Unmet Mental Health Needs of Traditionally Underserved Populations in New York State – In response to a legislative charge by the NYS legislature, on September 10, 2008, the Center for Practice Innovations assembled topic-area experts to participate in a planning day to design an evaluation to identify the unmet mental health service needs of traditionally underserved populations. The legislative charge is to identify those populations with high rates of unmet mental health service needs, including but not limited to: racial and ethnic minorities, persons with limited English proficiency, persons with unmet housing needs, high-risk demographic populations (children, adolescents, young adults and the elderly), persons with criminal justice contact, and those lacking sufficient mental health care coverage. A report of findings and recommendations is due on or before October 1, 2010. The purpose of the report is to identify populations with high rates of unmet mental health needs and make recommendations for improving mental health service delivery to such populations, with a focus on culturally and linguistically competent promising practices. Invited experts for this planning meeting included: Margarita Alegria, Ph.D., Carlos Blanco, M.D., Ph.D., M.S., Naihua Duan, Ph.D., Roberto Lewis-Fernández, M.D., Thomas McGuire, Ph.D., and Alan M. Zaslavsky, Ph.D. To see a summary of the meeting, please see below.
Unmet Mental Health Needs of Traditionally Underserved Populations in NYS
Planning Meeting Summary
New York State Psychiatric Institute, New York, NY
September 10, 2008

Attendees:

OMH
Sheila A. Donahue, M.A.
Susan M. Essock, Ph.D.
Carol Lanzara, M.S. J.D.

Harvard Medical School
Margarita Alegria, Ph.D.
Thomas McGuire, Ph.D.
Alan M. Zaslavsky, Ph.D.

Columbia University
Carlos Blanco, M.D., Ph.D., M.S.
Naïhua Duan, Ph.D.
Roberto Lewis-Fernández, M.D.
Thomas Smith, M.D.
Jennifer Wisdom, Ph.D., M.P.H.

NYSPI
Jennifer Manuel, Ph.D.
Andel Nicasio, M.S.Ed.
Ilana Nossel, M.D.
Denise Reed, M.B.A, M.P.H.

EBP-TAC
Sharon Aungst, M.S.
Nancy H. Covell, Ph.D.
Carlos Jackson, Ph.D.

Legislative charge
Sheila Donahue

The charge from the NYS Legislature is to study, evaluate, and report on the unmet mental health service needs of traditionally underserved populations (Bill 6820, unfunded mandate). The proposed study and evaluation is intended to identify populations with high rates of unmet mental health service needs, including but not limited to racial and ethnic minorities, persons with limited English proficiency, individuals with unmet housing needs, high-risk demographic populations (children, adolescents, young adults, and the elderly), persons with criminal justice contact, and those lacking sufficient mental health care coverage. The bill was drafted before Timothy’s Law went into effect, so the landscape for those lacking sufficient mental health coverage has changed.

The 2005 Mental Hygiene Task Force report prepared for the NYS Assembly noted that “the various impacts of mental illness on the community, particularly among underserved populations, have not been measured to a great extent in New York. Such impacts include: economic costs associated with use of high cost emergency/crisis health services; financial costs
and lost productivity to family members and affected individuals; and diminished quality of life of affected individuals and their significant others.”

A report of findings and recommendations is due on or before October 1, 2010. This report will identify populations with high rates of unmet mental health needs and include recommendations for improving mental health service delivery to them, with a focus on culturally and linguistically competent promising practices.

What is already known about this topic?
Margarita Alegria

Measuring need

Measuring need can be problematic. What is the appropriate denominator to calculate need? Should illnesses for which there are no mental health services (e.g., some personality disorders) be included in the denominator? Definitions of need vary across studies, and results can differ, depending upon the sample and definition used. Also, the denominator can change with the question. Both total population and disorder-specific denominators can be useful (e.g., knowing that 50 percent of people with depression are not getting services is helpful to know, as is knowing that 1 percent of the total population has a diagnosis of schizophrenia and is not receiving services).

Traditional definitions (such as those from SAMHSA, the Substance Abuse and Mental Health Services Administration), typically use severity of disorder (particular DSM-IV diagnoses) and impairment (Global Assessment of Functioning of 60 or less) to define need for service. However, some have challenged these definitions noting that some mental illnesses, even without significant impairment, need treatment.

Other ways to define need include:
- Expressed need—those who ask for services. These individuals might not necessarily need services and other issues might be in play. For example, they might need a statement for housing/disability.
- Normative need—those with a particular diagnosis or high score on measures of symptomatology.
- Felt need—those who don’t meet diagnostic or symptom criteria, but for whom functioning is impaired. Though defining need in terms of impaired functioning is important, it can be difficult to define the background against which to compare it to (e.g., someone who was previously a physician is now only able to work in an unskilled job; how is this captured?).

