Appendix B.

Chapter 2 covers existing studies and data, including the trauma module that was included in the MHSS (see above) and other national surveys that have collected data on this topic. Chapter 3 discusses the key concepts relevant in the context of measuring exposure to potentially traumatic events, PTSD, and other outcomes. The chapter also discusses the measures that are currently available. Chapter 4 focuses on issues specific to measuring trauma exposure and its effects in children and adolescents. The workshop participants' discussions of the key themes and possible next steps for SAMHSA are summarized in Chapter 5.

This report has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. The steering committee's role was limited to planning and convening the workshop. The views contained in the report are those of individual workshop participants and do not necessarily represent the views of all workshop participants, the steering committee, or the National Academies of Sciences, Engineering, and Medicine.

2

Existing Studies and Data

THE TRAUMA MODULE IN THE MENTAL HEALTH SURVEILLANCE STUDY

Rhonda Karg (RTI International) discussed the measures of trauma exposure and posttraumatic stress symptoms included in the Mental Health Surveillance Study (MHSS), conducted as a follow-on to the National Survey of Drug Use and Health (NSDUH) between 2008 and 2012, and she described the estimates that can be produced on the basis of these data.

The MHSS included the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (SCID), which Karg said is used by several studies as the "gold standard" in determining the accuracy of clinical diagnoses. The SCID is a semi-structured interview, which allows for flexibility in probing, as necessary, and it requires clinical judgment to make a diagnostic decision. Each SCID symptom is rated as: 1, absent; 2, subclinical; 3, present; and ?, need more information. For some analyses in the MHSS, the ? and 2 codes were recoded as 1. A minimum number of symptoms must be present (coded as 3), to meet diagnostic criteria, and the number of symptoms needed depends on the disorder.

The SCID includes screening items for certain disorders, including PTSD. The screening items typically assess the first criterion for the respective disorder. They also help to prevent respondents from "faking good" if they later realize that answering "no" shortens the interview, and they help the clinical interviewer estimate how long the interview will be.

Karg said that the SCID assessment of PTSD was according to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders Text Revised (DSM-IV-TR) PTSD diagnostic criteria. The screening was for lifetime trauma exposure, in combination with questions about whether the respondent re-experienced the traumatic event or became very distressed when recalling the traumatic event. If this screening yielded a positive result, the SCID was administered for the past year, until the criteria were no longer met. The study used the standard version of the SCID, which skips follow-up questions at the point at which the criteria are no longer met, rather than administering all questions to everyone, as is sometimes done in studies where responses to particular symptoms may be of interest. If a respondent reported having experienced more than one traumatic event, clinical judgment was used to decide which one to refer to in the follow-up questions about the outcome of the traumatic event.

For background, Karg provided an overview of the diagnostic criteria for trauma in the DSM-IV-TR. There are six criteria, labelled A-F:

- Criterion A is exposure to one or more traumatic events: A1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others; and A2) the person's response involved intense fear, helplessness, or horror (which has since been dropped by the DSM-5, but has been included in the MHSS).
- Criterion B is one or more re-experiencing symptoms: recurrent and intrusive distressing recollections; recurrent distressing dreams of the event; reliving traumatic event (e.g., "flashbacks"); or intense psychological distressed and/or physiological reactivity when reminded of traumatic event.
- Criterion C is three or more avoidance symptoms: avoiding thoughts, feelings, or conversations about the trauma; avoiding reminders of the trauma; inability to recall important aspects of the trauma; diminished interest in significant activities; feeling detached/estranged from others; restricted range of affect; or sense of foreshortened future.
- Criterion D is two or more hyperarousal symptoms: difficulty falling or staying asleep; irritability or angry outbursts; difficulty concentrating; hypervigilance; or exaggerated startle response.
- Criterion E is a duration of more than 1 month of the disturbance (symptoms in criteria B, C, and D).
- Criterion F is clinically significant distress or impairment in social, occupational, or other important areas of functioning caused by the disturbance (symptoms in criteria B, C, and D).

The SCID used in the MHSS was adapted from the original SCID research version in order to make the time for the PTSD assessment to be the past year, rather than for the respondent's lifetime or the past month. However, the screening questions for PTSD were about lifetime exposure to trauma and lifetime symptoms of re-experiencing or getting very upset by reminders of the traumatic event.

Subclinical PTSD was defined as a category for respondents who met criterion A (lifetime exposure and a reaction of intense fear, helplessness, or horror), criterion B (at least one re-experiencing symptom in the past year), and at least one criterion C symptom (avoidance in the past year). Thus, the "past year at least subclinical PTSD" category included respondents who also met the full criteria for PTSD.

Karg pointed out that the MHSS did not have adequate sample size to enable the researchers to look at three mutually exclusive categories: no subclinical or clinical PTSD, subclinical PTSD but not clinical PTSD, and clinical PTSD. This approach was consistent with how other studies have looked at subclinical PTSD (including clinical PTSD). Figure 2-1 shows a diagram of how traumatic event exposure and posttraumatic stress symptoms were assessed in the Mental Health Surveillance Study. Karg said that the interviewers administering the questions had graduate degrees in clinical psychology.

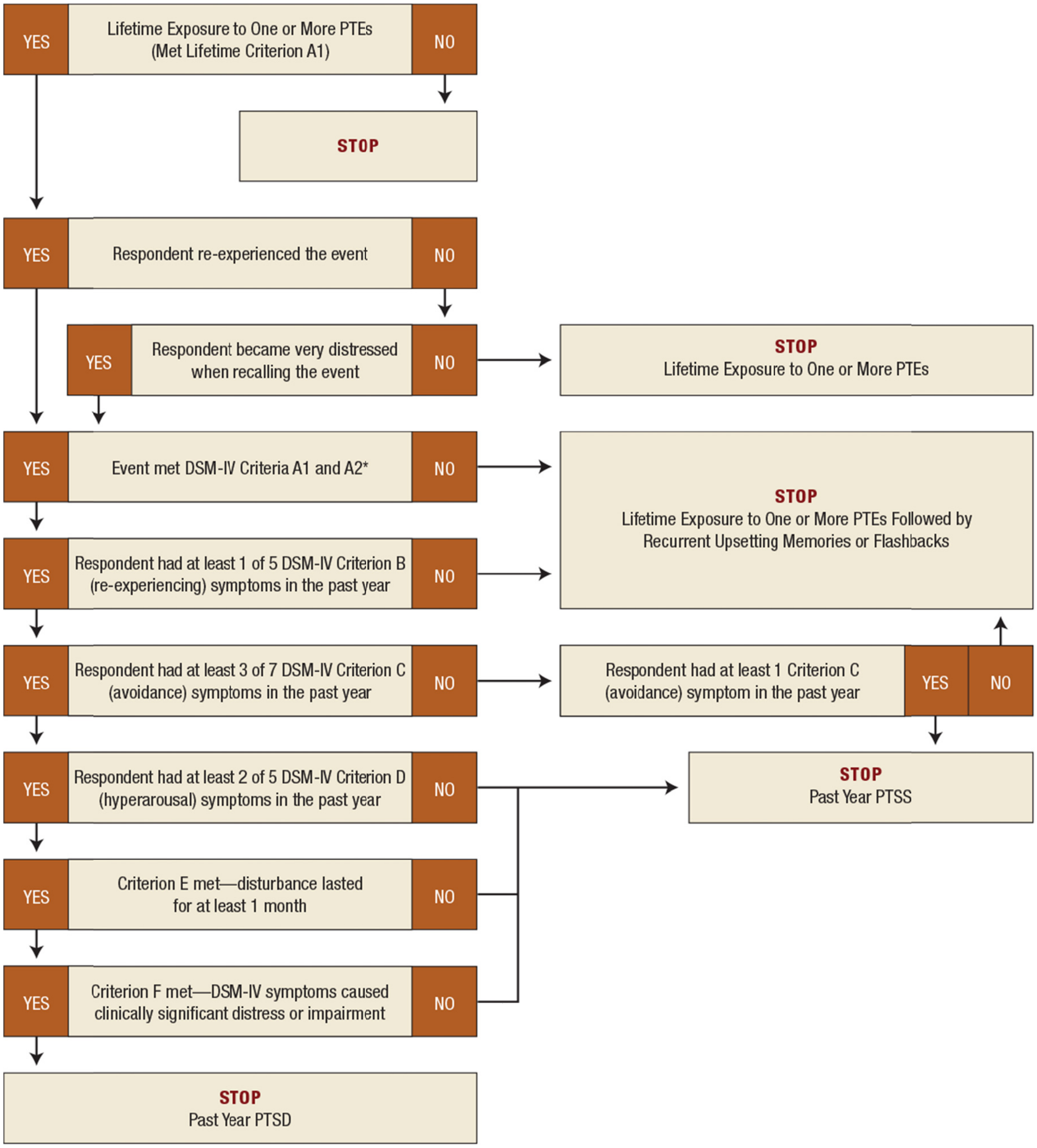

FIGURE 2-1 Assessment of lifetime exposure to one or more potentially traumatic events and posttraumatic stress in the Mental Health Surveillance Study.
SOURCE: Forman-Hoffman, V.L., Bose, J., Batts, K.R., Glasheen, C., Hirsch, E., Karg, R.S., Huang, L.N., Hedden, S.L. (2016). *CBHSQ Data Review: Correlates of lifetime exposure to one or more potentially traumatic events and subsequent posttraumatic stress among adults in the United States: results from the Mental Health Surveillance Study, 2008-2012.* Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Behavior Health Statistics and Quality.

Because the report discussing the results from the study has not yet been released at the time of the workshop, Karg provided a general overview of the types of analyses that can be conducted on the basis of the clinical interview data. The data can provide estimates of the percentage of: adults who had exposure to one or more traumatic events in their lifetime; past year subclinical PTSD (including clinical PTSD) among adults with lifetime trauma exposure; and past year clinical PTSD among adults with lifetime trauma exposure. The prevalence estimates of lifetime trauma exposure and past year subclinical and clinical PTSD can be analyzed by sociodemographic characteristics. Researchers can also examine mental health indicators, substance use, and chronic health conditions by lifetime trauma exposure and past year subclinical (including clinical PTSD).

Karg acknowledged that the MHSS had several limitations. One limitation was that the survey was conducted only in English, which meant that people who were not able to complete the survey in English had to be excluded. Another limitation was that the survey was primarily household based, and so it did not include some populations at higher risk for trauma exposure, such as people living in institutions, homeless people not living in shelters, and active-duty military personnel. In addition, due to the nature of the survey, the data could not be used to establish temporality or to suggest causal influences. Karg also added that the MHSS was based on the DSM-IV-TR, not the DSM-5.

One difficulty of a study design that involves an initial interview and a follow-up assessment is that as the time between the interviews increases, so does the risk of false positives and false negatives on the follow-up assessment. Karg said that the goal was to complete most of the MHSS clinical interviews within 2 weeks following the NSDUH assessment, but completing them up to 4 weeks after the assessment was allowed.

An additional limitation discussed by Karg was the use of the SCID, and in particular the version that was used. Although the instrument is useful for estimating serious mental illness, it may not be ideal for estimating specific disorders or subthreshold diagnoses. Unlike the Composite International Diagnostic Interview, used in the National Comorbidity Study Replication (NCS-R) or the Alcohol Use Disorder and Associated Disabilities Interview Schedule IV (AUDADIS-IV) used in the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC), the protocol used for the SCID in the MHSS called for stopping the administration of the disorder's module once the criteria were no longer met. As she had noted, the definition of at least subclinical PTSD (respondents who met criteria A and B and at least one symptom of criterion C) also had limitations. In contrast, the NESARC requires meeting criterion A and one symptom each from criteria B, C, and D.

As part of her presentation, Karg also briefly discussed published estimates from other sources of nationally representative data. Wave 2 (2004-2005) of the NESARC—which similarly to the MHSS, required PTSD criteria A1 (the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others)—estimated that between 68 and 84 percent of adults had lifetime exposure to one or more traumatic events. The Collaborative Psychiatric Epidemiology Surveys (CPES), the National Survey of American Life (NSAL), and the 2001-2003 National Comorbidity Survey-Replication—all of which required both PTSD criteria A1 and A2 (the person's response to the traumatic event involved intense fear, helplessness, or horror) —estimated that approximately 82-90 percent of adults had lifetime exposure to one or more traumatic events.

Karg noted that the results from the MHSS differ from the prevalence estimates obtained from other studies. The differences may be due to the use of screening questions: unlike other surveys, the MHSS included a set of screening questions in order to advance into the PTSD module. The MHSS respondents had to affirm lifetime PTSD criterion A1 and either of the lifetime criteria B questions asked to enter the SCID module that assessed past year PTSD.

Another potential explanation noted by Karg for the differences in the prevalence estimates may be related to the examples of traumatic events used by the different surveys. The instruments used to assess traumatic event exposure differed with respect to the number and type of examples of traumatic events that were provided in the first question. For example, the MHSS gave examples of traumatic events in a single statement that read "…things like being in a life threatening situation like a major disaster, very serious accident or fire; being physically assaulted or raped; seeing another person killed or dead, or badly hurt, or hearing about something horrible that has happened to someone you are close to." In contrast, the NESARC provided a much more inclusive series of questions about specific traumatic events. Karg added that the new SCID for the DSM-5 also provides a much more exhaustive list of traumatic events. The differences in the estimates could also be due to variation in the assessment of PTSD. The NESARC and the NCS-R used fully structured interviews to assess and define traumatic events and posttraumatic stress symptoms. The MHSS used a semistructured diagnostic interview that relied on clinical judgment in coding exposure to a traumatic event and the presence of posttraumatic stress symptoms. A final potential explanation provided by Karg for the differences relates to interviewer qualifications. The NESARC and NCS-R used lay interviewers who did not have input into the determination of whether or not an event was sufficiently traumatic to meet DSM-IV criteria. The MHSS used clinical interviewers who were trained to differentiate very stressful events from actual criterion A traumatic events, thereby reducing the possibility of false-positive reporting of symptoms.

In closing, Karg summarized the changes affecting the definition of PTSD as a result of the transition from the DSM-IV to the DSM-5. She said that in the DSM-5, criterion A2 (requiring fear, helplessness, or horror after traumatic event) was removed. The three clusters of DSM-IV symptoms are divided into four clusters in DSM-5: intrusion, avoidance, negative alterations in cognition and mood, and alterations in arousal and reactivity. DSM-IV criterion C (avoidance and numbing), was separated into two criteria: criterion C (avoidance) and criterion D (negative alterations in cognitions and mood). Three new symptoms were added in the DSM-5: persistent and distorted blame of self or others, persistent negative emotional states, and reckless or destructive behavior. In addition, several symptoms were revised to clarify expression.

