

**DEVELOPING MENTAL HEALTH INDICATORS FOR U.S.
CHILDREN AND ADOLESCENTS**

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OBJECTIVE

The goal of this CMHS- and NIMH-funded contract activity is to develop a set of scientifically grounded, yet easily understood and applied early warning signs and/or current indicators of children's *severe* mental health problems. The ultimate goal is to develop public health messages based on these scientifically grounded indicators that would improve parents', teachers', health care providers' and other social gatekeepers' ability to identify children with current or future mental health needs, and to assist these children in obtaining necessary care without incurring stigmatization. Although several organizations and workgroups have put forth early warning signs and mental-health indicators, these documents often represent expert opinions or consensus statements and are not necessarily supported by scientific evidence nor are they necessarily tested for end-user friendliness and appropriateness. In contrast, this effort is aimed at identifying science-based indicators/warning signs that are developmentally and culturally sensitive, as well as age and gender appropriate, and that are predictive of serious mental health outcomes.

It is anticipated that these indicators will not only be appropriate for use with the general public, but also that specific sets of indicators may be developed for teachers, health care providers, parents and other primary caregivers who, as gate-keepers, are well situated to recognize and identify children with mental health needs. These indicators are thus intended to assist all caregivers in recognizing when professional assessment of the child's emotional or behavioral functioning is indicated, and to encourage them to insure that the child or adolescent obtain this professional assistance. If appropriately deployed, such indicators/early warning signs may have the potential of facilitating earlier and more effective interventions as well as promoting a preventive approach towards children who currently have, or are at risk of developing, a serious mental health problem.

INTRODUCTION:

The Need for "Early Warning Signs" and/or Mental Health Indicators: Despite the substantial progress made in research on behalf of children's mental health over the last decade, significant gaps remain in actually identifying children in need of mental health care and ensuring that they obtain the necessary services. In fact, recent estimates suggest that a few as one-fifth of those with significant mental disorders are actually identified and receive any kind of help (Report of the Surgeon General, 1999). This persistent problem of under-identification likely has its roots in two core and intertwined factors prevalent in the general public: the social stigma of mental illness, and a surprising lack of knowledge/awareness relating to mental disorders. Thus, despite the growing body of research that indicates the importance of genetic and brain developmental factors in the onset and severity of mental illness in children and adolescents, simplistic notions about the causes of behavioral and emotional disorders in children persist in the general culture. Prevalent ideas of mental health etiology often implicate "poor parenting" or "family stressors" as the principal causes of children's mental health problems. For example, based on results from a national survey of 201 pediatricians in April 2000, Jensen (2002) reported that over 40% of pediatricians believed that depression was primarily the result of home and family problems. A

similarly high percentage believed that depression occurred because of youths' "difficulties coping," an interesting tautological notion that is in fact contravened by data: coping difficulties occur with the onset of depression, and improve as depression remits (Puig-Antich et al., 1993). Thus, potentially stigmatizing attitudes are not just a part of the general public's perceptions, but are commonly found among health care personnel as well.

As noted in the *Surgeon General's Conference on Children's Mental Health: A National Action Agenda*, children with mental disorders and their families shoulder extraordinary burdens of suffering. Extant data suggest that the number of children who experience substantial and continuing impairment is growing and it is likely that this is due in part to lack of appropriate recognition and treatment of their emotional, behavioral, and developmental needs (Murray and Lopez, 1996). For example, recent statistics compiled by the Center for Mental Health Services indicate that in the U.S., one in ten children and adolescents suffer from mental illness severe enough to cause significant impairment (Friedman et al., 1998). Yet, as noted above, in any given year, it is estimated that only one in five of these children receive specialty mental health services. To the extent that families (whether parents or youth) feel shame or blame in considering the possibility of a mental disorder, they will certainly be reluctant to seek evaluation and assistance for mental health-related problems.

To address these twin problems of social stigma and lack of awareness/knowledge, clear and consistent messages about mental health issues are needed. These messages must contain the understandable and pertinent warning signs of mental illness and what actions to take when children are identified as evidencing such indicators. Simultaneously these messages must de-stigmatize the open discussion of mental health problems. Finally, to insure relevance and enhance public trust, these messages need to be based on best available scientific findings of valid indicators of risk for current or incipient mental illness.

Challenges to Implementation: While the goals of early detection and better identification are meritorious, several substantial practical and theoretical issues are likely to hinder efforts to meet these goals. Previous research has shown that while some types of symptoms and behaviors are in and of themselves fairly stable, using them to develop decision-based criteria to identify which children are at risk for future problems has proven quite difficult. For example, Bennett et al. (Bennett, et al., 1998; 1999) have explored how well various cut-points on symptom scales can detect children at risk or in need of prevention/early intervention, but their findings indicate that prediction tends to be only poor to modest at best. Thus, their research suggests that developing a screen or indicator that can 1) detect 50% of future cases in need of intervention (sensitivity = 50%) and 2) is "right" at least one-half the time (i.e. 50% positive predictive value - PPV), has been quite difficult. They did note that it is possible for indicators to achieve somewhat better predictions among older (vs. younger) children, but even here the twin goals of 50% sensitivity and 50% PPV have proven difficult to achieve (e.g., Bennett and Offord, 2001).

On the first inspection of this problem, it might seem plausible that it would be easier to predict very severe cases (i.e., children in the top 5% of behavioral emotional problems, seriously emotionally disturbed, etc.) vs. children who are “milder” cases, i.e., those who may only fall in the top 20th percentile of symptoms. This possibility has not been fully empirically explored, although several investigator teams have noted that despite applying a multiple gating strategy (e.g., requiring not only that a child meet an initial severity criterion from one informant, but that the child meets a second threshold, perhaps from another informant) substantial numbers of misclassifications still occur, particularly if the disorder or problem to be predicted occurs with a base rate of less than 15% (Bennett et al., 1998; Bennett & Offord, 2001; Lochman and the Conduct Problems Prevention Group, 1995).

