Attachment W

Followup Interview Payment Receipt

Follow-up Interview Payment Receipt

United States Public Health Service

and

Research Triangle Institute

thank you for agreeing to participate in a special study for the

2012 National Survey on Drug Use and Health.

In appreciation of your participation in this important study, you are eligible to receive a \$30 cash payment.

Since maintaining the confidentiality of your information is important to us, your name will not be entered on this form. However, the interviewer must sign and date this form to certify you received (or declined) the cash payment.

Interviewer	Date	
Accepted Cash Payment		Declined Cash Payment

If you ever feel that you need to talk to someone about mental health issues, you can call the National Lifeline Network. Counselors are available to talk at any time of the day or night and they can give you information about services in your area.

1-800-273-TALK or 1-800-273-8255 1-888-628-9454 (Spanish) http://suicidepreventionlifeline.org/

If you ever feel that you need to talk to someone about drug use issues, you can call the Center for Substance Abuse Treatment's national referral service. This is a 24-hour service that will help you locate treatment options near you.

1-800-662-HELP or 1-800-662-4357 1-800-487-4889 (TDD) 1-877-767-8432 (Spanish)

http://findtreatment.samhsa.gov

Disposition: Top Copy to Respondent, yellow to Field Supervisor, pink to Field Interviewer.

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Attachment X

December 6, 2006 Expert Panel Meeting

Evaluation of National Data Sources and Measures for Determining the Prevalence and Characteristics of Persons with Mental Illnesses

Conference Summary

December 6, 2006

<u>Submitted to:</u> Jeffrey A. Buck, Ph.D. Project Officer Substance Abuse and Mental Health Services Administration 1 Choke Cherry Road Rockville, Maryland 20857

<u>Submitted by:</u> Thomson Medstat 4301 Connecticut Avenue, NW, Suite 330 Washington, DC 20006

<u>Report Authors:</u> Tami L. Mark, PhD Rosanna M. Coffey, PhD Cheryl Kassed, PhD

Purpose

This paper summarizes the discussion and recommendations that emerged from a meeting of experts and stakeholders that was held on December 6th 2006 at the Substance Abuse and Mental Health Services Administration.

The purpose of the meeting was to gather opinions from experts on existing data sources and measures that can be used to estimate the prevalence and characteristics of adults with mental illnesses and children with emotional disturbances. In particular, meeting participants were asked to address the following questions:

- 1. Mental Health Measures: What measures are available for use in data sources that can identify mental illnesses and serious mental illness (SMI) in adults and serious emotional disturbances (SED) in children?
- 2. Data Sources: What is the best data source or combination of sources for collecting national estimates and trends for the prevalence and characteristics of people with mental illnesses, SMI, or SED?

The focus was on measurement of mental illness in household populations, although other populations were noted as important.

Summary of Child Mental Health Discussion

Currently the main instrument that is being used on federal household surveys to collect data on children's mental health status is the Strengths and Difficulties Questionnaire (SDQ) which is administered on the National Health Interview Survey (NHIS) by the National Center for Health Statistics of the Centers for Disease Control. Meeting participants recommended continued Federal support for the SDQ on the NHIS.

In order to determine how the SDQ should be used to identify mental illness, the panel recommended that a subset of respondents receive a longer "gold standard" measure to identify mental illness and serious emotional disturbance to calibrate the SDQ for measuring SED. Many respondents felt that the calibration aspect was essential. However, there would need to be additional work to determine the appropriate gold standard calibration tool. The gold standard might include the Child and Adolescent Psychiatric Assessment (CAPA) or the Diagnostic Interview for Children and Adolescents (DICA). Some calibration work is currently being conducted by Jane Costello that might be useful in further identifying appropriate tools and evaluating the SDQ. The group did not recommend waiting until that work is complete. Ron Kessler also suggested that the cost of the interviews for calibration work on household surveys could be reduced by using small samples and pooling data over two or more years. Another useful investigation would be to determine how existing disability questions and scales might relate to SED (and SMI).

Participants also recognized that the SDQ may not be the best instrument to measure mental illness and serious emotional disturbances in children. In particular, while the domains were considered good, there was concern about whether it had response categories that were appropriate for a U.S. population as it was developed in the UK. Participants recommended continued Federal support for studies to validate the SDQ and to identify potentially superior screening scales or to develop new scales. If the SDQ is used, work by Ronald Kessler suggested that the 25-item version should be used and not the shorter version.

In terms of survey administration, the NHIS, National Survey on Drug Use and Health (NSDUH), and Behavioral Risk Factor Surveillance System (BRFSS) were all pointed out to have strengths and weaknesses.

The NHIS currently collects information on approximately 12,000 children under the age of 18 through parent or knowledgeable informants. The NHIS interviews sub-samples weekly throughout the interview year so that seasonal prevalence of mental illness can be studied as well as changes in prevalence in response to events. The NHIS has detailed information on medical co-morbidities, health insurance, and other demographic information. However, the NHIS cannot produce state-level estimates and does not have detailed information on mental health service utilization. Measures of MH service utilization could potentially be added to the NHIS if funding continues beyond 2007.