Robert Ursano (Uniformed Services University of the Health Sciences) asked Karg to clarify how it was decided which traumatic event to ask about in cases in which respondents reported multiple traumatic events. Karg said that respondents were asked to specify which event had the most impact on their lives, but the interviewer was allowed to override a respondent's answer on the basis of clinical judgment for the purposes of deciding which event to refer to in the follow-up questions. Ursano commented that, traditionally, the follow-up questions are either asked for the event that the respondent specifies or for an event that is randomly selected from all traumatic events listed by the respondent. Karg said that the decision to allow the interviewer to substitute clinical judgment was made because in some cases a respondent may want to avoid talking about the event that was most upsetting to her or him. However, this type of change was very rarely made, if at all. Graham Kalton (Westat) asked how situations were handled in which the most traumatic event happened in the distant past and the respondent said that it no longer affected him or her. Karg responded that in these situations the respondent would not be administered the PTSD module.

Jonaki Bose (SAMHSA) said that it is very useful for SAMHSA to understand the tradeoffs associated with asking about only one event. One question is whether that approach is still better than not having any data at all, or are the biases introduced so large that this is not worthwhile doing. She urged the workshop participants to revisit this question throughout the day as part of the discussions about measures.

SOURCES OF NATIONAL DATA ON TRAUMA

Dean Kilpatrick (Medical University of South Carolina) delivered a presentation (prepared in collaboration with John Boyle, ICF International) on existing national survey data on the prevalence of exposure to potentially traumatic events and PTSD. He began by discussing several key definitional and methodological issues that he considers key to understanding epidemiological research on these topics. He noted that the word “trauma” is used in two ways: (1) a stimulus, that is, a stressor event capable of having negative effects on mental health and behavior or (2) a response of PTSD or related disorder that follows exposure to a stressor events. Similarly, when measures of trauma are discussed, they sometimes refer to measures of exposure to stressor events, sometimes to measures of responses following exposure to the stressor events, and sometimes to both measures of exposure and responses.

Kilpatrick pointed out that part of the reason for the lack of clarity is related to the importance of stressor events in the PTSD diagnosis. PTSD criterion A defines the types of stressor events capable of producing PTSD. If a stressor is not a criterion A event, it cannot, by definition, produce PTSD, so other PTSD criteria are not assessed. Many researchers call criterion A events traumatic events or potentially traumatic events. Kilpatrick commented that potentially traumatic event is a better term because not everyone exposed to a stressor event develops PTSD: in other words, events are only potentially traumatic. In addition, there are a variety of cultural, individual, biological, and other factors that determine whether an event becomes traumatic or not. Kilpatrick urged greater precision when discussing these concepts.

Revisions to the DSM have further contributed to the lack of clarity because they often involve changes to the definition of potentially traumatic events. Kilpatrick noted that the PTSD criterion A definitions of potentially traumatic events are different in the DSM-III, the DSM-III-R, the DSM-IV (and DSM-IV-TR), and the DSM-5. These differences also make it difficult to compare exposure or PTSD prevalence in studies that measure potentially traumatic events or PTSD symptoms using different editions of the DSM. One of the problems with the DSM-IV and DSM-IV-TR definition, he noted, is the inclusion of the A2 criterion that requires a response involving intense fear, helplessness, or horror. Including that criterion may have made sense theoretically, but staying true to that definition is very difficult in epidemiological studies.

Kilpatrick described several additional methodological issues associated with measuring the prevalence of potentially traumatic events and PTSD in population studies. One challenge is to collect data in the most cost-effective way, using methods that facilitate willingness to disclose information about exposure to all relevant potentially traumatic events, including those involving sensitive topics. A critical issue is whether the survey uses behaviorally specific questions to assess potentially traumatic events, especially for people with the highest probabilities of increased risk of PTSD (such as those involving sexual violence, other interpersonal violence, and military combat). If some of these potentially traumatic events are undetected by the data collection instrument, the survey is likely to underestimate PTSD prevalence. Another challenge highlighted by Kilpatrick is measuring PTSD using current DSM criteria in a way that is capable of producing accurate estimates of partial, subthreshold, and subclinical PTSD. If the goal is to capture these forms of PTSD, then adequately measuring a wide range of symptoms is important.

Kilpatrick noted that there are some challenges specific to measuring exposure to potentially traumatic events that are associated with sexual violence and other interpersonal violence. These types of violence are very prevalent and more difficult to measure than other events because of stereotypes and stigma surrounding them. The stereotypical image of rape is much narrower than the legal definition, and researchers find that when behaviorally specific terms are used that meet the definition of rape (e.g., something that happened while under the influence of drugs or alcohol, something done by a person that the respondent knows well, etc.), as many as half the respondents in a typical survey do not consider these types of events as rape. This disconnect (between the legal and a common stereotypical definition of rape) means that if the question simply asks whether the person has ever been raped, without referring to a range of specific behaviors, many people will only think about reporting events that fit the stereotype. Terrence Keane (Boston University School of Medicine and Veterans Affairs National Center for Posttraumatic Stress Disorder) noted that a similar problem occurs when asking military populations about combat, which is defined in many different ways by people who have been in war zones.

Kilpatrick said that well-designed studies, such as the National Intimate Partner and Sexual Violence Survey, conducted by the Centers for Disease Control and Prevention, indicate that 18 percent of adult women and 1-2 percent of adult men in the United States have been victims of rape. In terms of intimate partner violence, 36 percent of women and 29 percent of men have been victims of rape, physical violence, or stalking by an intimate partner.

Kilpatrick noted that there is a lot of research indicating that these types of potentially traumatic events cannot be measured with simple gatekeeping questions. Although it may be tempting to group several items together and ask a general question to save time and reduce the survey burden, respondents need to be provided with some context and be asked several screening questions in order to be able to consider what they are being asked and think about their responses.

Kilpatrick reminded participants of the four-step model of survey response,[4] which was also discussed in a National Research Council report on estimating the incidence of

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[4] Tourangeau, R. (1984). Cognitive sciences and survey methods. In *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines.* Committee on National Statistics, Division of Behavioral and Social Sciences and Education, National Research Council. Washington, DC: The National Academies Press.

rape and sexual assault.[5] According to this model, respondents first need to comprehend the question and instructions. Second, they need to retrieve specific memories or information relevant to the question. Third, they need to make judgments about whether these memories or information match what is being asked in the question. Finally, respondents need to formulate a response based on a number of considerations, ranging from whether they think the answer is accurate to potential concerns about stigma or confidentiality.

Kilpatrick said that there are few studies that have produced national data on potentially traumatic events and PTSD. One notable exception is the NCS-R, which was conducted in the early 2000s, as a follow-up to the National Comorbidity Survey (which had been conducted in the early 1990s). The NCS-R was a nationally representative probability sample of English-speaking adults age 18 and older, and it involved in-person interviews conducted by lay interviewers and fully structured instruments. The data collected included DSM-IV diagnoses, using the World Health Organization Composite International Diagnostic Interview. The assessment of lifetime exposure to potentially traumatic events was very comprehensive, through a series of 26 questions about exposure to specific DSM-IV A1 criterion potentially traumatic events. These questions were followed by additional questions to find out which A1 events also met A2 criteria (the person having been terrified or frightened, helpless, shocked or horrified, or numb).

The NCS-R found that 79 percent of the respondents had been exposed to one or more potentially traumatic events on the basis of the DSM-III. Using the DSM-IV criteria, lifetime PTSD prevalence was 7 percent overall, 10 percent among women and 4 percent among men. Past 12 months PTSD prevalence was approximately 4 percent overall, 5 percent among women and 2 percent among men.

Kilpatrick also described was the NESARC, conducted in 2004-2005, which was also a nationally representative probability survey of adults. The interviews were conducted in person, by lay interviewers, using the AUDADIS-IV, which is a fully structured interview instrument. The survey assessed lifetime exposure to potentially traumatic events and PTSD using DSM-IV criteria. The exposure was assessed with 27 questions enumerating specific potentially traumatic events. In the case of respondents who had more than one event, the event that was the worst was identified. The PTSD module measured what was called full and partial PTSD, asking about all PTSD symptoms with no skip-outs (i.e., all questions had to be answered). The survey also measured functional impairment.

The results on exposure to potentially traumatic events in the NESARC were very similar to the results from the NCS-R: the survey found that 80 percent of the respondents were exposed to at least one event. Lifetime prevalence of PTSD associated with the only or worst event was approximately 6 percent. Lifetime prevalence of partial PTSD, defined as not meeting full diagnostic criteria for PTSD but having at least one symptom in each of the B, C, and D criteria, was 7 percent. Kilpatrick said that he was not able to locate data on past year or current PTSD from the NESARC. However, NESARC data are available for lifetime mood, anxiety, substance use disorders, and suicide attempts: those data show that

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[5] National Research Council. (2014). *Estimating the Incidence of Rape and Sexual Assault.* Panel on Measuring Rape and Sexual Assault in Bureau of Justice Statistics Household Surveys, C. Kruttschnitt, W.D. Kalsbeek, and C.C. House, Editors. Committee on National Statistics, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

respondents with full PTSD, as well as those with partial PTSD, had elevated rates for those characteristics.

Kilpatrick also briefly discussed the NSDUH MHSS follow-on study, which had been described by Karg earlier. As noted, the assessment of exposure to potentially traumatic events was less comprehensive in the MHSS than in other studies. Furthermore, in part because of the characteristics of the SCID, the PTSD symptom assessment module had many skip-outs, potentially excluding many respondents who may have had undetected events. Kilpatrick said that an approach such as the one used by the MHSS unavoidably leads to lower estimates of potentially traumatic events and PTSD than those obtained by other studies. Attempting to assess partial PTSD or subclinical PTSD using this method would be nearly impossible because respondents are not asked about the full range of symptoms. He added that the use of clinically trained interviewers in epidemiological studies of this type is also not ideal, because error variance could increase if the interviewers are substituting clinical judgment for respondents' reports and introducing differences in the way questions are asked or which questions are asked.

Commenting on the implications of the transition from the DSM-IV to the DSM-5, Kilpatrick said that due to the changes, data on exposure to potentially traumatic events and of PTSD that were based on the DSM-IV cannot be used to determine prevalence rates in accordance with the DSM-5. He summarized the key DSM-5 changes to criterion A events as follows:

- Potentially traumatic events no longer have to produce "fear, helplessness, or horror."
- The types of sexual violence events defined as potentially traumatic events were expanded.
- Learning about the unexpected death of a close family member or friend is no longer a potentially traumatic event unless the death was violent or accidental.
- A new category of potentially traumatic events was added that involves work-related repeated or extreme indirect exposure to aversive details of potentially traumatic events experienced by others.
- There is an explicit recognition that exposure to multiple potentially traumatic events is common and that PTSD can occur in response to more than one event.

In addition to changes in the criterion A events, Kilpatrick highlighted the following additional revisions in the DSM-5 (see the list of DSM-IV criteria above):

- Three new symptoms (D3, D4, and E2) were added and four others (D1, D2, D7, and E1) were modified.
- Symptom-based criteria restructured from three in DSM-IV to four in DSM-5.
- Nonspecific PTSD symptoms are now required to develop or worsen after exposure to a potentially traumatic event or events.
- There is in acknowledgement that PTSD symptoms can incorporate responses to more than one potentially traumatic event.

In conjunction with the DSM-5 PTSD work group, Kilpatrick was involved in the development of a web-based assessment instrument designed to evaluate the impact of the proposed diagnostic changes on estimates of PTSD prevalence, and he described some of the findings from that project. The instrument was used in two surveys: the National Stressful Events Survey (NSES) and the Veterans Web Survey (VWS). The NSES sample (N = 2,953) was recruited from a national online panel of U.S. adults,[6] while the VWS sample (N = 345) included veterans who had previously agreed to be contacted about research studies at the U.S. Department of Veterans Affairs National Center for PTSD in Boston.[7]

Kilpatrick discussed one of the two studies, the NSES. He said that the survey was self-administered but designed to mimic a highly structured clinical interview with follow-up questions. The instrument measured all DSM-5 PTSD criterion A events, DSM-IV A1 events scheduled for elimination, and DSM-IV criterion A2 events. In addition, all 20 DSM-5 PTSD symptoms were measured, and the instrument included follow-up questions to determine which traumatic event or events were involved with each symptom, how recently the symptom had occurred, and how disturbing the symptom was during the past month. For new and modified symptoms, follow-up questions were asked to determine which elements of the symptom were being experienced by the respondent. The survey also measured functional impairment. Kilpatrick said that the data collection demonstrated the feasibility of collecting information using DSM-5 criteria.

The study found slightly higher percentage of exposure using the DSM-5 criterion A events than had been found in the other studies discussed. Approximately 88 percent of respondents reported at least one such event. For events that were excluded from the DSM-IV, there was an approximately 4 percentage point drop when using the DSM-V criteria. Kilpatrick said that the percentage of people who experienced only one potentially traumatic event was very small (approximately 15 percent of all respondents), and this low rate underscores the importance of developing an approach that can take it into account.

Kilpatrick and his colleagues defined composite event PTSD “caseness” as cases that meet criteria B, C, D, and E symptoms with a combination of criterion A stressor events (must have at least one B, one C, two D, and two E symptoms to some combination of DSM-5 criterion A events) and also have functional impairment. They defined the requirements for same event PTSD “caseness” as: at least one B, one C, two D, and two E symptoms to the same DSM-5 criterion A stressor event, combined with functional impairment.

Parallel definitions were used for the DSM-IV criteria. One question for the researchers was whether the transition to the DSM-5 would lead to substantially increased estimates of prevalence. Kilpatrick said that in terms of the composite event and same event PTSD rates, the differences between the DSM-IV and DSM-5 rates were small, and to the

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[6] For details, see: Kilpatrick, D.G., Resnick, H.S., Milanak, M.E., Miller, M.W., Keyes, K.M., and Friedman, M.J. (2013). National estimates of exposure to traumatic events and PTSD prevalence using DSM-IV and DSM-5 Criteria. *Journal of Traumatic Stress*. 26(October), 537–547.