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TECHNICAL NOTE: *These above-described prediction difficulties cannot be easily overcome, as they have an intrinsic limitation, which is related to the probabilistic nature of diagnostic tests. This is best seen by considering odds ratios alongside probabilities, as certain equations simplify when using the language of odds. Recall that an odds is merely the ratio of the probability of something happening to the probability of it not happening. A fair coin has a fifty percent chance of falling heads and 1:1 odds of falling heads. Throwing a ‘6’ on a fair dice has a probability of 1/6 and the odds are 1:5. In a population with 5% illness, the odds of having the illness are 5:95.*

The odds of an indicator giving correct prediction of an illness (the equivalent of Positive Predictive Value (PPV)) is given by a simple multiplicative rule:

Odds of Correct Identification = (Evidentiary Value of Indicator) X (Population Odds of Illness)

Where the evidentiary value of indicator (also known as Bayes’ factor) is purely a function of the sensitivity and specificity of the test or indicator. The simple multiplicative form of the above equation makes its interpretation straightforward. No matter how good the indicator is, as captured in its “evidentiary value”, if the population frequency, or equivalently the population odds, are low, the post-test prediction will still be low. For example, if a given indicator, with a sensitivity and specificity that are both 90%, is applied to a population with a 10% illness prevalence, then the post-test odds of having the illness are 1:1 which is our desired 50% positive predictive value. If however we use the same indicator on a population with a 3% illness prevalence (i.e. odds of 3:97) then the post-test positive predictive value is only 22% correct! To achieve the 50% positive predictive value in this population would require that both sensitivity and specificity were 97%, a much more demanding specification for an indicator. While we can increase the sensitivity of an indicator as much as we like, this generally comes at the cost of lower specificity and is thus unlikely to increase its PPV.

One solution to these difficulties is to increase the effective population prevalence by pre-selecting the population before applying the indicator (Amsel, 2001). This is the strategy behind both the sequential testing method mentioned below and the method of focusing on a population of “known” high risk, as discussed below. In both cases it is, in effect, a way of enriching the population we run the test on with individuals who have the illness by pre-screening subjects. We are in effect dividing the original population into higher and lower risk subgroups, and then applying the indicator only to the higher risk subgroup, the subgroup with a higher prevalence of illness. A commonly known example of this strategy in a public health prevention campaign is the strategy of giving chest X-ray testing for TB only to those who have screened PPD positive. Among PPD positive persons a spot on the chest X-ray has a much greater probability of being correctly predictive of TB than the same spot would have in the X-ray of a random individual drawn from the whole population. END OF TECHNICAL NOTE

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 Another challenge that may make prediction and/or early identification difficult is that different thresholds and varying criteria may be required, based on such characteristics as children’s age, gender, or ethnicity. For example, the likelihood that a

particular symptom (e.g., “hitting other children” or “forcibly taking objects from other children”) is meaningfully predictive of later problems will differ in 4-year-olds (where such problems are quite common among preschoolers) than in 14-year-olds. Likewise, a given symptom or indicator (e.g., obesity) may be more predictive of depression in females than males, or in some ethnic groups (Caucasians) than others (Hispanic, African American). The added complexity of determining and applying different warning signs for different demographic subgroups may prove daunting to successful deployment of early warning signs/indicators, but these issues must be considered and empirically explored.

Possible Strategies for Improvement. To circumvent some of these challenges in improving the accuracy of a screen or indicator, several strategies might prove useful. Thus, Bennett and Offord (2001) have shown that predictive accuracy can be improved if multiple factors are considered, such as using multiple types of symptoms as predictors (rather than just one type) or by using both child indicators (e.g., aggressive symptoms) and family-contextual factors (e.g., household income adequacy, maternal education, maternal depression, parenting efficacy, family functioning). Although both of these strategies do improve accuracy of identification and prediction, these efforts still fall short of achieving the fairly modest goals of 50% sensitivity and 50% PPV.

Further complicating the use of indicators other than the child’s functioning (e.g., family or contextual factors, such as poverty, maternal depression, etc.) is that such variables used alone are frequently incorrect, and could be stigmatizing. So for example, a public information campaign that relied on the indicator of “poverty” or “welfare status” might stigmatize large groups of children, but also would identify children who have only modestly increased risk for behavioral or emotional problems than children without such risk factors (Achenbach, Conners, & Quay, 1993) and in many instances, may have no increased symptoms whatsoever.

One alternative application of the use of family-contextual factors might be to consider their deployment only in limited settings, such as among primary care providers whose role in the prevention of disease has always included the assessment of risk factors known to affect the likelihood of illness. In such settings, for example, a pediatrician’s awareness that a young mother is depressed might lead him or her to further explore the possibility of behavioral difficulties in a child, or if such are present, to consider that the child may be at greater risk than if he/she had behavioral symptoms without such complicating family factors. But focusing on “depressed mothers” as a public media strategy could prove problematic.

A closely related strategy might be to consider deploying screens/indicators/early warning signs in settings where the likely current or future prevalence of mental health need/disorder is already increased well above 15%, it might be possible to achieve PPVs greater than 50%. Thus, among children in foster care, special education, or juvenile justice, the use of warning sign screens or mental health indicators may be more easily justified and more likely to be correct in identifying children with current or future mental health needs, since research has suggested that 30-50% are at risk for mental

health problems. Such a strategy might even be applied to children who already have known current mental health problems, such as children with Attention-Deficit/Hyperactivity Disorder (ADHD). Applying early warning signs for aggression, conduct or substance use problems to such a population could yield substantial benefits in preventing long-term co-morbidity outcomes, if effective means are available to prevent these secondary consequences and/or more effectively treat the primary disorder (e.g., see MTA Cooperative Group, 1999, Jensen et al., 2001). Such an approach applies the principles of what Kessler has described as the “primary prevention of secondary disorders” approach. Relatedly, if one considers that many of the childhood disorders are chronic conditions, applying a chronic disease model and disease management approach to early identification and optimal intervention strategies for those with additional “warning signs” or indicators may prove a useful, non-stigmatizing, and effective strategy.

Yet another possible strategy to improve our ability to identify children in need would be to altogether avoid the notion of future prediction, and direct efforts instead towards improving current detection of mental health need. A further modification of this strategy would be to develop warning signs/indicators for children who are currently seriously impaired, i.e., in the top 5th percentile. If it is true that only one in 4 or 5 children with mental health needs are identified and get into appropriate care, does this same principle apply to the most severely impaired? If so, application of effective indicators in this subgroup may minimize the likelihood of misclassification and stigmatization. It might also avoid the risk of identifying milder cases that might well improve on their own. The potential merits of this strategy are clear, yet targeted analyses of appropriate data sets might be needed to adequately address the feasibility of this approach.

A final strategy for identification of children in need involves improving the risk-benefit ratios such that there are fewer stigmatization-associated risks. This might be accomplished by intentionally developing non-stigmatizing indicators, thus identifying the presence or absence of protective factors or “strengths-based” characteristics rather than indicators of psychopathology. Identifying the components and characteristics of mental health rather than illness could then be one means to help parents and providers identify children in need of intervention based on the absence of a critical *healthy*, emotional characteristic. For example health indicators might include “positive outlook and attitude about life,” “respectful towards adults,” “well-liked by others,” “exhibits constructive problem solving skills.” A glaring absence of one or more of these indicators would be a flag for further assessment or other screening. Of note, little is known about this strategy, and efforts to identify positive or protective factors have been limited by the relatively sparse literature in this area (Foundations and Agencies Network for Children’s Mental Health, 2000; Huffman et al. 2000). Nonetheless, positive messages may be more palatable to certain population segments or even the public in general, and they therefore warrant serious consideration.