Alignment of measures of need and use of services is not good. In the literature, people who use services are not necessarily those with the most need for services. For symptom measures, some evidence indicates that cultural factors can influence item response. For example, Asians tend to endorse certain symptoms at much higher thresholds than non-Asians; thus, they may
appear to have a low level of need, but this is an artifact of the tendency to endorse symptoms only under extreme circumstances.

Recommendations for measuring need include:

- Expand to be more inclusive and better aligned to service use, including moving beyond diagnosis and including symptom measures.
- Move from a dichotomous to continuous measure of need (e.g., create different indicators of needs from comorbidity, symptoms, and stress using additive weights). The group seemed enthusiastic about creating a continuous measure of need.
- Use a population level approach to define need.
- Expand criteria to include individuals at high risk of violence to others or self.

**Potential covariates**

The covariates chosen for analyses will make a big difference in outcomes (e.g., neighborhood characteristics, age, gender, and other demographics). Does the analysis become a poverty index or extend to effects of race and ethnicity beyond poverty?

The group’s recommendation was to follow the literature that both seeks to summarize by group what fairness or unfairness exists, independent of the cause, and at same time, ask what is causing any discrepancy.

**Review of relevant NYS data sources**

*Sheila Donahue*

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<tr>
<th>Mental health service user’s data</th>
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<tr>
<td><strong>OMH service use:</strong> Data are available on services that OMH operates directly, both inpatient and outpatient, across all payers. The information includes race, ethnicity, gender, age of person served, and language.</td>
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<td><strong>Medicaid Claims:</strong> OMH receives Medicaid claims for people who receive mental health services for a period of 3 years before and 3 years following a given mental health service. Data include claims for all services, medications filled, race, ethnicity, gender, age, and diagnosis (primary and secondary). The quality of data is fair (for race, the data are often blank), and claims lags are relatively short (a few weeks for medications filled; within 2 months for most mental health services). Separately, OMH receives encounter data that shadow claims for those covered by Medicaid managed care. This is more important for some populations, such as children, who are often covered under managed care through Temporary Assistance for Needy Families.</td>
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<td><strong>Patient Characteristic Survey (PCS):</strong> Every 2 years, OMH collects a one-week sample of demographic information for service recipients of all providers funded or licensed by OMH. This includes inpatient, outpatient, and residential services regardless of payer. The next survey will be conducted in fall 2009. The PCS represents the only data source for the number of people served in non-state-operated outpatient services where Medicaid is not the payer. Data include diagnosis, housing/living situation, education, employment, insurance coverage, veteran status,</td>
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and other characteristics. New questions to the survey can be added easily.

**Statewide Planning and Research Cooperative System (SPARCS):** The SPARCS system for acute care provides information on discharges, including diagnosis, from public general hospitals. Information about race and ethnicity can only be obtained through special request to the Department of Health.

### County-level data

Some user and population data can be analyzed in a way that provides information about counties.

### Population-based data

**The Behavioral Risk Factor Surveillance System (BRFSS):** BRFSS is the world’s largest ongoing telephone health survey system. It has tracked health conditions and risk behaviors in the United States annually since 1984. It produces a statewide sample that includes self-reported physical health and substance use, race, ethnicity, gender, age, whether an individual has sought treatment, and in spring 2009, the Patient Health Questionnaire 8 (anxiety and depression).

**National Epidemiologic Survey on Alcohol and Related Conditions (NESARC):** NESARC is a representative sample of the United States population; 43,093 Americans participated in the first wave, and 34,653 were re-interviewed in a second wave. The target population of the NESARC is the non-institutionalized household population, 18 years and older, residing in the United States. The following non-institutional group quarters housing units also were included as part of the NESARC sample: boarding houses, rooming houses, non-transient hotels and motels, shelters, facilities for housing workers, college quarters, and group homes. The two waves of NESARC provide detailed information on topics related to alcohol and drug use, abuse, and dependence and their associated psychiatric and medical disabilities. The second wave NESARC data file contains a few modified sociodemographic variables.

**Current Population Survey (CPS):** Estimates from the CPS include employment, unemployment, earnings, hours of work, and other indicators. They are available by a variety of demographic characteristics including age, sex, race, marital status, and educational attainment. They are also available by occupation, industry, and class of worker. Supplemental questions provide estimates on a variety of topics including school enrollment, income, previous work experience, health, employee benefits, and work schedules and are often added to the regular CPS questionnaire.

**The Medical Expenditure Panel Survey (MEPS):** MEPS is a set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage. The MEPS Household Component collects nationally representative data on demographic characteristics, health conditions, health status, use of medical care services, charges and payments, access to care, satisfaction with care, health insurance coverage,
income, and employment for individuals. The MEPS Insurance Component collects data on the number and types of private health insurance plans offered, benefits associated with these plans, premiums, contributions by employers and employees, eligibility requirements, and employer characteristics.

| The Area Resource File (ARF): | This is a collection of data from more than 50 sources designed to be used by planners, policymakers, researchers, and others interested in the nation’s health care delivery system and factors that can impact health status and health care in the U.S. This dataset can provide information on the distribution of providers across NY State. |

Dr. Alegria noted that New York State should be part of a group of pilot sites collecting race and ethnicity using different methodologies to determine which methodology is best; she will try to find out who in NY is involved in that larger study.