The NSDUH provides detailed information on substance use disorders and can yield state level estimates but currently does not collect information from parents about, or directly from, children younger than age 12.

The BRFSS is an extremely large telephone survey and can support state and local level estimates. Items are selected for inclusion on the core or on supplemental modules by a vote of state members. There is no information on substance abuse comorbidities and medical care, but there is information on mental health, and health conditions and behaviors, in many states. Total administration time for the full sample is only about 15 to 20 minutes, although longer interviews might be administered through telephone follow-back with sub-samples. One strength of BRFSS is its large size, which supports county level estimates in some states. Several panelists argued for the need for local data for planning where services are needed. The weaknesses of BRFSS include the limit on the number of questions that can be asked and that all states must agree to include any new module. However, two optional modules on mental health have been adopted for implementation by the states (the PHQ-8, 41 states, and the K6, 35 states,) for current or future implementation.

Ideally, one would include the same instrument (i.e., a small core of questions) on all three surveys and conduct small calibration studies on each. Should resources not allow this approach, the panel recommended continuing use of the NHIS for information on children since it currently collects the most comprehensive information on children. The panel also recommended using parent informants for information on children aged down to zero. Multiple informants (parents, siblings, and teachers) can be effective in identifying early childhood disorders.

<u>Summary</u>	of Child Mental Health Recommendations by the Panel
1.	Continue commitment to the Strengths and Difficulties Questionnaire on the National Health Interview Survey.
2.	Conduct a validation study of the Strengths and Difficulties Questionnaire by administering a longer, "gold-standard" diagnostic instrument to a sub-sample of the NHIS population.
3.	Maintain contact with experts on child psychiatric epidemiology who are conducting research on child mental health scales that might prove superior to the Strengths and Difficulties Questionnaire or that inform the use of the Strengths and Difficulties Questionnaire. Hold additional meetings with experts on children's mental health if useful.
4.	Collaborate with other agencies to consider the possibility of adding the same childhood measure to the NHIS, BRFSS, and NSDUH and of conducting a calibration study for each household survey instrument.

Summary of Adult Mental Health Discussion

Currently, the main mechanism for collecting information on adult mental illness, broadly defined, on household surveys is the Kessler Serious Psychological Distress Scale (the K6). This instrument has been or will be included on the NHIS, BRFSS (in 35 states in 2007), and NSDUH. The panel discussed the problems with the instrument such as context effects, lack of face validity, high prevalence rates, difficulties with the term "serious psychological distress," and lack of an impairment measure. People with psychoses are particularly hard to interview; informant reports (parents and siblings) are more effective for information on them although they are captured in broad screening scales such as the K6. Meeting participants recommended the following:

The K6 and WHO-DAS data that was collected for several years on the NSDUH should be analyzed to determine whether the several questions from the 12-item WHO-DAS could be used in conjunction with the K6. This would allow policymakers to not only understand the size of the population with serious psychological distress but the size of the population with impairments in functioning at various cut-points of functioning. The addition of the WHO-DAS would also provide face validity to the measure.

In subsequent years, a validation study should be conducted on a sub-sample of the NSDUH using the K6 and WHO-DAS. Prior to the study, one would need to determine the gold-standard that will be used for validation such as the CIDI or SCID. Ideally, the

small validation study would be ongoing which would allow a scale with minimal items to be continually calibrated as necessary.

Ideally, data from the K6 should be collected from the NHIS, the BRFSS, and the NSDUH and calibration studies conducted on each of the surveys. This would require that a standard K6 format be used. Currently, the NSDUH asks about symptoms in the worst month of the past 12 months, while the NHIS asks about functioning in the last month. The panel recommended using the worst month in the last year as the period of recall. If it was impractical to gather information on all three surveys, the NSDUH should be used.

Some other suggestions and observations were:

- 1. The objective with these surveys should be population-based measures, not accurate clinical diagnosis of individuals interviewed. Advocates for rare diseases must be helped to understand that these surveys generally will not identify rare or specific diagnoses.
- 2. Populations outside the households are also important to assess and the institutionalized populations are more likely to have higher prevalence of mental illness. They suggested assessments in nursing homes and prisons, in particular, and to take special note of foster care populations where mental health assessments are and need to be made.