IDENTIFICATION AND DEVELOPMENT OF INDICATORS OVERVIEW OF TASKS

The overall engine for defining and refining the goals and methods of this project has been the Children's Mental Health Indicators Steering Committee (SC) (David Offord, M.D., E. Jane Costello, Ph.D., Robert Friedman, Ph.D., and Barbara Huff). An early consultation/meeting with members of the SC and the Carter Center served as an initial project anchor. Subsequently, an iterative consultation process was created whereby the SC would meet regularly by phone to respond to project developments (*see APPENDIX I for the minutes*). This might include refinements in project conceptualization, theoretical issues in prevention approaches, as well as responses to data analytic results and to focus group feedback. While described below as a linear process for the sake of clarity, this process was far more organic and complex involving multiple feedback loops and emergent insights into the overall project direction and the methodology for achieving the identified goals.

Given the considerations outlined above and the perceived risk-benefit trade-offs, the initial overall goals defined by the SC were to minimize false positives and avoid stigmatization by employing a combination of strategies: 1) using high quality epidemiological data bases to empirically identify the most powerful indicators/warning signs; 2) ensuring that the indicators are culturally, developmentally, and gender appropriate; 3) ensuring that indicators are developed for specific target audiences where the risk benefit trade-offs differ (e.g., general public, parents, providers/professionals, educators, special service settings, etc.), 4) giving priority to developing indicators for purposes of identification/detection of disorder, rather than prevention/prediction; 5) focusing initially on developing indicators for the most severely impaired 5% of the child and adolescent population, rather than those children with "milder" forms of mental illness.

In order to begin to address these initial identified goals it became clear that the project simultaneously required high quality precise quantitative research and data analytic methods in order to ground the indicators in the best available scientific evidence, as well as open ended qualitative research into the best ways to translate the indicators into language and contextualized messages that had the best chance to effect increased understanding, decreased stigma and appropriate behavioral changes. Thus, the particular approaches employed have included a comprehensive review of the relevant literature, identification of the most appropriate existing data sets for analyses, analysis of data sets to determine optimal potential indicators, and development of a relative small set of six indicators. These potential indicators were then presented to focus groups of parents, teachers, pediatricians, and adolescents, in order to assess their acceptability, understandability, and utility among these key stakeholders. Of equal importance, the focus groups were designed to elicit suggestions as to the most effective ways of communicating these indicators, including recommendations for the most effective alternative phrasings, framings, contexts, and media.

Thus the SC came to consensus on four main principles to guide the project development:

- 1) Begin from the perspective of developing indicators for very severe symptom/conditions where there is an unmet need, and where most lay and professional persons alike would agree that the particular indicator/condition is severe enough to warrant a mental health evaluation.
- 2) Use careful wording of the indicator
- 3) Assess people's understanding of the indicator
- 4) Plan a prospective study to determine whether and how people's behavior changes when they receive this information

A more detailed description of the approach we have taken is outlined below organized according to task in the approximate chronological sequence in which they have taken place.

Task I:

Review of Scientific and Other Relevant Literature, and Identification of Optimal Databases: With the input and guidance of the SC, we have reviewed the existing literature on mental health indicators and the relevant related scientific literature through Grateful Med and PsychInfo search engines. This includes a review and compilation of federally funded epidemiological studies, as well as local community and clinical studies. While there are some merits for exploring indicators within clinical data sets (where denominators are not known), inferences from such clinical samples to the general population can be problematic, and the SC recommended against using such data sets for this purpose.

Because an important task is to determine indicators identifying children who have unmet mental health needs, given the uniqueness of North American culture and the nature of service barriers, priority was given to *U.S. and/or North American studies*, ideally of a longitudinal nature, with validated measures that include not only symptom level indicators, but also functioning, protective, and contextual factors (e.g., school performance, peer relations, family and neighborhood factors).

Characteristics of Optimal Data Sets: Fortunately, over the last decade a sizable investment has been made by various federal agencies and others to support the conduct of a substantial number of epidemiologic and clinical studies of children's mental health. Many of these data sets have already been well analyzed, in terms of their ability to predict those characteristics which presage children's future mental health problems and services needs. Examples of such data sets are the Oregon Longitudinal High School Study (Lewinsohn and colleagues), the Great Smoky Mountain Study (Angold and colleagues), and the Ontario Child Health Study (Offord and colleagues). While these various data sets differ in the type and quality of mental health variables available within them, many of these data sets are quite valuable in empirically determining a valid set of early warning signs/indicators. Initial Steering Committee input defined the following characteristics for an "ideal" data set:

DESIRABLE CHARACTERISTICS OF DATA SETS

longitudinal data, with 2 or more waves at least 1 year apart (these can be used for secondary analyses of prediction, once initial indicators have been identified)

careful definition, enumeration and description of one or more circumscribed community(ies) from which the sample(s) will be drawn
rigorous sampling methods applied to the defined community to ensure a representative sample

in-depth mental health diagnostic information based on psychometrically robust structured or semi-structured interviews utilizing a standard diagnostic nomenclature (e.g., DSM-IV or ICD-10)

assessment of demographic variables (age, gender, ethnicity, SES); plus repeated assessment of putative risk factors, child and family functioning, mental health services need/use, and neighborhood/peer/contextual variables,

75% plus participation in follow-up studies

reasonably current data set, i.e., based on information collected in the last 12 years

North American

For longitudinal data sets, good endpoint data must be available, since the task of prediction assumes that one must work backwards from the endpoints to the predictors. Endpoints might include services need/use, impairment, severe symptoms, medical necessity, disorder with impairment, etc. For cross-sectional data sets, variables must likewise include services need/use, impairment, severe symptoms, medical necessity, and/or disorder status with impairment.


Good age range coverage (0-18 years)...starting as young as possible

low refusal rates

multiple informants (parents, teachers, and/or youth)

adequate power/size of the sample

Using these criteria a number of data sets were initially identified (*See APPENDIX II for data set table and bibliography*):

- 1) Great Smoky Mountain Study (P.I. – Costello, J.) 
- 2) Oregon Adolescent Depression Project (P.I. – Lewinsohn, P.)
- 3) National Comorbidity Survey (P.I. – Kessler, R.)
- 4) The NIMH Methods for the Epidemiology of Child and Adolescent Mental Disorders Study (MECA) (P.I. – Lahey, B.)
- 5) Pittsburgh Youth Study (P.I. – Loeber, R.)
- 6) Psychiatric Disorders With Onset in the Preschool Years (P.I.–Lavigne, J.)
- 7) Mental Health in Pediatric Settings (P.I. – Horwitz, S.)
- 8) National Longitudinal Survey of Children and Youth (NLSCY-Canada) (P.I. – Bennett, K.)
9. Iowa-Georgia Rural Minority Sample (IOWA) (P.I. – Conger, R.)
10. Depression and Anxiety, Minority Youth, and Primary Care (TEXAS) (P.I. – Roberts, R.)