[7] For details, see: Miller, M.W., Wolf, E.J., Kilpatrick, D., Resnick, H., Marx, B.P., Holowka, D.W., Keane, T.M., Rosen, R.C., Friedman, M.J. (2013). The prevalence and latent structure of proposed DSM-5 posttraumatic stress disorder symptoms in U.S. national and veteran samples. *Psychological Trauma: Theory, Research, Practice, and Policy,* 5(6), 501-512.

extent differences existed, the DSM-5 rates were in fact slightly lower than the DSM-IV rates.[8]

Kilpatrick said that the data from the NSES show that it is feasible to develop a self-administered, structured survey instrument and collect cost-effective data that measure all potentially traumatic events following the DSM-5 criteria using behaviorally specific questions, all DSM-5 PTSD symptoms, and PTSD-related distress, along with functional impairment. This assessment strategy was able to determine which PTSD symptom occurred in response to multiple potentially traumatic events, which provides an approach that can be implemented in large-scale surveys to address the methodological challenges associated with measuring exposure to more than one event and with the fact that risk of PTSD is related to the number of potentially traumatic events experienced.

In closing, Kilpatrick emphasized that he believes that any epidemiological study attempting to measure PTSD needs to include a thorough, detailed assessment of exposure to potentially traumatic events, using behaviorally specific terms. Although the temptation to keep the number of questions to a minimum is understandable, studies that attempt to cut corners could be seriously flawed. On the other hand, if potentially traumatic events are adequately measured, it is relatively easy to determine based on survey data how exposure increases PTSD risk and the risk of other mental disorders. To obtain estimates of partial, subthreshold and subclinical PTSD, it is necessary to measure all DSM-5 PTSD symptoms. Although skip-outs are often used, Kilpatrick does not consider this to be a methodologically sound approach. He also noted that it is important to begin moving away from the notion that PTSD should be assessed in relation to only one event. When earlier versions of the DSM were published, the assumption was that exposure to multiple events was rare, but research has shown that this is not the case.

Kilpatrick also addressed the role of clinically trained interviewers in collecting PTSD data in large-scale surveys. Although clinician-administered semi-structured interviews are generally considered the “gold standard,” these interviews are not only expensive, but they can also be less reliable than standardized interviews conducted by lay interviewers because, as noted earlier, different clinicians using different follow-up probes and substituting their own judgments for what the respondent said can lead to greater error variance. He added that conducting the interviews in person may also not be necessary. Instead, multimode data collection approaches could be considered, with at least some of the interviews conducted through modes other than face to face, and the cost savings could be used to increase sample size.

Terrence Keane (Boston University School of Medicine and U.S. Department of Veterans Affairs National Center for Posttraumatic Stress Disorder) said that clinician judgment used to be very important in the study of PTSD, but over the course of the past few decades researchers have noted remarkable convergence of data obtained from surveys and from clinical studies. The success of the NSES survey points to a cost-effective mechanism for collecting these types of data and also provides valuable guidance for public policy in this area.

Terry Schell (RAND) commented that the main limitation of the NSES approach is the web-based sample, which is inexpensive but not truly nationally representative. However, if a nationally representative sample already exists, such as the NSDUH, then a

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[8] See reference in fn. 4, above.

web-based approach can be used for a follow-on survey, and it would have several advantages over a follow-on survey conducted by telephone. In addition to reduced costs, a self-administered questionnaire delivered by the web also represents a better substitute for the Audio Computer-Assisted Self-Interview used in the NSDUH. He noted that data show that trauma exposure, in particular, tends to be underreported in telephone surveys.

Hortensia Amaro (University of Southern California) asked whether a web-based assessment could introduce any biases due to lower rates of Internet access or lower proficiency with using the Internet among some population groups. Kilpatrick responded that survey methodologists are studying these questions and that it seems clear that multimode approaches are needed. Each mode has some advantages and disadvantages.

Kalton wondered whether it would be possible to begin with questions about PTSD, if that is the primary goal of the data collection, and then ask follow-up questions to try to determine the causes of the PTSD. This approach could reduce the problems associated with measuring exposure to multiple events, many of which are not relevant. Kilpatrick said that PTSD is different from other mental health issues, such as depression, because PTSD is a response to an event. Thus, it is important to get people to think about whether they have any problems that are in response to things that have happened to them.

Evelyn Bromet (Stony Brook University) commented that studies on exposure to potentially traumatic events, PTSD, and risk factors have been consistent in their findings over the past several decades and that more targeted research is needed to produce information that could be used for prevention, instead of focusing on prevalence rates. Keane responded that there have been changes in traumatic experiences and their impact on people’s lives, noting in particular a change since 9/11. Consequently, he said, it is important to continue to keep track of prevalence rates if it can be done at a modest cost. Updated prevalence rates also help keep the issue in front of policy makers. Kilpatrick added that prevalence rates for serious mental disorders drive funding allocation for states, and if PTSD is not included, then people with PTSD could be underserved in term of resource allocation.

3

Key Concepts and Measurement Challenges

CONCEPTUALIZING EXPOSURE TO TRAUMA AND TRAUMA-RELATED DISORDERS AND SYMPTOMS

Robert Ursano (Uniformed Services University of the Health Sciences) began his presentation by noting that SAMHSA has a requirement to collect data for a specific purpose, and that task is different from the goals of many researchers, which is to understand everything there is about trauma and stressor-related disorders. Nonetheless, he argued, consideration should be given to quick turnaround surveys in response to national threats and disasters, which could assess the impact, including PTSD, on affected communities. A large-scale survey such as the NSDUH would not be nimble enough to accommodate these types of needs as they arise, but Ursano said that he believes that federal agencies are in a better position than others to address such needs.

Ursano said that there are a range of outcomes that are relevant to the discussions of trauma and are important to measure, whether the goal is in-depth research or to estimate the number of people in need of services. He approached the discussion of key concepts from several different perspectives. In terms of mental health responses to trauma, disasters and public health emergencies, the most prevalent distress responses to trauma exposure are: a sense of vulnerability, change in sleep, irritability and distraction; belief in exposure; multiple idiopathic physical symptoms and multiple unexplained physical symptoms; and isolation. He pointed out that irritability is important to measure as a separate dimension because of associated outcomes, such as increased motor vehicle accidents, family violence, and suicide.

Ursano said that in most studies the emphasis is on psychiatric illnesses, such as PTSD, depression, and complex grief. From among these outcomes, grief is the least often included, but it is an important outcome in the context of trauma. In looking at health risk behaviors, such as alcohol and drug use, Ursano emphasized that the question that needs to be asked is not whether someone is addicted to alcohol or drugs, but rather whether they have increased their use in the recent past, such as in the past week.

Ursano said that it is well documented that the greater the exposure to traumatic events in a community, the more psychiatric causalities there are. He also noted, as have other workshop participants, that research has shown that the more potentially traumatic events a person is exposed to, the higher the likelihood of developing a disorder. However, he noted that it is still important to measure levels of exposure and prevalence rates for disorders. He said that he liked the emphasis on potentially traumatic events by Dean Kilpatrick (Medical University of South Carolina) (see Chapter 2): to really understand outcomes, it is important to study the events and what happens in response to those events.

He likened trauma to toxic exposure, with the need to understand the toxin. He noted that the DSM-5 revisions were an important step forward for research in this area.

To meet its goals, Ursano said that SAMHSA will need to collect dimensional, as well as categorical, data. In other words, as he had mentioned, it is necessary to understand whether a person has altered her or his drinking pattern, in addition to understanding whether the person meets criteria for alcohol addiction. He also emphasized the need to measure the "cascade of adversities" a person may be facing after exposure to a potentially traumatic event, in addition to measuring exposure to the event. Those adversities could include financial adversities or problems in the areas of housing, employment, or services.

Ursano also emphasized the importance of studying community-level resilience factors and exposures, whether that means a few blocks or a larger neighborhood. He noted that ZIP-code-level data already exist, and they can provide contextual information to understand potentially traumatic events and the associated morbidity and mortality. There are also contextual issues at the family level that could be important to capture. One example is the increased rates of child neglect in U.S. Army families that have been noted by researchers during recent wars.

Discussing the range of psychosocial responses to trauma and disaster, Ursano noted that there are many that warrant consideration for measurement, including some that are not typically included in studies of this topic. He listed the following for consideration:

- horror
- anger
- resilience and altruism
- fear
- sleep problems
- increased alcohol use and smoking
- grief
- anger at government
- blaming
- scapegoating
- social isolation
- demoralization
- loss of faith in social institutions
- guilt
- paranoia

Ursano pointed out that another way of thinking about what should be measured is from the perspective of health surveillance. If health surveillance is the primary goal, then the key measures may be different. For example, measuring distress and health risk behaviors rather than mental disorders may be more important. He reported that some of his research indicates that the question of whether a person has had difficulty balancing work demands with family concerns is a substantial predictor of the presence or absence of PTSD and depression. This question also provides data that can highlight a set of other potential needs in a family, which are not often assessed. Ursano summarized a potential list of post-disaster community mental health items as follows:

- distress
- psychiatric illness or symptoms
- health risk behaviors
- risk perception
- safety perception
- changes in behavior
- preparedness behaviors

Ursano also touched on the topic of resilience and listed the following concepts that have been highlighted by Dennis Charney as relevant:[9] optimism; recovery skills; self-regulation of emotions; attachment and social support; altruism; active or passive responses (instrumental). For example, knowing how optimistic an individual is or knowing the level of optimism in that person's neighborhood or ZIP code can provide useful information about the person's probability of recovering from a large-scale disaster event.

Collective efficacy, or the extent to which members of a community take care of each other, is another predictor of PTSD highlighted, Ursano noted. A study that looked at the probability of PTSD among Florida public health workers found that higher levels of collective efficacy at the community level were associated with lower probabilities of PTSD.[10]

Focusing specifically on the concept of PTSD, Ursano agreed with previous speakers that exposure to potentially traumatic events is very common. By a certain age, most people have experienced a potentially traumatic event in their lifetimes, and the question is whether that leads to chronic PTSD or not. Acute PTSD is frequent even in people without a psychiatric history, but rapid recovery is the norm. Ursano cautioned about focusing on only those with functional impairment because this approach would be similar to trying to understand cardiac disease by only studying people who have myocardial infarctions.

A research area of interest for the future is capturing the trajectory of PTSD, which Ursano noted due to its implications in terms of the need for interventions, but also as a measurement challenge. Although it is possible to ask three or four questions about how things were last month, the month before, and the month before that, understanding trajectories would ideally require a longitudinal study. For example, a four-wave study would enable researchers to classify people into groups with different trajectories and study predictors, such as the characteristics of the event.

As a final issue that is relevant to measuring exposure to traumatic events and PTSD, Ursano highlighted traumatic brain injury. He said that recent wars have underscored the importance of measuring traumatic brain injury, such as episodes or loss of consciousness or being dazed, as part of any data collection on this topic. In addition, data from the Army STARRS study show that about half of all soldiers have had an episode when they lost consciousness due to traumatic brain injury before even joining the Army, often due to concussions. In other words, traumatic brain injury is widespread, and research has found that parts of the brain that are affected are related to the ones that are affected by PTSD.

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[9] Charney D.S. (2004). Psychobiological mechanisms of resilience and vulnerability: Implications for successful adaptation to extreme stress. *American Journal of Psychiatry*, 161(2), 195-216.

[10] Ursano, R.J., McKibben, J.B.A., Reissman, D.B., Liu X, Wang L, Sampson, R.J., and Fullerton, C.S. (2014). Posttraumatic stress disorder and community collective efficacy following the 2004 Florida hurricanes. *PLoS ONE* 9(2), e88467. doi:10.1371/journal.pone.0088467.

Many postconcussive symptoms also overlap with PTSD. In addition, there are associations of those symptoms not only with PTSD, but also with generalized anxiety disorder, event-related panic disorder, and event-related depression, and understanding these connections can enable the better targeting of treatments. Ursano also pointed out that some studies have also found traumatic brain injury to be a predictor of suicide.

Robert Pynoos (University of California, Los Angeles) commented that studies have also examined the impact of traumatic brain injury among children and found that subsequent to episodes that involved loss of consciousness, young children's IQs dropped by several points and stayed lower for more than a year before they recovered.

Terrence Keane (Boston University School of Medicine and U.S. Department of Veterans Affairs, National Center for Posttraumatic Stress Disorder) noted that in some cases traumatic brain injury and PTSD are associated with the same events, but in other cases they are not. Sometimes there is subsequent alcohol and drug use, and the associations among these outcomes are not always easy to tease out. Ursano responded that this highlights the need to measure health risk behaviors, not just disorders. In other words, if the interest is in morbidity and mortality, then the question is what is a person doing that has increased his or her risk of morbidity and mortality?

MEASURING EXPOSURE TO TRAUMA, PTSD, AND SUBCLINICAL PTSD

Terrence Keane discussed approaches to measuring exposure to trauma, PTSD symptomology, and subclinical PTSD. He noted that subclinical PTSD first became of interest as part of the National Vietnam Veterans' Readjustment Study (NVVRS) because researchers noticed that there was a large group of people who did not fit the definition of PTSD because of a single criterion: avoidance. With national samples of Vietnam veterans and their peers, the NVVRS found that many of the participants had been involved in the antiwar movement and the veterans' benefits movement, which meant that they were not avoiding thoughts of the traumatic events. Keane said that although subclinical PTSD was a useful concept at the time and it continues to be used in various ways, it is not clear that the concept is still useful today. It is possible that the use of the term is in fact contributing to confusion.

Keane noted that there are many different measures of trauma exposure and PTSD symptomology, and he pointed out that further information is included in his presentation slides and can also be found online. He then listed several measures that he considers to have acceptable reliability and validity for exposure and symptoms.

For exposure, the options for self-report measures include:

- Traumatic Life Events Questionnaire
- Traumatic Events Questionnaire
- Trauma History Questionnaire
- Life Events Checklist
- Stressful Life Events Screening Questionnaire
- Traumatic Stress Schedule
- Trauma Assessment for Adults – Self Report

- The Life Stressor Checklist – Revised
- Trauma History Screen
- Brief Trauma Questionnaire

In terms of self-report measures for symptoms, one of the main considerations highlighted by Keane is whether the measure has been updated for the DSM-5. Keane noted that some of the most common measures have already been updated or are in the process of being updated. He highlighted three measures that are fully updated for the DSM-5: the PTSD Checklist; the Life Events Checklist; and the Primary Care PTSD screen.