Summary of A	Adult Mental Health Recommendations by the
<u>Panel</u>	
1.	Analyze the WHO-DAS and K6 data from the NSDUH to determine whether a subset of WHO- DAS questions might be used with the K6 as a measure of serious psychological distress at various levels of functioning.
2.	Continue to use the K6 and add the WHO-DAS or some WHO-DAS questions on the NSDUH.
3.	Conduct a study to calibrate the K6/WHO-DAS questions against a "gold-standard" measure using a subset or of the NSDUH.
4.	Collaborate with other agencies to consider the inclusion of the same K6/WHO-DAS questions on the NSDUH, BRFSS, and NHIS with calibration studies on each of the household surveys. If it was impractical to gather information on all three surveys, the NSDUH should be used.
5.	In general, agencies should work together more collaboratively on the definitions and identification of mental illness through household surveys, including consultations with experts in identification of mental illnesses.

Characteristics to Collect

In addition to recommendations concerning improvements to measurement of MI and SED and SMI on household surveys, the group also discussed desirable information to collect on the characteristics of respondents with MI and SED and SMI.

The following characteristics were initially described to the panel as those which SAMHSA is interested in collecting.

- Demographics: Age, gender, race/ethnicity, family income
- Insurance/program status: Uninsured, private insurance, Medicare, Medicaid/SCHIP, VA, DoD, other State and local programs
- Employment: Full-time, part-time, unemployed
- Payer of MH services
- Mental illnesses: any, SMI, SED
- MH treatment:
 - Access to treatment
 - Any received?
 - Utilization of treatment
 - Specialty of primary MH provider: GP/specialist, general/specialty facility, school, justice system

The panel suggested that it would be useful to know:

- What percentage of people received adequate treatment as opposed to any treatment (panelists noted that additional work would be needed to develop a precise definition of "adequate treatment" that was short enough to be practical for inclusion on household surveys).
- What percent of people did not complete treatment and why.
- Experienced side-effects associated with psychotropic medications.
- Determinants of whether an individual received care or not (such as barriers to receipt of care -- benefit design, attitudes, perceived lack of necessity).
- Presence of substance use disorders and mental illness.
- Presence of non-psychiatric comorbidities.

The panel did not make explicit recommendations regarding characteristics.

Attachment Y

NSDUH Confidentiality Pledge

2012 National Survey on Drug Use and Health (NSDUH) CONFIDENTIALITY PLEDGE

Conducted by: Research Triangle Institute (RTI) *Under contract to: Substance Abuse and Mental Health Services Administration (SAMHSA)*

Assurance of Confidentiality

RTI assures each respondent that the confidentiality of their responses to this survey's information request will be maintained by RTI and that no information obtained in the course of this activity will be used for any purpose other than the statistical purpose for which it was supplied. This assurance of confidentiality is required by the Privacy Act and supported by Section 511 of the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA). The Confidential Information Protection and Statistical Efficiency Act of 2002 ensures the confidentiality of all information provided is protected under Federal Law and protects the privacy of research subjects by stipulating that all information collected shall be used exclusively for statistical purposes.

Under the authority vested in the Secretary of Health and Human Services by Title V of the Confidential Information Protection and Statistical Efficiency Act of 2002 (PL107-347), all persons who --

- 1. are employed by RTI and its contractors and cooperating agencies; and
- 2. have, in the course of that employment, access to information which would identify individuals who are the subjects of a research project referred to as "National Survey on Drug Use and Health,"

are required to protect the privacy of the individuals who are the subjects of that research by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research.

Agreement and Pledge

I have carefully read and I understand the Assurance of Confidentiality that pertains to the confidential nature of all data to be handled in regard to this project. As someone who will have access to data from the NSDUH, I pledge that I will not disclose any confidential information obtained under the terms of this contract to anyone other than authorized project staff at RTI or SAMHSA. I understand that under the Confidential Information Protection and Statistical Efficiency Act of 2002 [Section 513] I am subject to criminal felony penalties of imprisonment for not more than five years, fines of not more than \$250,000, or both, for violation of the Act. I have also completed and fully understand the CIPSEA training provided to me.

I further understand and agree to comply with the following confidentiality provisions:

- 1. Any materials that would permit the identification of survey participants are to be treated as confidential. These include both hardcopy and electronic records.
- 2. When confidential records are in use, access to all such records is limited to persons who have signed the project Confidentiality Pledge.
- 3. Confidential records must be kept in a secured (locked or password-protected) location when not in use.
- 4. Information obtained from the data collected or used under this contract may not be released to unauthorized persons.
- 5. No data, tabulations, or analyses obtained under this contract may be released or used without prior written approval of SAMHSA. At the close of the contract all data must be returned to SAMHSA.
- 6. Any breach of confidentiality must be reported immediately to the RTI Project Director. This information will be shared with the SAMHSA Project Officer.
- 7. Obligations under this agreement will survive the termination of any assignment with RTI.

Name (Print)

RTI ID #

Signature

Date

Attachment Z

Followup Interview Reminder Card







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We appreciate you taking time for this important study and look forward to speaking with you soon.

Your suggested contact days and times are:

Day	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Time							

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Research Triangle Institute Research Triangle Park, NC 27709-2194

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Research Triangle Institute Research Triangle Park, NC 27709-2194



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