11. Antisocial Behaviors in U.S. and Island Puerto Rican Youth (P.I. – Bird, H.)

The identified data sets and their key characteristics are contained in a table in the attached Appendix II. While each of the data sets in this tabled Appendix meet most if not all of the criteria above, the SC determined that no single data set could achieve all of the project's objectives. Nevertheless, valuable information can likely be gleaned from each of them, particularly if a given data set has some unique advantages (e.g., it covers an age or cultural group not addressed in other data sets, or contains some unique contextual or risk factors, etc.). Before determining which data sets were optimal, the Steering Committee reviewed them with attention to the quality of specific studies, how well each meet the characteristics noted above, and how well each characterizes possible warning signs across various age, gender, SES, and cultural/ethnic groups.

After the SC reviewed the available data sets, it noted differences between ideal data sets for determining indicators, and what is actually available in extant data sets. The SC further refined its goals based on the extant data sets, in order to determine where compromises were acceptable relative to these goals and which factors were crucial to a valid and useable interpretation of the findings from less than ideal measures and data sets. This led to a refined focus on the following characteristics at least for the initial data sets to be analyzed:

- 1) be rich in psychopathology measures
- 2) cross-sectional or longitudinal data
- 3) ascertain whether the child is currently receiving services at the time that psychopathology was assessed.
- 4) take place in North America
- 5) from 1990 or later
- 6) have a large community-representative sample

When examining the initial nine data sets listed above, the SC investigated each of the following measures with detail:

- 1) DISC (2.3 and 4)
- 2) DICA
- 3) K-SADS
- 4) CAPA
- 5) Two utilization measures (SURF and CASA)

With further evaluation and data availability, the SC settled upon the three data sets highlighted in the above list, namely the MECA, Iowa, and Texas data sets. In particular the measures of interest in these datasets that were thoroughly analyzed during subsequent conference calls were the DISC 2.3 and the DISC 4.

Task II

Develop a Conceptual Framework for Warning Signs/Indicators, as informed by the Literature Review and Identification of Appropriate Databases. The first steps to developing potential set of indicators involved the initial exploratory analysis of identified databases, selected as discussed above, in concert with the literature review and

expert input from the SC. This initial exploratory analysis of the data sets confirmed the hypothesis that there were high rates of unmet need and that items contained in the relevant structured interviews might serve as components of an indicator construct.

As a second step, with the assistance of Christopher Lucas, MD, an analysis of 3,146 interviews using the DSM-IV DISC across 7 communities was completed. For these analyses, predictors of mental health disorder and global impairment were examined, based on specific individual symptoms, using both adolescents and parents as informants. Using logistic regressions of items from the DISC predictive scales, a determination was made concerning which items predicted current mental health need (disorder plus impairment). These are listed below separated for indicators derived from youths' versus parents' reports. The commonalities and differences in which items are predictive of *mental disorder + impairment* status are illuminating, and immediately suggest that different messages for youth vs. adults may be needed.

Potential Indicators (Based on Youth Reports)

- 1) Nervous or uncomfortable in a group
- 2) Often feeling nervous when in front of other people
- 3) Getting very sick or upset when away from parents or attachment figures
- 4) Afraid of the dark (9-17 year olds)
- 5) Ever having a panic attack
- 6) Afraid to go out of house for fear of panic attack
- 7) Tense, difficult to relax
- 8) Wetting self during day after age 5
- 9) Thinking serious about killing self
- 10) Hard to keep mind on things
- 11) Stolen from others
- 12) Lied to get money
- 13) Broken into house, building, or car
- 14) Expelled from school
- 15) Getting into arguments with family/friends due to drinking
- 16) Used marihuana 6 or more times
- 17) Used cocaine/crack in past year
- 18) Used Opiates in past year

Potential Indicators (Based on Parent Reports)

- 19) Getting very sick or upset when away from parents or attachment figures
- 20) Afraid of bridges or tunnels, or going out of the house alone (9-17 year olds)
- 21) Ever having a panic attack
- 22) Thinking seriously about killing self
- 23) Belief in one's "special powers or abilities"
- 24) Often cannot do things that require attention
- 25) Hard to keep mind on things
- 26) Refuses to do what told to do by adults
- 27) Getting even by hurting or messing up people
- 28) Doing mean things on purpose

- 29) Lied to get money
- 30) Broken into house, building, or car

Of note, when the youth had 4 or more of these symptoms a PPV of 51% and sensitivity of 73% were obtained. While it has not been empirically tested, it is likely that the additional requirement of “severe” and persistent” might result in a better PPV, but potentially at some loss to sensitivity (which might be affordable, if the goal is 50%). While these are extremely compelling findings, the SC noted some limitations to basing indicators on these items. While as individual items they are significantly correlated with “caseness” or current mental health need, each item can predict only a very small fraction of that need. On the other hand the alternative of presenting a cluster of these items taken together as an indicator though possibly useful for mental health professionals, might undermine the use-ability and clarity of the concept of an indicators that members of the general public could use.

As a third step, the team, armed with the above preliminary research convened a meeting at the Carter Center November 2001 in which the GPO, the Federal Workgroup, mental health advocates, consumer participants and the Steering Committee (SC) could deliberate together to craft preliminary recommendations on the indicator characteristics and on communication/dissemination issues.

At the meeting Drs. Jensen and Offord presented the above findings as well as a set of core premises from which the discussion preceded: 1. At any given point in time, most children (3/4ths) with significant emotional and behavioral disorders are not being identified and do not receive mental health treatment. 2. It seems likely (and is presumed) that at least some of the difficulties with identification have their roots in a) lack of awareness of the signs and symptoms of mental illness, b) stigma, c) communication differences and different terminologies across different settings and disciplines. 3. Following the Surgeon General’s call to Action for Children, there is a need for common terms/definitions, so that there is a more shared understanding across the general public and across various disciplines what in fact are the most appropriate warning signs/indicators of mental health need, particularly a need that has not be recognized or met.

In the final step, feedback from the Carter Center meeting was incorporated into preliminary findings and the development of a conceptual framework aimed at constructing a set of indicators as guided by the principles outlined below. It was noted that a variety of approaches have been recommended to denote which children are most in need of mental health services. The various approaches differ across agencies such as the CMHS, World Health Organization, and the Department of Education. In addition, mental health need might be identified not only by mental health outcomes, but also by other physical and social outcomes, such as employment, marital success, physical health, or various adverse outcomes: medical illness, suicide, unemployed/on welfare, etc. Yet another consideration might be related to whether the indicator identifies children with conditions that can be effectively treated or prevented. The final conceptual

approach taken here considered these alternative definitions of mental health need, in determining optimal indicators.