Keane noted that he considers the World Health Organization Composite International Diagnostic Interview (CIDI) to be a very comprehensive measure of symptoms. He said that he also likes the approach used by the National Stress Events Survey approach, which was developed with Kilpatrick's leadership. Keane then listed several additional symptom measures that are available:

- PTSD Checklist, Civilian
- Davidson Trauma Scale
- Posttraumatic Stress Diagnostic Scale
- Trauma Symptom Checklist
- Modified PTSD Symptom Scale
- PTSD – Interview
- National Women's Study PTSD Module
- Purdue PTSD Scale – Revised
- Screen for Posttraumatic Stress Symptoms
- Self-Rating Inventory for PTSD
- CIDI – PTSD Module
- Impact of Event Scale – Revised
- PTSD Symptom Scale – Interview
- Symptom Checklist – 90 PTSD Scales
- Penn Inventory for PTSD
- Los Angeles Symptom Checklist
- Trauma Symptom Inventory
- Distressing Events Questionnaire
- Posttraumatic Symptom Scale
- Minnesota Multiphasic Personality Inventory – 2 Keane PTSD Scale
- National Stress Events Survey
- Harvard Trauma Questionnaire
- Revised Civilian Mississippi Scale

Keane pointed out that the earlier discussions highlighted the role of comparability among surveys. If researchers could agree on a reasonably standardized approach, the resulting comparability would have some advantages for everyone. However, it is important to note that some of the measures were developed with a focus on specific types of traumatic events, such as sexual assault or interpersonal violence. These measures may not work well in other contexts.

Keane said that a primary consideration when selecting a measure is the amount of time that can be allocated to administering the items and the topics covered by the other questions on the survey. Some of the relatively short screening instruments are the Traumatic Stress Schedule, the Traumatic Events Questionnaire, the Brief Trauma Questionnaire, the Trauma Assessment for Adults, and the Trauma History Screen.

As others have noted, exposure to traumatic events can lead to a range of outcomes. Keane said that researchers need to carefully consider the extent of psychopathology and the comorbidity they intend to measure. The related concepts of functioning, impairment, and quality of life are also important. Another decision that is needed prior to selecting a measure is whether the goal is to understand current symptoms, perhaps by specifying a time frame, such as the past month or past 3 months, or to understand lifetime symptoms.

Other considerations include the sensitivity and specificity of the measure and utility analyses more broadly, to determine whether the questions are measuring the concepts of interest to the researchers. Keane commented that one could debate whether a “gold standard” exists to evaluate the measures: he does not believe that there is one.

The mode of administration is another factor that needs to be considered when selecting a measure. If interviewers are to be used, one consideration needs to be the time and cost involved in training them. For a national survey, this can be a large front-end expense. Keane said that he is becoming increasingly more convinced about the value of web-based self-administered approaches, such as the ones described by Kilpatrick, particularly because they enable increased standardization.

Web administration could also make it more feasible to design a longitudinal study and follow the same sample over time in order to collect data on trajectories, levels of recovery, and resilience. However, Keane noted, in order to implement a longitudinal study successfully, it is important to take into consideration how multiple administrations could affect the measure and whether any drift could be expected.

Benjamin Saunders (Medical University of South Carolina) commented that some of the measures reviewed have been developed for use in clinical settings, while others were developed for research purposes. The clinical measures tend to be the ones that are more concise, and this characteristic needs to be taken into consideration.

Terry Schell (RAND) agreed that some of the measures were developed to assess the severity of symptoms in a clinical setting, and although there may be scoring algorithms for evaluating sensitivity and specificity, these measures were not designed for probable diagnoses. He said that it is not clear how important it is to SAMHSA to collect data on diagnostic prevalence in contrast with obtaining a more in-depth understanding of the role of posttrauma mental health problems or psychopathology on a continuous scale. The use of the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (SCID) in the Mental Health Surveillance Study would indicate that diagnosis was the sole topic of interest.

Larke Huang (SAMHSA) said that SAMHSA is looking at population health broadly and would like to understand the differences between people who are at risk, people who have mild problems, and people who have serious problems. Understanding comorbidities with the conditions that SAMHSA is mandated to look at is another important part of the current effort. Keane responded that it appears that to meet SAMHSA’s needs both dimensional and categorical measures would be needed. He added that it is well documented that trauma exposure among populations with serious mental illness is associated with more severe impairment; consequently, additional measures on serious mental illness are also important to include. Kilpatrick noted that it is also well known that people with serious mental health problems have higher rates of exposure to interpersonal violence.

Huang asked what is known about how two estimates of exposure from different studies fit together: those of exposure to certain types of traumatic events and those of exposure to any traumatic event. Kilpatrick said that researchers' understanding of what constitutes a traumatic event and the definitions have changed over the years. The DSM-III referred to a "psychologically distressing event that is outside the range of usual human experience," but over time it became clear that these experiences are more common than previously assumed and that many people have been exposed to more than one traumatic event, some of which may be more toxic than others. It is also better understood that the effects are cumulative. This evolution explains in part the differences in estimates obtained by different studies, and it contributes to the increasingly more complex task of identifying the relevant events and then determining how multiple events may be related to outcomes of interest.

Keane added that many of the existing measures of exposure are dichotomous, and for each type of event, they simply ask whether it happened or not. Some of the most recent measures follow up each affirmative answer by asking how many times it happened and when was the last time it happened. These are useful additional dimensions to measure, although the number of times only shows a detectable difference in the data up to a certain point. Ursano commented that asking about how old the respondent was when the traumatic event was experienced would be the most useful addition to measures.

Jonaki Bose (SAMHSA) asked the participants to clarify whether there could be potential benefits to asking a very small number of questions on this topic, for example, by adding the items to the National Survey on Drug Use and Health. Some very short scales, such as the Primary Care PTSD Screen, do exist, but many of the comments seem to suggest that these would not provide adequate information for SAMHSA's purposes. Schell responded that the Primary Care PTSD Screen does not collect any information about the potentially traumatic event, only about symptoms. Keane added that keeping the topic of trauma in the center of attention is valuable in and of itself, but a well-designed study would set the stage for really understanding the prevalence of exposure and responses.

CHARACTERISTICS OF GOOD MEASURES OF TRAUMA

Schell discussed procedures for developing, scoring, and evaluating the performance of a trauma scale. He began his presentation by saying that measures of trauma exposure are very different from scales that one might develop on other topics and that applying psychometric theory and techniques to trauma scales can be counterproductive.

As background, Schell provided an overview of the psychometric theory of reflexive, or effect-indicated measures, which are measures with items that are theorized to share a common cause. The common cause is the construct to be measured, and the items reflect the influence of the construct or are the effect of the construct. The items are correlated with each other because they have the same cause, but they may otherwise be very dissimilar. For example, weight loss and suicidal thoughts are sometimes included on the same depression scale because they are both considered to be manifestations of a problem in a person's brain, but they are otherwise dissimilar. Most standard psychological measures are reflexive, and casual assumptions of this type are the basis of most psychometric analyses in general, including classical test theory, factor analysis, and item response theory.

Items in a reflexive measure are correlated due to their shared cause, and the quality of the measurement can be inferred from the correlation between the items. Schell noted that summing correlated items converges on an error-free measure of the common cause as the number of items goes to infinity, and the correlation between items approaches 1. This occurs because the interest is in the covariance term, not the variance. Schell said that for most scales, adding items leads to a better measure. In other words, one gets a better measure of the common cause if more items are averaged because as more items are added, the covariance of the items has increasingly bigger effect on the variance of the scale. He noted that reviewers of journal articles often ask authors to discuss Cronbach's alpha, which is a measure of the extent to which the covariance terms dominate in the variance of the sum, which is a function of the number of items and the average correlation between them.

Advanced psychometric methods can enable a measure to converge to being error free more quickly than a simple sum of items: for example, one can give more weight in the sum to items that are more correlated with the other items or by subtracting out of the scale the portion of variance that appears to be unique to an item, in other words, the one that is not caused by the common cause. However, Schell pointed out that an error-free measure of the common cause of the items is not necessarily an error-free measure of the intended construct. For example, the causal model could be wrong, or the measure may be reliable but not valid. There may be multiple shared causes, some of which the researcher did not intend to measure. An example of this is response bias, such as order effects. Schell said that he and his colleagues have noticed strong order effects when examining the data from some of the common PTSD scales, such that each item is correlated more strongly with the next item than would be expected under any of the available models. These serial correlations can affect studies that use factor analysis.

Schell argued that exposure to traumatic events is not a reflexive construct because the goal is not to measure the common cause, but, rather, the opposite, to measure the common outcome. Exposure to a traumatic event can be described as a formative construct, a cause-indicated construct, or a composite construct. The events can be very different, yet they are often combined by researchers because they are seen as a class of events.

Schell said that summing items creates a measure of the common cause, but this approach cannot be used unless the events are uncorrelated and equally predictive of the defined outcome. Because of that, he argued that summing up the items does not work for measuring exposure to traumatic events, even though it is commonly done in the field. A solution for scoring a formative scale is available on the basis of a theory that is applicable to life event scales. Schell noted that estimating the way to score the scale can be done through regression of that criterion on the items. This approach is particularly useful if a study included a measure of the effects of the exposure to a traumatic event, as specified by the theory. However, he added that this approach is rarely used, and he reiterated that key to its use is defining the criterion that the scale is supposed to predict first. Defining the scale is not possible without defining the criterion first, which in this case would be PTSD symptoms.

Schell said that the approach he described will weight the items in a way that helps figure out what combination best predicts the effect. For example, combat trauma could predict whether the person is in a wheelchair or not, and it could also predict whether the person has PTSD symptoms or not. However, the items are not weighted the same way for the prediction. This difference leads to essentially different scales, even with the same set of items. Schell suggested that instead of trying to think about items for traumatic events, it may be possible to think of a series of potentially traumatic events that have some relationship with PTSD symptoms, but that might have a different relationship with drug use, and a different relationship with other problems.

Schell pointed out that the concept of unidimensionality does not apply in this situation. In addition, each item is intended to have unique variance that is not error. In other words, one item may be useless for predicting PTSD but useful for predicting drug use. That situation would not mean that the item is filled with error: instead of thinking about items that are not correlated with the item total as bad items, in the context of trauma it is necessary to have items that are unique.

Another implication, Schell pointed out, is that in the case of formative scales that are theoretically defined by predictive criteria, the focus is generally on validity instead of reliability. Although test-retest reliability can be defined, it is usually not assessed. These types of items should not have high internal consistency reliability, otherwise they may be closing in on an error-free measurement of the same domain, rather than capturing different domains.

Schell summarized the three characteristics of formative scales in comparison with reflexive scales:

- optimally efficient when items/events are uncorrelated (which means that a shorter list could be used);
- less valid with higher values of Cronbach's alpha when they have been scored as summed scales; and
- less influenced by items that are highly correlated with other items, rather than more influenced by them.

Schell acknowledged that formative scales are very difficult to work with. There is no reason to believe that the various indicators can be treated as homogenous with respect to a risk factor. Rape has one set of risk factors, for example, which are different than the risk factors for auto accidents. These kinds of differences mean that a trauma scale cannot be used as a good outcome in a causal model.

Keane asked whether there are exceptions, such as externality and high risk taking that could be considered latent variables underlying exposure to a variety of different types of traumatic events. Schell agreed that some types of exposure can have common causes, and impulsivity is an example of that. If the items on a trauma scale are summed, the result could be an impulsivity measure, and that is why they should not be summed. However, if some of the items have common causes, they can be clustered into highly correlated dimensions, but this clustering is probably not worth doing unless there is a theoretical reason for it.

Schell said that although a regression equation is a potential solution for scoring these types of scales, this is not always possible or desirable to use. There are several other approaches that may be reasonable. One would be to score according to the strict construct definitions, when they are available. For example, in a study that involved measuring sexual assault based on the Uniform Code of Military Justice definition of sexual assault, the researchers did not need a criterion variable to know how to score that because the definition was very specific.

Respondents could just be presented with a list of events and asked whether they had experienced any of them. However, Schell said, he does not consider this a good approach for measuring trauma because a good enough definition of trauma is not available to enable one to decide what should be on the list and what does not need to be included. Relying on findings from earlier studies is certainly a possibility, and SAMHSA could design a study that looked at a comprehensive list of potentially traumatic events and their characteristics and figure out how to combine them to predict PTSD symptoms, drug use, and other outcomes of interest. Based on those data, Schell said, it may be possible to develop an approach to scoring the scales. Then that scoring could be used even in data collections that do not measure the criteria.

Schell said that the most common approach is to combine events without summing them, but he reminded participants that this could reduce the variance to the point at which it looks as though everyone has been exposed to trauma. This possible outcome illustrates an unavoidable tradeoff between the completeness of the trauma measure and its usefulness for any possible analysis.

A rarely utilized option is to minimize covariance before summing by dropping, combining, or down-weighting redundant items. For example, if data were collected on six items about sexual assault and they are all highly correlated, then one could review the covariance matrix and keep only the best item. Schell said that, theoretically, it would also be possible to keep the full set of items, but weight them in a way that is inversely proportional to their covariances. He added that he does not know of any study that has used this approach.

Schell said that even when a theorized criterion has been measured, it may be desirable to use a unit-weighted summed scale. One approach would be to figure out which subset of items, when summed, is the best predictor of the outcome. This analysis would be similar to doing a regression in which the betas are constrained to either be a 1 or a 0, and it can be done if it does not involve a significant loss of power. The result is a shorter list of traumatic events that can be summed to produce a predictor of PTSD. However, Schell reminded the participants, there is no such thing as a single scale from formative items, and the same set of items might not work as a predictor for a different item.

Schell concluded with an example of a measure of combat trauma that he and his colleagues have used on several occasions in military populations. The measure was derived from an initial set of 30 items by identifying the items that, when unit weighted, were the best predictors of PTSD. This approach worked well in the initial context, but when they tried to use it to predict physical aggression in people's homes, it no longer worked. The analysis showed that some deployment-related traumatic events have positive effects on violence in the home, while others have negative effects, so the measure that worked for PTSD did not work for this context.