OMH does not have its own needs methodology in terms of prevalence; it uses percentages supplied by SAMHSA’s uniform reporting system (statewide basis only) for individuals with serious mental illness (SMI) and children with serious emotional disability (SED).

Currently, OMH has little information about the cultural competence of the mental health workforce. OMH knows something about race and ethnicity of employees, though provision of that information is optional. The information available about licensed providers is location of practice and age; the workforce is aging and is concentrated in NYC, Buffalo, and Rochester. Psychiatric nurses can not be separated from the larger category of nurses.

**Design to meet legislative charge**

This design is contingent on securing funding.

**General approach**

User data are complicated, difficult to use, and limited to individuals in the user population. One suggestion was population-based analyses, followed by county-level analyses (if NY State has an interest). Any user-level analyses should be targeted and selective.

Another approach could be to take a fully served population (if one exists) and produce a model that predicts getting services in that population (e.g., using demographics, distress, diagnosis, etc.). The resulting model is then used to compare service use in other populations (like a disparities model) by determining the difference between need and actual use. Some concern was raised about what the fully served population would be, with a suggestion to compare instead to what is optimum.

The group favored using multiple datasets, triangulating information in a way that takes advantage of each dataset’s strengths to provide an estimate or range of estimates of need and unmet need. (The group believes that there are no good datasets for children at this point). To the extent that the state impacts the model, the analyses would have to rely more heavily on
NY State data. On the other hand, if state data appear unrelated to the prediction model, national samples can be used for NY State.

The group concluded that estimating both need and unmet need is important for NY State. While the bill is designed to target unmet need, an estimation of need is helpful as providers plan how to reach underserved populations. When calculating unmet need, NY State data will become more important, since unmet need depends upon both individual characteristics and characteristics of the system. These calculations will include estimates by county (some smaller counties may need to be combined) that are normalized using z-scores to produce a distribution of county scores. These analyses would also explore predictors of met and unmet needs, including language.

Small area estimations

*Synthetic estimation.* This process involves obtaining estimates of rates for defined groups, using census data for each county, and multiplying census information by rate to create an estimate of need. Limitation of this approach is that it assumes that the rate for a group is consistent across areas (e.g., if using synthetic estimation for poverty, that assumption would be violated). An advantage is that the calculations are simple. (Chuck Holzer uses this approach for rates of disorder using national survey data).

*Regression estimation.* This process involves using information that is available for every area, building a regression equation that includes both individual and area characteristics to predict the probability of particular need or disorder. One advantage to this approach is that it can include more predictor variables including ecological effects such as the percent of poverty in the area or crowding. A potential disadvantage is that the model is only useful if the predictors are related to need. There are statistical models to combine local data with a larger sample that weights estimates according to the reliability of the information (i.e., the more local information that is available, the more weight it would have in the predictive model).

Quality of Care

Quality of care analyses are important, but separate, from need analyses. Part of these analyses could include a more fine-grained look at global unmet need estimates (e.g., within diagnoses). Quality analyses also include analysis of current existing best practices for addressing disparities. This topic could require a second planning day.

Work plan and next steps

With the report due to the legislature by October 1, 2010, the analyses must be completed at least 6 months before that to allow time for review and development of recommendations. Ideally, this would also include 6 months for quality analyses.

Three components have been identified:
1) Population-based estimates from national datasets
2) County-level needs, combined with spending (i.e., is the state allocating funds geographically in response to measured need?)
3) Quality of care analyses (involves large and complicated datasets)

Data will be analyzed in parallel at Harvard and Columbia, based upon which datasets each feels most comfortable using.

An executive team will describe the analyses to be conducted at each location and how that data will be merged for the report (Scope of Work). The team will meet regularly to oversee the process.

The Scope of Work will:
- Identify datasets that are suitable
- Define key concepts (e.g., need, service use)
- Identify covariates in data relevant to NY State’s purposes (e.g., race, ethnicity, language)
- Identify methods that will allow compatible and comparable estimates of need and unmet need
- Suggest additional questions to be included on the next PCS survey (e.g., racial/ethnic profile of staff, turnover rates, etc.)
- Estimate cost for the work

Next Steps:
1) Dr. Covell will create a summary of the meeting
2) Drs. McGuire, Algeria, and Zaslavsky will turn the summary into a first draft for scope of work to be done at Harvard.
3) Drs. Blanco and Lewis-Fernández will turn the summary into a first draft for scope of work to be done at Columbia.
4) Ms. Donahue will investigate possible data sources that could provide information about costs.
5) Dr. Alegria will explore the NYS pilot sites to determine which are collecting race and ethnicity information using different methodologies, to determine which methodology is best.