After considering these factors the SC noted that the activities outlined above are quite ambitious, but this activity is framed as a multi-phase project, such that we may only outline (rather than complete) a number of activities, analyses, and objectives in the current phase. Completing all of these outlined activities is assumed to require further phases of the work under subsequent funding arrangements. This suggested the importance of prioritizing activities, and proceeding on the basis of focusing first on the most severe unmet needs as a way of putting “first things first,” while simultaneously identifying the needed future activities that the federal government should pursue. The conceptual framework delineated below operationalizes this priority setting function of the SC.

CONCEPTUAL FRAMEWORK FOR DEVELOPING WARNING SIGNS/INDICATORS:

Focus on Clinically Meaningful Phenomenon. Traditional sensitivity and specificity characteristics are important in the evaluation of the usefulness of proposed indicators/predictors. Yet the characteristic most relevant to an optimal set of indicators/predictors is, as discussed above, the positive predictive value (PPV), that is, the extent to which persons with that particular characteristic actually eventually demonstrate real mental health need. If an indicator/predictor identified many persons as “positive” who did not actually have a mental health need, even if highly sensitive, that indicator would lose credibility, undermine the public’s belief in real mental health needs, unduly “label” or “target” children, and lead to increased stigma. Likewise, if an indicator or warning sign is highly specific, but ignores the most common mental health needs experienced among children, it too may be of limited value. And of course, in addition to showing a relatively high (50%) PPV, an indicator ought to be related to *clinically meaningful phenomena*, that is, it should pass muster within experienced clinicians as indicating conditions that meet the criteria for “medical necessity...” -- deserving of treatment, and for which effective interventions exist. Thus the first principle our conceptual framework considers that an optimal set of indicators must consider the following factors:

- 1) Appropriate sensitivity and PPV to DSM-IV Disorder with Impairment among children not currently being served (e.g., the “unmet need” group, see below for further discussion)
- 2) Appropriate sensitivity and PPV to some threshold for symptomatic impairment (to be decided) *among children not currently being served* (unmet need)
- 3) A given behavior constitutes an ethical imperative (based on the community standard of practice) such that any child with that behavior should get a MH assessment (e.g., suicidal plan or behavior, other imminently dangerous behaviors, etc. “Gray” issues might include multiple contacts with police, school expulsion, runaway behavior, etc.)

Focus on Current Problems: Moving Away from “Early Warning Signs” (Predictors) to “Mental Health Indicators.” (Current Problems). Given the considerations noted in the introduction concerning the difficulties of predicting future mental health need, early SC discussion centered around the implications whether it made better sense to develop indicators/warning signs to identify the most severely impaired 5%, of whom we believe only a fraction perhaps 1 in 4 or 1 in 3 is identified and receives services. One potential benefit of restricting the efforts of the indicators initiative to the most impaired 5% is that indicators for this group of children need not be predictive of **future** mental health services need, since these children presumably would need services **now**. Thus, the problems of the generally low power of prediction, and the possible problems of misidentifying/mislabeling children who do not eventually develop significant problems, could be circumvented. Simply focusing on better indicators of the 5% who are currently not being identified and not receiving services could be of great assistance, and would be much less likely to do harm. Thus the principle of focusing on **severe conditions** and that of focusing on **current need** emerged together. Thus the SC decided that while predicting future need and possible future disability was important, focusing on children and adolescents with current mental health needs was the most first step to take. However the SC noted it would be necessary to empirically validate the belief that even in this extremely severe group only 1 in 4 or 1 in 3 was being seen by mental health provider.

Focus on Unmet Need. Given the above considerations, the SC noted it would be necessary to empirically validate the belief that even in this extremely severe group, on which we are focusing, only 1 in 4 or 1 in 3 was being seen by mental health providers. At the same time the SC noted that there might be a set of severe emotional problems for which appropriate services were being delivered or for which current level of public awareness campaigns could be judged to be adequate. Such conditions would then have less priority in our development and dissemination of relevant indicators.

Focus on Persistence & Severity. Given the apparently increased value and PPV of indicators that are persistent over time, given indicators might be modified and enhanced by specifying that they are *persistent* and noted *over time*, and show a *critical number* and/or severity as noted above. However, these issues should be explored within the context of the available longitudinal data sets, since it is possible the requirement of persistence and/or severity may increase PPV, but at a severe cost to sensitivity. Thus, if data suggest that the presence of depressive symptoms might be useful as an indicator, its potential PPV might be enhanced by specifying “severe depression lasting more than one month.”

Focus on Robust Indicators. Given the goal of developing an evidence-based set of indicators and the identified group of data sets, it became clear that a necessary condition for an potential indicator should be a *replication of findings* across multiple relevant data sets that demonstrate the usefulness and value of the indicator across these studies, regardless of geographic, ethnic, socio-economic, cultural, and methodologic differences that characterize different data sets.

Age and Gender Factors: Ideally, if indicator signs are to serve their optimal purpose, they must be based on scientifically-based evidence derived from epidemiological and clinical data bases that document longitudinally which variables or factors are most likely to predict a child's need for services. Furthermore, a substantial body of research has indicated that males and females are likely to show different forms of mental health signs/indicators, but even these general trends vary by age. For example, prior to puberty, boys and girls experience similar levels of depression and depressive affect, regardless of whether these levels are compared above or below the threshold for major depressive disorder. During and after puberty, among females the frequency and severity of depression and depressive affect rise substantially, more than doubling over pre-pubertal levels. Among boys, however, rates of depression remain the same, while rates of alcohol and substance use rise greatly, well beyond that of girls. Thus, warning signs and early indicators must take into account both age- and gender- related factors that lead to different expressions of risk for mental health problems.

The three most prominent age periods that characterize estimable differences in mental health problems are the infant-toddler-preschool years (ages 0-4), child (ages 5-12), and adolescent (ages 13-18). Because very young children are growing and changing so rapidly, and tend to be quite labile in their expressions of symptoms as a function of their current environments, the classical definitions of psychopathology based on the Diagnostic and Statistical Manual, Version 4 (DSM-IV) may not apply to the same extent that these criteria fit the older child and adolescent age groups. Because of young children's prominent emotional reactions when separated from their caretaker, and their often more diffuse forms of symptom expression as a function of contextual factors, for these reasons, other nosologic systems have been proposed, such as the Zero to Three diagnostic nomenclature. Nonetheless, it is likely that a different set of warning signs or early indicators will need to be developed for this younger age group. To further avoid stigma in this very young group, public messages about mental health might best be framed in positive terms with an emphasis on school readiness and indicators of barriers to this readiness rather than focusing on psychopathology per se.