4

Collecting Trauma Data About Children

OPERATIONALIZING THE CONCEPT OF TRAUMA IN CHILDREN

Robert Pynoos (University of California, Los Angeles) discussed ways of operationalizing the assessment of exposure to potentially traumatic events and the assessment of posttraumatic stress reactions in children. He began by saying that the approach to collecting data on these topics in children has evolved differently from the data collection approaches in adults. Unlike for adults and adolescents, there is no checklist of potentially traumatic events for children. In addition, the literature of trauma in children is much more nuanced and focused on details, such as age of onset, duration, and serial or sequential occurrence.

Pynoos described the SAMHSA-supported National Child Traumatic Stress Network (NCTSN), coordinated by the University of California at Los Angeles (UCLA) and Duke University National Center for Child Traumatic Stress. The NCTSN uses the UCLA PTSD Reaction Index for DSM-5, including the Trauma History Profile, as part of their core dataset. The scale includes 23 individual traumatic event types. Pynoos noted that clinical studies of children show that witnessing a parent’s rape produces levels of PTSD that are essentially equivalent to being sexually abused. A threat to a parent or sibling is considered to be one of the elements of feeling life threat among children. Because of this, the scales for children include a category for direct victimization and a separate category for being a witness.

Pynoos said that the literature on trauma in children also differs from the literature on trauma in adults in the way it addresses issues related to bereavement and the interplay of trauma and grief reactions. A relatively higher proportion of the deaths experienced by children occur under traumatic circumstances compared to the deaths experienced by adults. One example is the sudden death of a primary caregiver among young children.

One of the points underscored by Pynoos was that in psychiatric epidemiological studies it may be important to oversample children with comparatively rare, but high magnitude exposures. This could include children who witnessed homicide or the rape of a parent in order to evaluate severity of impact and outcome. This approach is similar to the study of rare medical conditions among populations.

Pynoos said that it is important to be mindful of the developmental epidemiology of exposure. Exposure to certain types of traumatic events is more likely at certain ages, and the profile of the event changes depending on age. Some events are more likely to co-occur among children, especially in early childhood. For example witnessing domestic violence, physical abuse, psychological maltreatment, neglect, and impaired caregiving can form a constellation of early childhood exposures. In addition these same conditions often are associated with lack of supervision and increased risk for dog bites, serious burns, and near drownings. The literature focused on trauma in adults rarely takes account of this co-occurrence when discussing early childhood exposure. These items are important to include in order to understand the full context of trauma history.

The exposure configuration changes in adolescence. Being a driver or passenger in a fatal car accident, witnessing gang rape, criminal victimization, and trafficking become more relevant. In addition, the adolescent experience is not the same as that of a younger child either. For example, being an adolescent driver or passenger in a car accident is different from being in a car accident while being driven to school by a parent.

Pynoos said that the risk of exposure specific to different events increases at different points over the life course. Thus, it is useful to think about the developmental epidemiology of exposure, rather than just thinking of a list of events. Researchers have also observed a "risk caravan," meaning what additional risks are accrued with the accumulation of different types of exposures.

Figure 4-1 shows the differences in the pattern of trauma types in early childhood, school age, and adolescence, based on data collected by the NCTSN. Pynoos said that the data are not from a nationally representative sample, but they show informative differences based on a large-scale (N=19,088) database of children and adolescents receiving services in the United States.

Based on the NCTSN data, Pynoos and his colleagues have been able to isolate cases of only emotional abuse in early childhood, and examine its effects in relation to its own characteristics and as a component of the early childhood constellation. They learned that emotional abuse under age six produces similar levels of PTSD as other traumatic events, perhaps because emotional abuse, such as threats of abandonment, is experienced by children as a life threat.

Pynoos said that the data also show how exposures to several different events work together. Emotional abuse has an additive effect when co-occurring with physical abuse, neglect, and witnessing domestic violence. In addition, symptom profiles may change as exposures occur across developmental periods. For example, when childhood sexual abuse is added to other early exposures, the symptom profile is dominated by posttraumatic stress relations related to the sexual abuse, perhaps masking some of the other trauma-related reactions. The data also shows a cascade of effects for exposure: sexual abuse at age 6 increases the risk of sexual assault by age 9. Through childhood and into adolescence, the risk for other issues that SAMHSA is interested in also tends to accumulate, including drug abuse, HIV, and various risky behaviors, representing a caravan of risk. Pynoos commented that this finding also means that it is possible to identify the many different points where one can intervene and possibly prevent the emergence of the next risk factor.

In terms of the debate about the advantages of a systematic review of trauma exposure in comparison with asking gateway questions, Pynoos said that in his work he benchmarks exposures against developmental periods, rather than asking about lifetime exposure. His method involves providing blocks of time that respondents can use to reference their experiences: for example, when you were little, before you went to school, in elementary school, in junior high school, or in high school. This approach can increase the reliability of responses in children and adolescents.

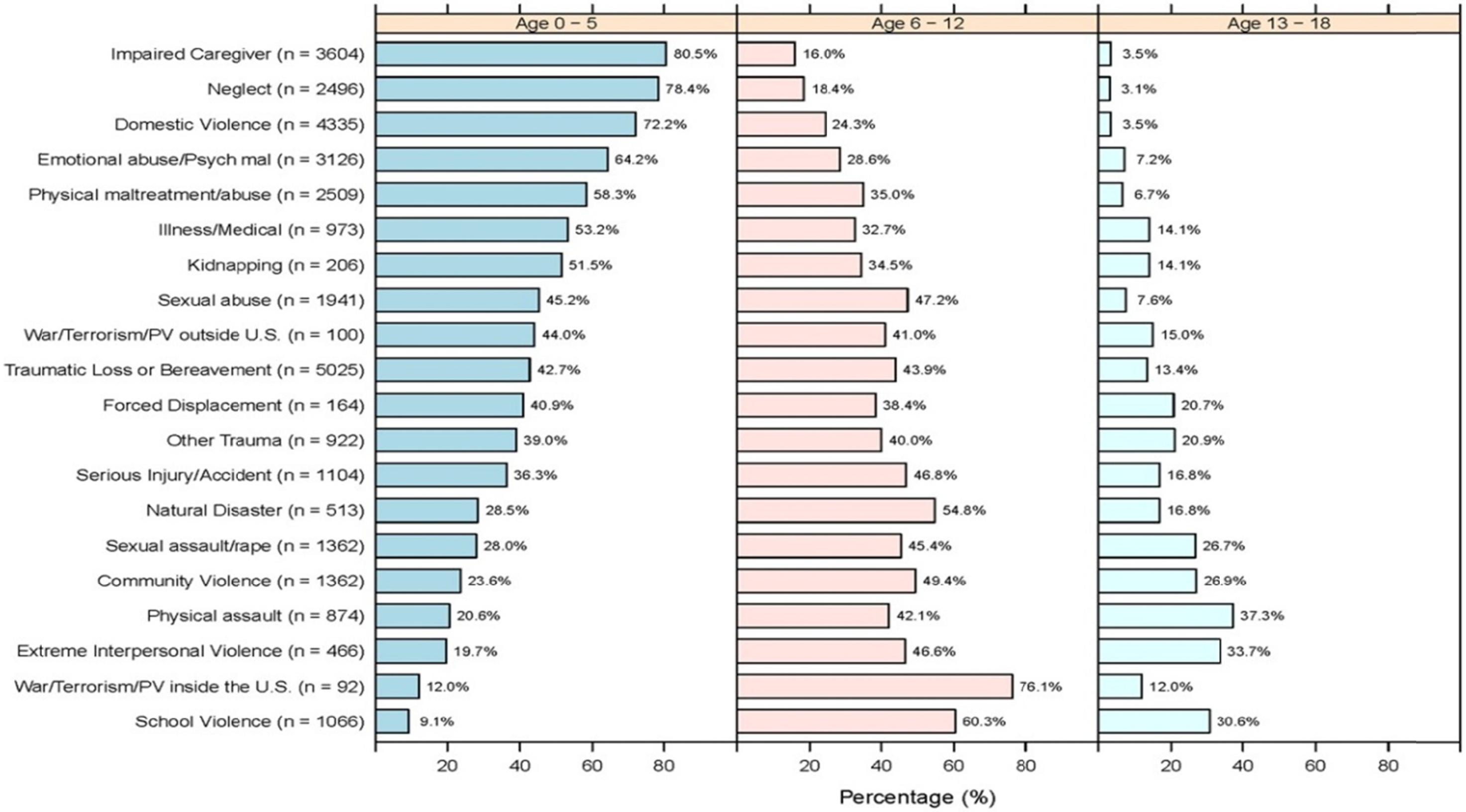

FIGURE 4-1 Developmental epidemiology by age of onset of trauma.
SOURCE: Pynoos, R.S., Steinberg, A.M., Layne, C.M., Liang, L.J., Vivrette, R.L., Briggs, E. C., Kisiel, C., Habib, M., Belin, T.R., & Fairbank, J. (2014). Modeling constellations of trauma exposure in the National Child Traumatic Stress Network Core Data Set. *Psychological Trauma: Theory, Research, Practice, and Policy, 6*(Suppl 1), S9-S17. Published by the American Psychological Association, reprinted by permission.

In the case of adolescents with exposure to multiple events, Pynoos said that he and his colleagues ask respondents to construct a hierarchy of events by ranking them and then indicating which ones are the most disturbing to them in their current lives. Sometimes they ask respondents to construct two hierarchies, one for childhood and one for adolescence, because research shows that adolescents mentally split off their adolescent experiences from their younger experiences. The responses are often unexpected: for example, when an adolescent ranks standing at a bus stop when he was thirteen and seeing a man brutally beating his wife as more intrusive than a recent experience of being in a shooting.

Pynoos said that children down to the age of 8 can reliably self-report, and provide comparisons to evaluations using structured interviews, such as the Clinician-Administered PTSD Scale (CAPS) and the child version of the Schedule for Affective Disorders and Schizophrenia (Kiddie-SADS). Children can be accurate reporters if the questions are phrased carefully with developmentally appropriate wording, and if they are adequately tested. However, there are certain types of data that children are not very good at reporting. For example, some of the typical gateway questions about upsetting memories and flashbacks do not work well in children. Some of those data, such as reports of restless, agitated sleep, can be collected with better accuracy from the parents. In addition, the 6 and younger criteria for PTSD in DSM-5 notes that children can have repetitive play, re-enactment behavior, and intrusions without overt signs of distress.

In terms of criteria C, Pynoos said that the lack of endorsement of avoidance symptoms is one of the main reasons why children do not meet diagnostic criteria for PTSD. For example, children are typically unable to describe “feeling numb”. The challenge with asking about avoidance is that children do not often have a choice for physical avoidance. In the DSM-5 the wording was changed to “efforts to avoid” and associated behaviors are included, such as a child throwing a tantrum when the parents want to take her or him somewhere that might serve as a reminder of a traumatic event. When it comes to avoidance, children are more likely to endorse the “do not want to talk about it” response option. Among category E symptoms, sleep disturbance is important, especially because in a young child it can have an enormous impact on learning.

Pynoos reiterated that the symptom profile can change as children become older. For example, in some of the studies of New York City school children, conducted in the aftermath of 9/11, school-aged children tended to report efforts to avoid, while adolescents did so less frequently, instead describing other problematic behaviors.

In terms of the transition to the DSM-5, Pynoos noted that the UCLA PTSD Reaction Index Trauma History Profile and the CAPS for children and adolescents are available. These now include wording for the new symptom items D and E (see Chapter 2), including negative emotions, such as guilt and shame, which require developmentally appropriate wording. They also include child-specific items for other trauma-related expectations, and child and adolescent worded questions about irritable and aggressive behavior, and reckless or self-destructive behavior. Pynoos emphasized that it is very important to thoroughly test these types of items.

One of the challenges raised by Pynoos is related to formulating questions for adolescents about current PTSD when the traumatic event happened before the age of 6. The criteria for children 6 and under are different from the criteria for those who are older. Deciding which criteria to use is not immediately obvious. Pynoos said that asking about dissociative subtype is particularly difficult, but evidence suggests its importance even among young children.

In order to establish symptom presence, Pynoos and his colleagues use pictorial tools as anchors. For example, to get reliable frequency in days per month, they use a calendar that illustrates each answer option. To collect data on degree of intensity and determine how much the symptoms bother respondents, they use pictures of glasses filled to various levels. Pynoos believes that this technique leads to more reliable reporting in the case of children and adolescents than using verbal labels alone.

A question that has not yet been settled in the context of the DSM-5 is that of the cutoffs for counting a symptom as present. A cutoff is needed even in the case of a continuous scale if the goal is to arrive at a conclusion that is a diagnostic probability. Pynoos said that he and his colleagues have a study in progress to help answer this question. Another outstanding question noted by Pynoos is the extent to which a proxy symptom question for some level of lifetime PTSD would work in children and adolescents.

Pynoos also discussed the concept of functional impairment, a key criterion of PTSD in the DSM-5. The text of the DSM-5 provides a developmental framework regarding functional impairment, including in school and among peers. In young children, avoidant behavior may lead to restricted play or exploratory behavior; in adolescents, it may lead to reduced participation in new activities or missed developmental opportunities, such as dating and learning to drive. Pynoos emphasized that developmental outcomes need to be considered along with what has typically been considered to be functional impairment. For example, studies have shown that sexual abuse in childhood can lead to diminished self-care in adulthood. Such behavior is not a functional outcome the way it is normally defined, but as a developmental outcome it has profound influences on health behavior. In contrast to developmental delays, adolescents may show developmental accelerations as an outcome of traumatic experiences that increase the risk of further exposure.

NCTSN data show that among adolescents that have had multiple traumas earlier in childhood, there is a substantial subgroup that has subclinical levels of PTSD that are associated with major functional impairments. In addition, children and adolescents who meet only criteria B and D can have significant functional impairment, and different clusters of symptoms may have different causal relations to outcomes (for example, risk behavior, health consequences). He noted that if a study design calls for skipping some items, it could mean skipping the ones that would otherwise be the most highly endorsed by respondents.

Research on comorbidity has shown some interesting patterns in children and adolescents. For example, studies on the aftermath of disasters and terrorist attacks, such as 9/11, have found increased separation anxiety disorder in adolescents, which is not typically expected in that age group. Pynoos emphasized that in examining issues such as substance abuse in adolescents, it is important not to overlook exposure to death as a possible contributing factor. When bereavement leads to substance abuse, the associated behaviors are better understood in adults, and they need to be further studied in adolescents. He and his colleagues developed the Persistent Complex Bereavement Disorder Checklist for use in clinical research.