By the age of 5, a number of well defined, relatively persistent forms of behavioral and emotional difficulties can be identified, such as Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, and various anxiety disorders. In fact, the age period of 5-12 circumscribes the peak ages of onset for all of these conditions, suggesting again the need for a number of different warning signs/indicators for this age group. Similarly, the adolescent years circumscribe the peak ages of onset for major depression, serious conduct disorder, and alcohol/substance abuse, suggesting the need for indicators specific to that age period.

Language, Cultural/Ethnic, and SES Factors: By and large, in the area of child mental health, language and cultural factors have not been shown to be related to differences in expressions of psychopathology per se (in contrast to studies of adult populations across different ethnic/cultural groups). In other words, cultural and socio-economic variables appear not to lead to different forms of emotional/behavioral disturbance. Instead, when these factors are salient, they simply change the likelihood that a child will shown a

behavioral or emotional disturbance (sometimes leading to an increase, sometimes to a decrease), and they lead to different interpretations by others of the meaning of the child's symptom or behavior. For example, a child who is aggressive within a socially and economically advantaged Caucasian neighborhood may be viewed with different suppositions about the causes and meaning of his/her symptoms, versus a similar aged African-American child in high poverty, high crime neighborhood. These considerations suggest that while a given set of indicators/warning signs may have similar positive predictive values across different ethnic and SES groups, they may be *interpreted* quite differently by the various communities. For these reasons, if warning signs/early indicators are to serve their intended purpose, they must have the input and acceptance of the various communities and children to whom these indicators may be applied.

Being End-User-Friendly: Paying Attention to Language Acceptability and Interpretability Issues. As will be discussed in greater detail below in the section on focus groups, many terms current in use in the mental health sector, while taken for granted among knowledgeable members of the mental health community, might be used pejoratively or otherwise associated with stigma in the general public sector. Consider the common terms *mental health*, *mental illness*, and *mental disorder*, and how the term “mental” has been used as a sole pejorative term by comedians, youth, and others, i.e., “He’s *mental!*” Thus, even fairly benign terms such as “depression” when used as an indicator within a message may connote potentially stigmatizing messages. One strategy to minimize this effect would be to use more every-day words to denote the same constructs, i.e., “sadness” rather than “depression,” or “tense” rather than “anxious.” Yet the term “sadness” may not connote quite the same construct as “depression,” and some persons may assume that sadness is because of some external cause, while depression may not be. Quite possibly, it might make some sense to combine the terms, if in fact different segments of the population could then understand the overall construct. Then the terms might be modified further to increase their mental health salience and potential usefulness as “indicators” by augmenting them with severity and persistence terms, i.e., “severe sadness or depression lasting more than a month.” While such approaches may be sensible at first glance, they must be empirically, if qualitatively, tested through a variety of focus groups involving members of the general public as well as specific role-based end-users.

Thus, scientific information alone about the predictive nature of a putative indicator cannot be a sole criterion for the development of indicators. In addition, they must be crafted on the basis of end-user input with a goal of end-user-friendliness. Thus they must be vetted and it must be demonstrated through empirical qualitative research that they are indeed understood, acceptable and palatable to various groups and communities in which messages about the indicators will be deployed. Quite possibly, a given warning sign or early indicator may need to be tailored so that its language and level of understanding is appropriate for different age groups (child, youth, adult), possibly also as a function of whether the target audience is the lay public, a teacher, or a primary care provider. In addition, because of the substantial investment that the mental health advocacy communities have in this area, it is essential that their input be obtained on the early

warning signs and indicators as well, so that “buy-in” and deployment of the indicators/warning signs can be as wide as possible.

Contextual Factors. Contextual factors should not be discarded a priori, but initial consideration of their application as mental health need indicators suggests that their deployment should be restricted to settings where consideration of contextual factors is already an integral part of an assessment process (e.g., primary care, foster care, special education, etc.).

Segmenting the Target Audience: As noted above, analyses might be done in various settings, since indicators may work quite differently across the general public, in special ethnic groups, among primary health care providers, in educational system workers, among head start and preschool personnel, and within mental health providers, juvenile justice personnel, and welfare/foster care workers. Rather than developing a host of indicators that differ across various settings, it might be reasonable to develop one set of indicators for the general public, and one for primary and special care settings.

Based on these principles outlined above the SC proposed six indicators for further data analysis and for presentation to focus groups. The operationalized form of these indicators as used in statistical analysis will be discussed below. Here we present the indicators as they were presented to the focus groups.

1. Severe Depression with Impairment:
Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.
2. Suicidal Thoughts with Plan or Any Attempt:
Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.
3. Severe Anxiety with Impairment:
Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.
4. Any Panic Attack:
Imagine a child that has expressed symptoms of being very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.
5. Severe Aggression with Impairment:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

6. Eating Disorders with Impairment:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors have affected relationships with family, and have caused concerns at school and with friends.

In addition to these behaviors, The SC suggested two other behaviors to warrant further consideration, namely impulsivity and mood instability. *(Please note: this list of 6+2 indicators continued to grow, up to a total of 12, as additional analyses were done and feedback from focus groups and advocacy organizations was received. See Appendix IX for Phase I final list of Indicators).*

In comparing this list with the thirty potential indicators derived from Lucas' analysis it should be noted that the decision to focus on the most severe 5% who currently manifest symptoms rather than focusing on a broader group or risk for later psychopathology thins the ranks of the potential indicators. Nevertheless when severity is taken into account these six indicators can be interestingly compared to the territory covered by the thirty items in Lucas' list above. Thus items 1-7, 19, 20, 21 are all anxiety symptoms covered by the notion of anxiety with severe impairment. Unsurprisingly, suicide shows up in both the parental and youth reports, 9, 22. The areas covered by 11, 12, 13, 14, 26, 27, 28, 29, 30 create a controversy as mental health indicators as they might just as well be seen as behavioral or moral flaws at least by some segments of the general public. The solution suggested here was to focus on the most severely impaired. Thus the SC concluded that a category of physical aggression when severe and persistent as indicated by certain criteria would cover those forms of behavioral and legal problems that uncontroversially belonged in the realm of mental illness. On the other hand the SC noted that these behaviors might also be related to impulsivity and mood instability (possible early onset bipolar disorder) which are the two areas placed on the agenda for further consideration. In this regard item 23 involving belief in special powers is likely related to bipolar disorder and or other psychotic disorders manifest in youth. On the other hand 10, 24 and 25 deal with ADHD an area that is receiving considerable public attention, as is teenage substance misuse as covered in items 15, 16, 17, and 18. Finally item 8 (wetting after age 5) was thought to be too nonspecific for inclusion among indicators of serious mental health problems.

With this list of potential indicators in hand the subsequent tasks involved testing them against the available databases and discussing them with focus group participants. As discussed below the focus group participants were also asked to suggest further potential indicators that they thought would be useful.

Task III

Coordination and Methods of Data Analyses:

The three steps involved in the initial analysis of data sets included deciding on the data sets, focusing on the particular measures used within these data sets, and operationalizing the indicators into data analytic algorithms in order to test them within the given data bases. As described above the SC settled on three initial databases to analyze, namely the MECA, Rand Conger's Iowa Study, and Bob Roberts' Texas HMO Study. The main two measures used within these datasets were the DISC 2.3 and the DISC 4.

After looking through all the measures, the SC concluded that it seemed possible to identify kids according to our risk factors, though some clarification was required. For example, as noted by the SC, various measures phrase their symptom questions according to different time periods, such as in the past month (DICA), 3 months (CAPA), or 6 months (DISC), raising the question of how current symptoms need to be for inclusion. However, it was pointed out, that since parents usually answer questions according to the last month, regardless of whether they were asked about 3 or 6 months, the time differences may not be that crucial.

In particular the first questions examined in the DISC 2.3 focused on the child's sadness. The main issue was what questions (if answered positively) would meet the criteria for severe depression and/or suicidality. It was decided that the reasons for depression were less important (i.e. if the depression was situational) than the symptoms themselves. After reviewing the items, it seemed clear that the DISC would allow us to operationalize both 1) suicide ideation + plan and 2) depression + severe impairment.

As an example of operationalizing the indicator for severe depression with impairment we examined the items related to depression. The chosen items with text are as follows:

Depression text (page 1):

- #1a. When (he/she) feels sad this way, does it last most of the day?
- #1f. Did this go on for 2 weeks or more?

Impairment text (page 10):

- #34. In the past 6 months, has feeling (VERY SAD/GROUCHY/NOTHING WAS FUN/NOT INTERESTED IN THINGS) caused problems with how (he/she) gets along with people at home?
- #35. Have these feelings caused problems in getting along with friends or other people (his/her) age?
- #36. Have these feelings caused problems for (him/her) at (school/work)?

Service text (page 14):

- #40d. Did (he/she) see anyone for this in the last 6 months?

Assuming that yes=1, no=0, and missing=0 for the depression items, and “a lot of the time/some of the time”=1, “hardly ever/refuse to answer/don’t know”=0 for the impairment items, the operationalized data extraction rule was then given by:

1. Set Depression With Severe Impairment to “yes” if (SUM(1a AND 1f)=2) AND (SUM(34, 35, 36)>=2).
2. Check for service utilization by CROSSTAB to 40d.
(The “CROSSTAB” function refers to answering the service question if the child endorsed the criteria and impairment formula.)

In order to operationalize the indicators, similar patterns for the DISC items were selected for the rest of the six indicators (*See APPENDIX III for a complete list of items from the DISC 4*).

Results of Data Analyses:

The results of the analyses on the three chosen data sets are illustrated below in tabular form. For each data set, we determined the number of children that were highlighted by our chosen indicator items according to parent, child, and combined reports, as well as the number of these children that were currently in service use. The combined results were calculated by assuming “yes” if the parent OR child answered “yes” to the item. We also examined the number of these children that meet full criteria for the diagnosis (other than anxiety). For age and gender analyses, the child reports from all three data sets were combined and examined according to the median age. The parent reports were also combined and analyzed, however since Texas parent reports were not available, only the MECA and Iowa reports were used, changing the median age slightly in this group (*See APPENDIX IV for results of all data analyses (EXCEL file)*).

MECA (B. Lahey):

With a sample size of 1285 children, the MECA data set was examined on all six-indicator criteria. Parent, child, and combined reports were available (*See APPENDIX V for description of data set*).

Depression: According to the combined report, 34 of the 1285 children (2.7%) said “yes” to our depression indicator (severe depression plus impairment). Of these 34 children, 12 of them (35.3%) were in services. In other words, a little less than two-thirds of the children that needed services, according to our indicator, were not currently in them. Of the 34 children picked up by the indicator, 30 of them (88.2%) had a diagnosis of major depression. Thus, this indicator found many children that had full criteria for depression, however they were not currently in service, fulfilling its purpose as an indicator. Similar findings were found across all informants. The combined report for the depression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Depression with Impairment |
|-----------|--------------------------------|---------------------------------------|
| Combined | “Yes” to Indicator | 34/1285 (2.7%) |
| | Of Those, Who is in service? | 12/34 (35.3%) |
| | Meet Full Diagnostic Criteria? | 30/34 (88.2%) |

Suicide: According to the combined report of both parents and youth, 37 out of 1285 children (2.9%) had a suicidal plan according to our indicator, while 20 of the 1285 children (1.6%) had actually attempted suicide in the last year. Of the 37 with a plan, 11 of them (29.7%) were currently in services. Of the 20 that had attempted suicide, 6 of them (30%) were currently in services. Thus, 70% of the children that had planned OR attempted suicide in the last year according to combined report were not receiving any mental health treatment. According to the diagnostic criteria for major depression, 18 of the 37 (48.7%) planners fulfilled the diagnosis, while 14 of the 20 (70%) attempters fulfilled the diagnosis. The combined report for the suicidal indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Suicidal Plan | Indicator: Suicidal Attempt |
|-----------|--------------------------------|-----------------------------|--------------------------------|
| Combined | "Yes" to Indicator | 37/1285 (2.9%) | 20/1285 (1.6%) |
| | Of Those, Who is in Service? | 11/37 (29.7%) | 6/20 (30%) |
| | Meet Full Diagnostic Criteria? | 18/37 (48.7%) | 14/20 (70%) |

Anxiety: According to the combined report, 115 of the 1285 children (9%) fulfilled our requirements for the overall anxiety indicator. Of these 115 children, 23 of them (20%) were currently in service use. Thus, 80% of children who met diagnostic criteria for the anxiety disorders, thus presenting a need, were not in services. Since our indicator criteria included the need for diagnostic criteria, all 115 children met full criteria for an anxiety disorder. The combined report for the overall anxiety indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Overall Anxiety |
|-----------|------------------------------|----------------------------|
| Combined | "Yes" to Indicator | 115/1285 (9%) |
| | Of Those, Who is in Service? | 23/115 (20%) |

Panic: According to the combined report, 33 of the 1285 children (2.6%) met our indicator criteria for panic. Of these 33 children, 2 of them (6.1%) were currently in service use. The combined report for the panic indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Panic |
|-----------|------------------------------|------------------|
| Combined | "Yes" to Indicator | 33/1285 (2.6%) |
| | Of Those, Who is in Service? | 2/33 (6.1%) |

Aggression: According to the combined report, 67 of the 1285 children (5.2%) fulfilled our requirements for the aggression indicator, namely multiple fights and/or weapon use. Of these 67, 14 of them (20.1%) were currently in services. However, 36 of these 67 children (53.7%) met diagnostic criteria for conduct disorder. That result seems to show that this disorder is not being recognized (a.k.a. "fighting is normal with boys" train of thought) and the children who need services are currently not receiving them. The combined report for the aggression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Severe Physical Aggression (Multiple fights and/or weapon use) |
|-----------|--------------------------------|--|
| Combined | "Yes" to Indicator | 67/1285 (5.2%) |
| | Of Those, Who is in service? | 14/67 (20.1%) |
| | Meet Full Diagnostic Criteria? | 36/67 (53.7%) |