Finally, Pynoos said, another particularly important issue is multiple comorbid conditions among adolescents with complex trauma histories. A new diagnosis that has been proposed by a collaborative group of the NCTSN is developmental trauma disorder that gives priority to disturbances in development.

MEASUREMENT AND IMPLEMENTATION CONSIDERATIONS FOR COLLECTING DATA ON TRAUMA IN CHILDREN

Benjamin Saunders (Medical University of South Carolina) discussed the measurement of potentially traumatic events and PTSD in children, with specific focus on implementation considerations. He agreed with Pynoos that the most difficult cases to measure and treat involve children who have been exposed to multiple traumatic events. He added that there are events that can be potentially traumatic to children, but would not be similarly traumatic to adults, or even adolescents, so the developmental aspects of what may or may not be traumatic based on age is something that is important to consider when deciding what needs to be measured. In addition, asking an adult about things that are meaningfully important to them at the present that were potentially traumatic when they were children could result in a list that does not correspond to the types of events that are included among the DSM-5 criterion A events (see Chapter 2).

Starting with the premise that no single study can measure everything related to potentially traumatic events, PTSD, and related outcomes, Saunders discussed several strategies for narrowing down the list of items to those that are key to include in a particular study. Starting with reviewing the prevalence rates in the population for specific traumatic events would be a reasonable approach. Another useful initial step would be reviewing existing data on impact, in other words, the percentage of people with a certain type of experience who develop PTSD or the percentage of people who have PTSD as a result of the experience. He noted that some events, such as sexual assault, are included in almost all data collection instrument on the topic because of the broad agreement about their potentially traumatic nature.

In some cases, a particular topic may be of interest for a specific study or become more relevant due to current events generally. An example is sexually exploited children: 15 years ago, it was not a topic that was typically assessed in data collections on trauma, but it is now almost always included because of the increased visibility of the issue.

Saunders commented that Schell's discussion (see Chapter 3) about formative scales and the idea of identifying the outcomes of interest before the relevant traumatic events was useful. That approach could reduce the likelihood of items being introduced simply because they happen to be of interest to someone at a particular moment or are subjectively considered potentially more traumatic than others by particular researchers.

Beyond measuring potentially traumatic events, understanding the incident characteristics, the context of the event or events, other background information about respondents can also be critical because they are often associated with the development of PTSD. Robert Ursano (Uniformed Services University of the Health Sciences) mentioned the importance of understanding the community context, and Saunders pointed out that geocoding may be useful to add to data collection. Other data that are typically collected as part of studies on the topic of trauma include whether the event was a single event or part of a series of events, the duration of the event, and the respondent's age when the event first happened and when it stopped. In the case of children, in particular, traumatic events are often repeated incidents.

Saunders underscored the importance of understanding trajectories and the sequence of exposure that leads to increasingly more risky behavior, a topic that was also discussed by other speakers. He said that understanding the neurobiological and sociological processes involved and the reasons why some children develop difficulties and other do not are currently the most promising areas of research in the field of trauma. He pointed out that the complex interactions among events, outcomes, mediators, and moderators, can be particularly difficult to tease apart with data from large national surveys, and it is not clear to what extent is it possible for SAMHSA to undertake a large-scale project, but he argued that examining these issues would move the field forward. Nonetheless, he warned that even a hypothetical study that had unlimited resources would be challenged in developing an approach that would come close to fully capturing all the relevant information. The nature of the topic is such that there will always be a river of possible alternative explanations for outcomes running below the data.

An important consideration when collecting data about trauma in children is that if children are interviewed, permission from their parents is required. And for some age groups, parent interviews need to be substituted for the interviews with children. Researchers have to decide when it makes sense to interview a child, said Saunders. In some cases, parent interviews can produce reasonably good information, and interviewing parents may be more efficient if they need to be contacted to obtain permission.

Saunders summarized the characteristics of a good screening approach:

- includes multiple questions covering the range of experiences within type;
- assures that items are behaviorally specific to reduce interpretation;
- uses language level consistent with the target age group;
- cues retrievable memories of past events; and
- matches respondents' interpretations and labeling of experiences.

He pointed out that the last item on the list (assuring that the questions match a respondent's interpretation and labeling of experiences) is the most challenging in the context of interviewing children. Researchers need to develop questions with language that corresponds to the schema used by children and their views of the experiences.

Saunders said he agreed with Terrence Keane (Boston University School of Medicine and U.S. Department of Veterans Affairs National Center for Posttraumatic Stress Disorder) that questions on this topic are very susceptible to order effects and that the sequence of the sections also deserves careful attention. In his research, Saunders said, he likes to begin with easy questions, followed by the sensitive questions, and then another set of easy questions, which may be followed by a debriefing.

Some of the common errors he noticed in instruments on this topic include:

- not asking key questions;
- "gate" questions and single screening items;
- undefined terms that are open to significant interpretation by respondents (e.g. physically abused, sexually abused, fondled, bullied, raped, molested, attempted, domestic violence);
- double- (or more) barreled questions;
- lengthy or overly wordy questions; and

- asking follow-up questions after each screening hit.

Questions with the shortcomings highlighted above can be especially difficult for children and adolescents and can lead to higher error rates in some age groups. For example, questions that are open to interpretation or are lengthy can present more challenges for children than for adults. Asking follow-up questions after each screening hit can lead to response bias in any age group, if it cues respondents that a "yes" answer will lead to more follow-up questions, and they begin altering their responses as a result.

Saunders also listed several factors that can affect case detection:

- level of perceived confidentiality offered; concerns of getting self or others in trouble, fear of retribution;
- context of the screening setting
    - location of respondent (home, school, other)
    - method (in-person, group, telephone, paper, computer)
    - who is present? (interviewer, parents, teacher, peers, siblings);
- recall of events by respondents
    - experiences not recalled, forgotten, and not accessible
    - experiences partially forgotten, but retrievable with the right cuing
    - remembered experiences, but not defined by the respondent in the same way as the screening question is worded
    - remembered experiences that are willfully withheld; and
- willful nondisclosure.

Saunders said that perceived confidentiality is a particularly important consideration when interviewing children because they tend not to understand or believe that the information they provide will be kept confidential. A related issue is willful nondisclosure. While adults can also be reluctant to talk about traumatic events, such reluctance is more common among children and adolescents. The reasons for this may be in part that, for children, the questions are more likely to be about something that happened in the recent past rather than an event that happened decades ago in the case of adults. Children may have had less time to process the event and develop a perspective on it.

Other reasons for willful nondisclosure include:

- sense of stigma, shame, guilt, self-blame;
- threats or instructions by a parents;
- fear of punishment, "getting into trouble";
- fear of consequences to family and family members;
- cultural and familial beliefs about privacy;
- psychological distress about events;
- fear of retribution by assailant; and
- history of negative outcomes from prior disclosures (disclosure inoculation).

Saunders said that a history of negative outcomes from prior disclosure can be particularly challenging to overcome. Some children may be "inoculated" against talking about what happened to them because they had tried to talk about it before and bad things happened, or nothing happened. Careful question wording can help reduce some of these challenges.

Saunders noted that there are several ethical questions that arise in the context of research on trauma about children. One question is whether the interviews will be overly distressing. He said that he and his colleagues, as well as other groups of researchers, have conducted studies to examine this issue and concluded that the interviews do not appear to be overly distressing. However, less is known about the reactions of younger children than about adolescents.

Another question that comes up is whether the parents get upset when they learn about the types of questions that are being asked of their children. Saunders said that some parents do have objections, and it is important to think through the concerns they might have prior to contacting them.

A related issue is whether asking the questions could place some children at risk from their parents. Saunders said that their longitudinal studies seem to suggest that this is not the case because they found that children with trauma histories are more likely to participate in the follow-up waves of the studies, after the initial interview, than children without trauma histories. This finding could be an indication that these children did not experience any repercussions after participating and that they found the explanation and information provided to them as part of the study helpful.

Saunders also pointed out that collecting data about trauma in children means collecting data that can have legal implications. He said that it is important to carefully consider how the identifying information is stored and who has access to it, as well as whether the data can be subpoenaed. There are also mandatory reporting laws that may apply, and these can be different by state, so a plan is needed for how to manage situations in which this issue may arise. Saunders said that he and his colleagues also use a “child in danger” protocol, similar to what SAMHSA used in the Mental Health Surveillance Study, and it seems to work well.

Graham Kalton (Westat) asked whether there are ways to deal with situations in which a parent is abusing the child and so does not grant permission for the interview. Saunders said that this is likely happening and that the most one can do is to develop survey materials that reduce this problem as much as possible. He acknowledged that it is likely that this leads to underestimates of child trauma in all surveys. However, he noted that in his studies usually less than 10 percent of parents decline to have their children interviewed after the parent interview is completed. Schell noted that some of the phenomena that are being measured are very rare in the population, so refusals can make a big difference. Pynoos added that an additional issue with the proliferation of cell phones is that survey researchers are less likely to be calling a landline and then being able to continue the interview with the child, on the same line, after obtaining permission from the parent. The fact that most people and many children have their own cell phones complicates the data collection process.

Kilpatrick commented that if the survey is about a variety of topics, researchers do not need to being the conversation by saying that they would like to ask children about whether they had been abused. For example, one of their studies, the National Survey of Adolescents, was about a range of topics that are important to parents and families, such as community violence and alcohol and drug use. He said that it is important to provide an accurate description of what the study is about, but providing too many specifics can increase nonresponse bias.

Kalton said that it has been noted that child reports often differ from parent reports and that some studies that include teacher reports find that the teacher reports are also very different. Some researchers argue that multiple reports are necessary to measure issues of this type. Saunders agreed that there are typically significant differences in what is reported, depending on who is providing the information, and that this is generally the case with topics of this type. He noted that, in some sense, all of these reports may be accurate from the perspective of the person who is reporting. There is typically more convergence in data about child behavior than about internalizing problems, such as depression or PTSD, which definitely represents an analytic challenge. Pynoos commented that the topic of trauma presents special challenges in this regard because the link between traumatic exposure and behavior is rarely identified by parents and even less often by the schools.

James Jackson (University of Michigan) asked Saunders to clarify why he thinks that children and adolescents are more skeptical of promises of confidentiality. Saunders said that many children are afraid of consequences, such as getting into trouble or getting someone else into trouble. Convincing them that what they say will be kept confidential is especially difficult if, as part of the informed consent process, they are also told that in some cases what they say may have to be reported (e.g., in mandated reporting situations). He reiterated that very careful wording is crucial. Jackson said that his own research with adolescents leads him to think that adolescents are skeptical about adults' ability to "keep secrets," which is a small, but important distinction, and that understanding these nuances is crucial in order to be able to address the concerns. Pynoos commented that his research indicates that adolescents are more likely to disclose exposure to traumatic events when the questions are administered by computer rather than in person.

5

Key Themes and Possible Next Steps

This chapter summarizes the discussions that took place at the end of the workshop. The focus of the discussions ranged from synthesizing key themes to identifying areas that need additional research and attempting to pinpoint the most promising approaches that meet SAMHSA's goals for the measurement of trauma.

Evelyn Bromet (Stony Brook University) said that the field has matured in the past three decades and that the discussion of measuring trauma in children was especially interesting because researchers only began focusing on this topic in recent years. She noted that it has become clear from the presentations that trauma is ubiquitous, even if most people do not meet the criteria for PTSD, and that PTSD is more likely to be associated with some types of traumatic events than others. The interesting question is why the likelihood of developing PTSD varies so much by individual. She said that a typical limitation of existing studies is that they do not collect enough information about symptoms, beyond the PTSD symptoms spelled out in the Diagnostic and Statistical Manual of Mental Disorders (DSM). It may be that people who experience potentially traumatic events and do not have PTSD symptoms instead have other symptoms.

Another limitation of the studies to date, noted by Bromet, is that they do not ask about how people have dealt with a potentially traumatic experience in a positive way. Although there is increasing interest in the concept of resilience, there are few good resilience measures. Bromet said that collecting data on resilience would be one of the most important contributions SAMHSA could make in the field. She also commented that in terms of survey design, asking everyone some basic questions and then selecting subgroups for detailed follow-up questions would be a useful way to focus the effort, because a lot is already known from prior research about which groups are at highest risk.

Bromet expressed concern about the limitations of interview protocols in general, because responses cannot be independently verified, and it is also not clear whether the respondent (or even the interviewer) really understands what each question is asking. She recalled a 1988 meeting on the definitions of trauma and its consequences, when using a trauma checklist was proposed. She said that she was concerned at the time about the lack of rapport building that is characteristic of the checklist method, and she was pleased to hear the discussion that reflected a better understanding of these issues today, in particular in the presentation by Benjamin Saunders (Medical University of South Carolina); see Chapter 4. Another way in which the field has changed is that there is a broader understanding of the types of traumatic events that may affect people, beyond personal traumas, which was highlighted in the presentation by Robert Ursano (Uniformed Services University of the Health Sciences); see Chapter 3. Bromet argued that the broader community traumas need to become integrated into the data collections, in order for the studies to remain relevant.

Bromet noted that one topic that was not discussed during the workshop is trauma in elderly people. There seems to have been little research on that topic, but perhaps focus groups could provide useful information on the experiences of elderly people and their families.

Hortensia Amaro (University of Southern California) said that new data collected by SAMHSA on the topic of trauma has the potential to inform policy and programs and really affect people's lives. In that context, she noted that the United States is becoming increasingly more diverse, and data collections do not always pay adequate attention to that change. The same is true for special populations, such as non-household populations, which are particularly important to consider in the context of trauma. The rates of trauma and negative consequences may be higher among some groups that are underrepresented in typical household surveys, such as homeless people and people in prisons. This likely underrepresentation can affect the estimates based on national surveys, as well as the programs and services available to those who are most marginalized in the society.

Amaro commented that a topic that has not come up is historical trauma. She argued that structural violence and chronic discrimination are significant issues in some communities. For example, there is literature that focuses on historical trauma in Native American populations, and there is increasingly more scientific evidence about the negative effect of that trauma on health. She urged SAMHSA to keep these types of traumas at the center of attention.

Amaro also highlighted trauma in refugee and immigrant populations as issues that deserve more emphasis than they have had in the past. Many of the recent refugees currently in the United States have been through war and government persecution. There are also immigrants who are not refugees but come from countries where the likelihood of experiencing potentially traumatic events was high, due, for example, to the violence associated with drug trafficking in some of Latin American countries. She also noted the trauma that may be experienced as a result of fear of deportation and separation from family. Amaro noted that there have been some recent studies focused on these populations, especially refugees, but measures are needed that can capture these experiences. Robert Pynoos (University of California, Los Angeles) agreed that the unique characteristics of some of the subpopulations have a large societal impact and in terms of resources for services.

Dean Kilpatrick (Medical University of South Carolina) agreed with Amaro that many of the marginalized and understudied populations are likely to have a higher prevalence of exposure to potentially traumatic events. However, he pointed out that developing approaches to study these populations is challenging, and the design should be based on SAMHSA's ultimate goals in this area. He noted that the U.S. Department of Housing and Urban Development does a focused survey of the homeless population every year and estimates the homeless population (those who are homeless on a given night) to be between 500,000 and 600,000. Considering the size of the U.S. population overall, including the homeless in a national survey would require a complex sampling frame. An added difficulty for some of the special populations, such as the prison population, is that there are a variety of rules and procedures about access for interviews.

Kilpatrick argued that for producing national estimates, a good household survey is what is needed, because that would capture most of the population. However, he added that SAMHSA also needs to devise a plan for collecting information about special populations, and for those data collections specialized surveys may be needed. Such specialized surveys could also gather relevant additional information, focused on the particular needs of those groups. The fact that this approach would be more difficult than a typical household survey need not be a deterrent.

Ursano commented that the active duty military population is larger than the population of many states and, although the fact that they are not included in such surveys as the National Survey of Drug Use and Health (NSDUH) is not surprising, it is nonetheless an important consideration. Jonaki Bose (SAMHSA) pointed out that the NSDUH captures reserve veterans and information on military families, but agreed that the exclusion of active duty military personnel is an important limitation for a survey on substance use and behavioral health.

In terms of SAMHSA's primary goal of measuring PTSD using DSM-5 criteria, Kilpatrick said that the discussions and experience of previous surveys suggest that this is feasible to do in population-based surveys. There are suitable approaches for screening for exposure to potentially traumatic events. It is also possible to measure the most relevant related topics, with the understanding that this would further increase the length of the survey. He also noted that the discussions also underscored the need for different strategies to measure trauma in children and adolescents, compared with the approaches used for adults. In the case of adolescents who are 12 and older, it is possible to interview them directly about trauma-related topics, although the implications of mandatory reporting are important to consider.

Kilpatrick emphasized that problems of comorbidity are common, and PTSD is not the only outcome that needs to be considered in connection with exposure to potentially traumatic events. However, data on PTSD are especially useful from a clinical perspective because effective treatments exist. He also agreed with the speakers who argued that collecting additional contextual information about potentially traumatic events is useful and that asking about these topics is feasible in a survey. He said that in the case of multiple events, the information could be collected for at least some of the events, and, in particular, the most recent event. The context of the first traumatic event is also relevant because it is often something that happened in childhood during an important developmental period. If asking about the first event, the next step could be to ask whether there was another event that had either a bigger effect on the person or was worse. In other words, the questions could be introduced with some additional descriptive information, rather than just simply asking whether an event happened.

Terry Schell (RAND) offered a different perspective on the apparent tension between the goals to measure trauma in a nationally representative sample of the whole population and collecting sufficient data from subgroups. He argued that the goal should be to develop measures that work equally well in any population. He also noted that it is difficult to obtain funding for using a scale in a special population until it has been used in a nationally representative sample. Once a scale has been fielded with a national sample, the data from it can be used for comparisons with data from special population samples. If SAMHSA focuses on getting the measure right and collecting nationally representative data, it will enable others to more easily collect data with specialized samples.

Kathleen Merikangas (National Institute of Mental Health) pointed out that SAMHSA is interested in measuring behavioral health in several areas. Discussions at previous workshops, for example, about specific mental illness diagnoses with functional impairment, highlighted the need to consider focusing on the individual rather than disorders, especially because of the widespread comorbidity.[11] It may be that what is needed is to ask about whether people are currently impaired and suffering and then dig deeper to understand the causes or reasons. Many of the same people will have not only PTSD, but also a history of psychosis, substance abuse, and other difficulties. The effects of exposure to traumatic events can be exacerbated by other problems, such as anxiety. Merikangas argued that understanding these interactions may be more useful than simply counting the number of people with PTSD.

Larke Huang (SAMHSA) said that for SAMHSA it is useful to learn about how to translate clinical work to large-scale population surveys in any population group. She agreed with Merikangas that research that shows the pervasiveness of comorbidity highlights the need to understand how exposure to traumatic events contributes not only to PTSD, but also to other mental health issues, substance abuse, and risky behaviors. SAMHSA also wants to know why some people develop PTSD and other problems and other people do not, why some people develop more severe symptoms, and how resilience factors in. The agency also wants to better understand what steps can be taken to prevent negative outcomes, reduce their impact, and move people toward recovery. She said that the discussion pointed at several substudies that could be conducted and that perhaps a multi-study research agenda is needed to gain an in-depth understanding of some of the issues.

Huang noted that the discussion revealed that there are several methodological challenges specific to measuring exposure to traumatic events and PTSD. SAMHSA would need further input on whether a survey is the correct mechanism for measuring these topics, and if yes, how to implement such a survey. She pointed out that the Mental Health Surveillance Study (MHSS) collected data on several of the related issues that have been discussed at the workshop, such as mental health and homelessness, and the agency already has experiencing with collecting some of those data.

Benjamin Druss (Emory University) agreed with Merikangas that functioning seems to be the common element that ties together the different topic areas of interest for SAMHSA's current effort of expanding data collections on behavioral health. It is clear that the interface of events and issues that occur in people's brains and lives is complicated, but, ultimately, functioning is paramount: thus, functioning may be the goal, and researchers and analysts could work back from that goal in order to address what SAMHSA really needs to know about from a public health perspective.

Kilpatrick commented that PTSD as a construct has advanced the field because it communicates in a clear way that one can have the same symptoms and impairments as a result of a variety of different events. As discussed, PTSD in turn leads to a variety of health risk behaviors, such as substance abuse. In that sense, Kilpatrick argued, PTSD can be the unifying concept that helps researchers look at other related issues, especially health risk behaviors.

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[11] See National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Specific Mental Illness Diagnoses with Functional Impairment: Workshop Summary*. J. C. Rivard and K. Marton, Rapporteurs. Committee on National Statistics, and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health Sciences Policy, Institute of Medicine. Washington, DC: The National Academies Press.

Merikangas noted the importance of understanding the course and sequence of events. She acknowledged that SAMHSA cannot collect data on the whole life span, but sometimes surveys that rely on the DSM to determine skip patterns do not ask a sufficient number of follow-up questions that could be relevant. People who are subthreshold are often skipped out of sections because they do not meet what is an arbitrary criterion. The concept of spectrum is useful, but survey instruments often need to arrive at a yes/no answer. Another challenge in the context of surveys, Merikangas said, is that sometimes people who are being treated are difficult to categorize without further clinical follow-up or additional understanding about their histories, and such information is beyond the scope of the types of data collections that SAMHSA intends to do.

Merikangas also discussed the importance of obtaining the perspectives of multiple respondents from a household. In the NSDUH, in most cases children over 12 provide information for themselves, but there is also interaction with a parent to obtain permission. The parent who provides permission, or, ideally, both parents, could also be asked to complete some of these modules in order to obtain richer information and a family perspective.

Bose responded that such an approach would require changing the structure of the NSDUH, but that is not out of the question. She commented that the workshop raised a number of issues that cut across multiple domains, including special populations, measuring trauma in children, and traumatic brain injury. Some of the questions raised are related to feasibility. It is clear that SAMHSA will need to think about what its primary analytic goals are and perhaps discuss how those goals fit into broader goals of the U.S. Department of Health and Human Services. The workshop provided a good overview of the issues that can serve as a background for those discussions.

Nora Cate Schaeffer (University of Wisconsin) said that it appears that a comprehensive study would require a new data collection. However, it might be very useful to also have some questions on the NSDUH because that survey already collects other relevant data about drug and alcohol use. One question is whether additions to the NSDUH would result in information that expands what has already been done. She argued that perhaps SAMHSA should not think about these options as mutually exclusive.

Bose said that SAMHSA would want to learn more about what is possible to obtain from sets of questions that are brief enough to include in the NSDUH. SAMHSA would also like to better understand whether the short scales that might be available can be considered proxies for PTSD or for other outcomes of interest to the agency, such as other adverse health outcomes, increased substance use, or increased risk behaviors. Schaffer responded that to the extent one of the problems with the short scales is that they include variance that is due to such factors as depression or anxiety that originate from something other than a traumatic event, including these questions in a survey that already collects data on those other issues can help with beginning to partition the variance. She added that it appears that measuring both causes and effects in the current NSDUH would be a big challenge.

Graham Kalton (Westat) said that it appears that the primary goal is to measure PTSD, or other effects of traumatic events, and not exposures to traumatic events. Given that goal, it is not clear why it is not possible to ask about PTSD first and then follow up with questions to find out the cause, at least if the primary goal is to estimate the number of people with PTSD. He also asked the participants to weigh in on the role of clinical interviewers in the context of measuring PTSD. Based on the literature from other medical fields, it seems that lay interviewers with a standardized instrument can produce better quality data, and there are large cost implications associated with this decision.

Schell said that he generally prefers standardized interviews. Allowing interviewers to deviate from a standardized script can be especially counterproductive when the intent is to communicate a subtext to respondents to encourage them to provide information that they otherwise may not want to provide. Having looked at questions that interviewers came up with in these situations leads him to believe that this is not a good idea. He acknowledged that establishing rapport is important, but improvised questions lead to substantial variance, and they are less useful in a survey than in an evaluation for clinical treatment.

In response to Kalton's suggestion to measure the symptoms associated with PTSD and then follow up with questions about a series of life events to understand the relationship between them, Schell said that he agrees that building the definition of trauma exposure into the measurement of PTSD only complicates the problem. However, separating the two concepts is difficult, in part because the DSM integrates them. For example, re-experiencing is one of the criteria (see Chapter 2), and generally established instruments first define the range of events before asking about memories. He noted that the nonmilitary version of the PTSD Checklist has a very loose definition of a potentially traumatic event, and that approach seems to work. This solution would generally be more acceptable if the intent is a dimensional approach, rather than probable diagnoses. Kilpatrick noted that when the PTSD Checklist is used, there is typically a context already established, and he believes that it is always better to be as specific as possible in a survey and assure that the respondent understands exactly what is meant by the questions. He reminded participants that the quintessential characteristic of PTSD is that it is in reference to life experiences and cannot happen without those experiences.

Pynoos commented that in the DSM-5, the PTSD section is in a new chapter that is about the centrality of life experiences. There is a lot of research being conducted in the fields of medicine, public health, and psychology that are focused on the centrality of life experiences, of which traumatic exposures are one form. He used the example of his own research on Native American reservations where exposure to traumatic deaths happens at a rate that is much higher than in other communities. He argued that trauma is a cross-cutting issue and that SAMHSA has an obligation to go beyond mental conditions to understand the science of life experiences and its outcomes on health, on life, and on psychiatric and medical disorders. Druss commented that if the goal is to understand life experiences and individual context in order to gain a synthesized view that is similar to the social determinants of health, then perhaps the focus should not be on PTSD, which is an extreme and specific case.

Keane noted that he used to think that the adverse health outcomes associated with PTSD were secondary to risky behaviors, unhealthy behaviors, and addictions. In the Boston health care system of the U.S. Department of Veterans Affairs, there is a study under way involving around 500 participants who receive very comprehensive, full-day examinations and testing. The researchers are finding compromised cortical thickness among the recently returned war veterans with PTSD, who are often people in their late 30s, which is a major issue. More importantly, it seems possible that some of this might be mediated by the presence of metabolic syndrome, which does not appear to be related to the use of atypical anti-psychotic drugs because, unlike with Vietnam veterans, atypical anti-psychotic drugs are rarely used in this population.

Keane said that the group has also started publishing articles about the issue of accelerated aging, secondary to the exposures and the development of the conditions, suggesting that perhaps metabolic syndrome or telomere length or other similar factors are playing a very serious role in comorbidities that have previously been essentially considered byproducts of PTSD. It could also be that this accelerated aging is driven by a separate process, exacerbated by alcohol and drug use, but there could also be a unique ongoing neurological process that is secondary to these exposures. Keane said that given the prevalence of the problems, this new research indicates the possibility of a very serious public health problem and also helps provide a better picture of what may be most effective in terms of services provided to returning veterans and others with PTSD.

Kilpatrick asked Keane to clarify whether he believes that this supports the argument of measuring PTSD. Keane responded that he is conflicted about this issue. He said that surveys that cannot provide data that is conclusive are not useful. What would be needed are surveys that can provide convincing evidence to inform strategies for next steps. He added that this issue is not exclusively a mental health problem.

Pynoos clarified that when he emphasized the centrality of life experiences he was not suggesting that he would not include PTSD, because some of the symptoms of PTSD are very different than those of other mental health conditions. For example, reactivity to reminders is pervasive and can persist through a person's life. This can have physiological responses, as shown in cardiovascular studies, and there is also a better understanding of the role of C-reactive protein. Keane commented that recovery from surgery can take several days longer in people with PTSD than in people who do not have PTSD, and there are many other medical consequences. Pynoos said that the latest developments in the field bring a new scientific perspective and that these discussions are at the forefront of that. It is not surprising that it is not always clear how to proceed.

Saunders pointed out that these psychological and neurological changes can have more severe consequences in children because they have many more life years ahead of them. From his perspective, this fact underscores the need to measure exposure to potentially traumatic events, rather than simply measuring PTSD symptoms, even if the latter were possible. There may be other processes related to the exposure that are not full PTSD and may not even be detectable.

James Jackson (University of Michigan) commented that while there are clearly some promising areas of emerging research, SAMHSA staff have been charged with a specific task. Kilpatrick responded that it is clear that it is possible to measure in a survey at least what the DSM-5 defines. In some ways the task becomes easier than it was with using the DSM-IV because the DSM-5 definition no longer includes the "intense fear, helplessness, or horror" criteria. It is also possible to measure a variety of life events, and it is clear what events are in the DSM-5. There is a lot of literature on this issue, and the challenge is to decide which approach to use. Jackson said that a lot of the research on exposure to potentially traumatic events, PTSD, and related outcomes is influenced by a period in time when it was assumed that traumatic events were rare. Measuring the events made sense in that context, but what was learned over time is that these issues are very common in the population, and the focus has become the etiology of the negative consequences of traumatic events. This development might require a readjustment of how researchers think about different approaches, particularly because truly understanding the nature of a traumatic event can be very expensive in a national survey.

Schell said that if one thinks of the range of events that can potentially lead to PTSD, the conclusion is that almost everyone has experienced at least one of them. Exposure to the types of events that are the most potent predictors of PTSD is much more limited. However, he agreed that adequately measuring the events would have to go beyond just asking the person whether they experienced any of the events on a list. He added that national surveys, such as the National Comorbidity Survey Replication, measured exposure to a broad range of traumatic events with follow-up questions to capture specific characteristics of the events. Work could be done to reduce the list of traumatic events to a smaller subset, which could then potentially be included in the NSDUH. For example, a list of the 10 most relevant events could be developed, if it can be demonstrated empirically that adding an 11th item would only contribute very small additional value. Schell said that research of this type has not yet been carried out. The challenge is that a broad range of events needs to be included in a nationally representative sample to understand what is important. Researchers have tried, for example, to compare data about rape victims to data about flood victims, from different samples, and they have found that what can be learned from these comparisons is more limited than what could be accomplished with national samples.

Schaeffer commented that it appears that while exposure to potentially traumatic events is common, the extreme stress responses are not as common. The relationship is moderated by a variety of variables, and it seems that if one wants to look at PTSD, collecting these additional data on intervening variables is essential in order to have a meaningful study.

Appendix A

Workshop Agenda

WORKSHOP ON INTEGRATING NEW MEASURES OF TRAUMA INTO SAMHSA'S DATA COLLECTION PROGRAMS

The National Academies of Sciences, Engineering, and Medicine
Keck Center, Room 101
500 Fifth Street, NW
Washington DC 20001
December 17, 2015

PUBLIC SESSION

9:00-9:20 **Welcome and Introductions**

Dean Kilpatrick, *Workshop Chair, National Crime Victims Research and Treatment Center, Medical University of South Carolina*

Connie Citro, *Director, Committee on National Statistics*

9:20-9:40 **SAMHSA's Goals and Challenges Related to Measuring Trauma**

D.E.B. Potter, ASPE

Neil Russell, *Director, Division of Surveillance and Data Collection,*
CBHSQ, SAMHSA

9:40-10:20 **The Mental Health Surveillance Study Trauma Module**

Rhonda Karg, *RTI International*

10:20-10:30 ***Coffee Break***

10:30-11:20 **Existing Surveys and Sources of Data on Trauma**

Dean Kilpatrick, *National Crime Victims Research and Treatment Center, Medical University of South Carolina* (with John Boyle, ICF International)

11:20-12:00 **Conceptualizing Exposure to Trauma and Trauma Related Disorders and Symptoms**

Robert Ursano, *Center for the Study of Traumatic Stress, Uniformed Services University of the Health Sciences*

12:00-1:00 **Working Lunch to Continue Discussion of Measures**

Third Floor Atrium

1:00-1:40 **Measuring Exposure to Trauma, PTSD, and Subclinical PTSD in Large Scale Surveys**

Terrence Keane, *Boston University School of Medicine and Department of Veterans Affairs National Center for Posttraumatic Stress Disorder*

1:40-2:20 **How Can We Determine Whether We Have a Good Measure of Trauma?**

Terry Schell, *RAND*

2:20-2:55 **Considerations Specific to Operationalizing Trauma in Children**

Robert Pynoos, *National Center for Child Traumatic Stress, University of California, Los Angeles*

2:55-3:10 ***Coffee Break***

3:10-3:45 **Measurement and Implementation Considerations for Collecting Data on Trauma in Children**

Benjamin Saunders, *National Crime Victims Research and Treatment Center, Medical University of South Carolina*

3:45-5:00 **Panel Discussion**

Dean Kilpatrick, *Workshop Chair, National Crime Victims Research and Treatment Center, Medical University of South Carolina*

Hortensia Amaro, *University of Southern California*

Evelyn Bromet, *State University of New York at Stony Brook*

5:00-5:30 **Floor Discussion and Wrap-Up**

Dean Kilpatrick, *Workshop Chair, National Crime Victims Research and Treatment Center, Medical University of South Carolina*

5:30 **Adjourn Public Session**

Appendix B

Biographical Sketches of Steering Committee Members and Speakers

Hortensia D. Amaro ***(Member, Steering Committee)*** is associate vice provost for community research initiatives and dean's professor of social work and preventive medicine at the University of Southern California. Previously, she served as associate dean and distinguished professor of health sciences and of counseling psychology in the Bouve College of Health Sciences and as director of the Institute on Urban Health Research at Northeastern University. Her research interests include alcohol and drug use and addiction among adolescents and adults, substance abuse and mental health treatment for Latinos and African Americans, and alcohol and drug use among college populations. She is a member of the National Academies of Medicine. She has received numerous awards from professional, government, and community organizations and honorary degrees from Simmons College and the Massachusetts School of Professional Psychology. She founded five substance abuse treatment programs for women in Boston and served for many years on the board of the Boston Public Health Commission. She received a Ph.D. in psychology from the University of California, Los Angeles.

John Boyle ***(Member, Steering Committee)*** is senior vice president and survey research line of business lead for ICF International. Previously, he was executive vice president of Abt SRBI, a senior partner of SRBI, and senior vice president of Louis Harris and Associates. His study areas include epidemiology, health care utilization and outcomes, violence and posttraumatic stress disorder, service quality assessment, program evaluation, and policy analysis. He has worked extensively in the design, execution, and analysis of surveys related to sexual assault and victimization and abuse, including both military and national civilian surveys. He directed the National Violence Against Women Survey and the National College Women Sexual Victimization Survey, among others. He has a Ph.D. from Columbia University.

Evelyn J. Bromet ***(Member, Steering Committee)*** is distinguished professor of psychiatry and preventive medicine and director of the epidemiology research group at the School of Medicine at Stony Brook University. Her research focuses on the psychological aftermath of nuclear power plant disasters; the epidemiology, treatment, and epigenetic sequelae of PTSD; respiratory comorbidity in responders to the World Trade Center disaster; and the long-term course of illness in individuals hospitalized with schizophrenia and affective psychoses. She also directed the first psychiatric epidemiologic study in Ukraine as part of the World Mental Health Survey Consortium. She is a recipient of the Rema Lapouse award from the American Public Health Association, the Brigitte Prusoff Memorial Prize from the Department of Epidemiology at Yale University, and the Hamilton Award from the American Psychopathological Association. She is also an honorary fellow of the Ukrainian Psychiatric Association. She has served as an advisor or consultant on many national and international panels and studies. She has an M.Phil. and a Ph.D. in epidemiology and public health from Yale University.

Rhonda Karg ***(Speaker)*** is senior research clinical psychologist at RTI International. At RTI, her primary roles have included designing, implementing, and analyzing results from studies designed to assess and reduce substance use and mental illnesses. She is also a licensed and practicing clinical psychologist and Certified Health Services Provider and maintains a part-time independent practice. She has extensive experience in designing and conducting mental and behavioral health research. She holds professional and community service positions for local, national, and international organizations. She has a Ph.D. in clinical psychology from Auburn University, with minors in behavioral pharmacology and substance abuse.

Terrence Keane ***(Speaker)*** is a professor and vice chair in psychiatry and professor of clinical psychology at Boston University. He is also the associate chief of staff for research and development at Boston health care system of the U.S. Department of Veterans Affairs and director of the Behavioral Science Division of the National Center for Posttraumatic Stress Disorder. He has conducted research for many years on psychological trauma. He is a fellow of the American Psychological Association and the Association for Psychological Science and past president of the International Society for Traumatic Stress Studies, and the Anxiety and Depression Association of America. He is the recipient of many honors, including the Lifetime Achievement Award and the Robert Laufer Award for Outstanding Scientific Achievement from the International Society for Traumatic Stress Studies, the Outstanding Researcher in Behavior Therapy Award from the Association for Advancement of Behavior Therapy, the Outstanding Research Contributions Award and the Distinguished Service Award from the American Psychological Association. He has a Ph.D. in clinical psychology from Binghamton University.

Dean G. Kilpatrick ***(Chair, Steering Committee)*** is distinguished university professor of clinical psychology and director of the National Crime Victims Research and Treatment Center at the Medical University of South Carolina in Charleston. His primary research interests include measuring the prevalence of rape, other violent crimes, and other types of potentially traumatic events, as well as assessing the mental health impact of such events. He has served as a board member and president of the International Society for Traumatic Stress Studies. He has provided invited testimony on the topics of rape, sexual harassment, and compensation for PTSD to committees of the U.S. House of Representatives and the U.S. Senate. He was awarded the Allied Profession Award for promoting crime victims' rights, services, and needs in the mental health field by the Congressional Victim's Rights Caucus. He has a PhD in clinical psychology from the University of Georgia.

D.E.B. Potter ***(Speaker)*** is program analysts with the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE). Previously she was a senior survey statistician at the Agency for Healthcare Research and

Quality (AHRQ). She leads an ASPE, AHRQ and Centers for Medicare & Medicaid Services joint project to develop risk adjustment methods for quality measures for home and community-based services (HCBS) populations. Other responsibilities include managing the development of behavioral health quality measures and advancing quality measurement for the population with dementia. She serves on numerous technical expert panels and cross-agency workgroups. She has an M.S. in biostatistics from Georgetown University.

Robert Pynoos ***(Speaker)*** is director of outpatient trauma psychiatry and co-director of the National Center for Child Traumatic Stress at the University of California, Los Angeles, where he is also professor of psychiatry and biobehavioral sciences and professor in residence at the Semel Institute for Neuroscience and Human Behavior. He leads a nationwide network of academic and community-based centers dedicated to raising the standard of care and improving access to services for traumatized children and families throughout the United States. His research has focused on model building, multidimensional assessment, dose-of-exposure research methodology, empirically supported interventions, and public mental health policy regarding children, adolescents, and families in the field of child and adolescent traumatic stress. He has received numerous honors, including the American Academy of Psychiatry and the Law Award for his outstanding contribution on child witnesses to homicide; the American Psychiatric Association Bruno Lima Award for excellence in disaster psychiatry; the Lifetime Achievement Award from the International Society for Traumatic Stress Studies; American Professional Society on the Abuse of Children's Outstanding Professional Achievement Award; and the European Society for Child and Adolescent Psychiatry Award for Contributions to the Field of Child Trauma. He has an M.D. from the Columbia University College of Physicians & Surgeons.

Neil Russell (***Speaker***) is director of the Division of Surveillance and Data Collection in the Center for Behavioral Health Statistics and Quality at the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services. His areas of expertise include behavioral health statistics and epidemiology; basic and applied research in behavioral health data systems and statistical methodology; as well as surveillance and data collection. He has a Ph.D. in sociology from Arizona State University with a focus in survey research.

Benjamin Saunders ***(Speaker)*** is professor in the Department of Psychiatry and Behavioral Sciences at the Medical University of South Carolina in Charleston, where he also serves as the associate director of the National Crime Victims Research and Treatment Center. His research, training, and clinical interests include the initial and long-term effects of violence and abuse on children and adolescents; the epidemiology of trauma, violence, and abuse; treatment approaches for abused children and their families; and effective methods for implementing evidence supported interventions in community service agencies. He is a recipient of the Research Career Achievement Award from the American Professional Society on the Abuse of Children and was the invited speaker for the society's William Friedrich Memorial Lecture. He has a Ph.D. in clinical social work from Florida State University.

Terry L. Schell ***(Speaker)*** is a senior behavioral scientist at the RAND Corporation. Much of his recent research has focused on posttraumatic stress disorder among civilian survivors of community violence as well as service members who served in Iraq and Afghanistan. Previously, he conducted a number of investigations into basic psychosocial issues, such as effects of attitudes and norms on behavior and biases in social perception that lead to discrimination. At RAND, he has worked on a variety of projects as a social psychologist and psychometrician, including studies of the long-term effects of violence on mental health, the effects of advertising on adolescent drinking, the effectiveness of criminal rehabilitation programs, the effectiveness of terrorism security measures, the evaluation of drug treatment programs, the relationship between traumatic stress and substance use, and assessing racial equity in policing. He has a Ph.D. in social psychology from the University of California, Santa Barbara.

Lisa Schwartz ***(Member, Steering Committee)*** is senior vice president for business practice at Mathematica Policy Research and a leading expert in health survey research with experience designing and managing qualitative and quantitative studies of vulnerable populations. Before joining Mathematica, Schwartz was a senior research scientist at the National Opinion Research Center at the University of Chicago and associate program manager for the American Time Use Survey at the Bureau of Labor Statistics of the U.S. Department of Labor. Her work has also included designing multimode surveys, one-on-one semi-structured interviews, cognitive interviews, focus group protocols, interviewer and respondent debriefings, split-ballot pre-tests, and usability testing. Her work has been recognized for exceptional achievement by the secretary of the U.S. Department of Labor. She has a Ph.D. in cognitive developmental psychology from the University of Maryland.

Robert Ursano ***(Speaker)*** is professor of psychiatry and neuroscience and chair of the Department of Psychiatry at the Uniformed Services University of the Health Sciences. He is founding director of the Center for the Study of Traumatic Stress. Previously, he served in the U.S. Air Force medical corps, retiring as colonel, and he continues to serve as an adviser on psychological response to trauma to the U.S. Department of Defense. In the Air Force, he served as the U.S. Department of Defense representative to the National Advisory Mental Health Council of the National Institute of Mental Health. He is a distinguished life fellow of the American Psychiatric Association and a fellow of the American College of Psychiatrists. He was the first chair of the American Psychiatric Association's Committee on Psychiatric Dimensions of Disaster. He has an M.D. from the Yale University School of Medicine.

COMMITTEE ON NATIONAL STATISTICS

The Committee on National Statistics was established in 1972 at the National Academies of Sciences, Engineering, and Medicine to improve the statistical methods and information on which public policy decisions are based. The committee carries out studies, workshops, and other activities to foster better measures and fuller understanding of the economy, the environment, public health, crime, education, immigration, poverty, welfare, and other public policy issues. It also evaluates ongoing statistical programs and tracks the statistical policy and coordinating activities of the federal government, serving a unique role at the intersection of statistics and public policy. The committee's work is supported by a consortium of federal agencies through a National Science Foundation grant.