Eating Disorders: According to the combined report, 33 of the 1285 children (2.6%) met our criteria for the binging indicator, while 5 of the 1285 (0.4%) met our criteria for the vomiting/laxative indicator. Of the 33 with binging, 5 were currently in service (15.2%) and of the 5 with vomiting/laxative use, 3 were currently in service (60%). Six of the 33 with the binging criteria (18.2%) met the full criteria for an eating disorder, while none of the 5 (0%) who had the vomiting/laxative indicator met full diagnostic criteria for an eating disorder. The combined report is illustrated in the table below.

| Informant | Analytic Items | Indicator: Multiple Binging | Indicator: Vomiting/Laxative Use |
|-----------|--------------------------------|--------------------------------|-------------------------------------|
| Combined | "Yes" to Indicator | 33/1285 (2.6%) | 5/1285 (0.4%) |
| | Of Those, Who is in Service? | 5/33 (15.2%) | 3/5 (60%) |
| | Meet Full Diagnostic Criteria? | 6/33 (18.2%) | 0/5 (0%) |

IOWA (R. Conger):

With a sample size of 853, the Iowa dataset was examined on four of the six indicator criteria, with the exclusion of panic and eating disorders since they did not look at these disorders. Parent, child, and combined reports were available (*See APPENDIX V for description of data set*).

Depression: According to the combined report, 14 children out of the sample size of 853 (1.6 %) said "yes" to our depression indicator (severe depression plus impairment). Of these fourteen children, seven of them were in service (50%). In other words, half of the children that needed services were currently not in them. This indicator was then tested against the full criteria for a diagnosis of major depression in the past year. Of the fourteen children that said "yes" to our indicator, six of them qualified for the full criteria of major depression. Similar findings were found across all informants. The combined report for the depression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Depression with Impairment |
|-----------|--------------------------------|---------------------------------------|
| Combined | "Yes" to Indicator | 14/853 (1.6%) |
| | Of Those, Who is in service? | 7/14 (50%) |
| | Meet Full Diagnostic Criteria? | 6/14 (42.9%) |

Suicide: According to the combined parent and youth report, 16 out of the 853 children, (1.9%) fulfilled our requirements for the suicidal plan indicator. Almost double that amount of children (3.2%) fulfilled our requirements for the suicidal attempt indicator. Only 1 out of the 16 children (6.2%) who had a suicidal plan were in service, and shockingly, none of the 27 children that made suicidal attempts were in service. Of the 16 that said "yes" to having a plan, three of them (19%) had the full criteria for a diagnosis of major depression. Of the 27 that said "yes" to a suicidal attempt, two of them (7%) illustrated full criteria for major depression. The combined report for the suicidal indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Suicidal Plan | Indicator: Suicidal Attempt |
|-----------|------------------------------|-----------------------------|--------------------------------|
| Combined | "Yes" to Indicator | 16/853 (1.9%) | 27/853 (3.2%) |
| | Of Those, Who is in Service? | 1/16 (6.2%) | 0/27 (0%) |

| | | | |
|--|--------------------------------|--------------|-------------|
| | Meet Full Diagnostic Criteria? | 3/16 (18.8%) | 2/27 (7.4%) |
|--|--------------------------------|--------------|-------------|

Anxiety: According to the combined parent and youth report, 25 out of the 853 children (2.9%) fulfilled our requirements for the overall anxiety indicator. Of these 25 children, 7 of them were currently in service use. Thus, over 70% of the children who met diagnostic criteria for the anxiety disorders, thus presenting a need, were not in services. Since our criteria for the indicator included the need for diagnostic criteria, all 25 children meet full criteria for an anxiety disorder. The combined report for the anxiety indicator is illustrated in the table below. NOTE: The Iowa data set did not include panic disorder, so this indicator has been omitted.

| Informant | Analytic Items | Indicator: Overall Anxiety |
|-----------|------------------------------|----------------------------|
| Combined | "Yes" to Indicator | 25/853 (2.9%) |
| | Of Those, Who is in Service? | 7/25 (28%) |

Aggression: According to the combined parent and youth report, 23 out of the 853 children (2.7%) in this sample fulfilled our aggression requirements, which including multiple fight initiation or weapon use but no impairment. Of those 23 children, 1 of them was currently in service use. Thus, over 95% of the children who were had severe enough problems to be picked up by our indicator were not in service. Of the 23 children picked up by the indicator, 11 of them (47.8%) met full diagnostic criteria for conduct disorder. The combined report for the aggression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Severe Physical Aggression (Multiple fights and/or weapon use) |
|-----------|--------------------------------|--|
| Combined | "Yes" to Indicator | 23/853 (2.7%) |
| | Of Those, Who is in service? | 1/23 (4.4%) |
| | Meet Full Diagnostic Criteria? | 11/23 (47.8%) |

NOTE: The Iowa data set did not include any eating disorders, so this indicator has been omitted.

TEXAS (R. Roberts):

With a sample size of 4210, the Texas data set was examined on all six of our indicators. Only child report was available (*See APPENDIX V for description of data set*).

Depression: According to the child report, 52 of the 4210 children (1.2%) fulfilled the requirements for our depression indicator. Of these 52 children, 28 of them were currently in service (53.8%). 35 of the 52 children met diagnosis criteria for major depression. Thus, more than half of the children that we picked up were in service and had a diagnosis of major depression. The combined report for the depression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Depression with Impairment |
|-----------|--------------------------------|---------------------------------------|
| Child | "Yes" to Indicator | 52/4210 (1.2%) |
| | Of Those, Who is in service? | 28/52 (53.8%) |
| | Meet Full Diagnostic Criteria? | 35/52 (67.3%) |

Suicide: According to the child report of parents and youth, 48 out of the 4210 (1.1%) said “yes” to the indicator for a suicidal plan, and 170 out of the 4210 (4%) said “yes” to the indicator for a suicidal attempt. 10 of the 48 (20.8%) who said “yes” to the suicidal plan were currently in service. Only 17 of the 170 (10%) who said “yes” to the suicidal attempt indicator were currently in service. As for diagnostic criteria, 14 of the 48 children (29.2%) who had a suicidal plan and 16 of the 170 children (9.4%) who had an attempt made full diagnostic criteria for major depression. The child report for the suicidal indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Suicidal Plan | Indicator: Suicidal Attempt |
|-----------|--------------------------------|--------------------------|-----------------------------|
| Child | “Yes” to Indicator | 48/4210 (1.1%) | 170/4210 (4%) |
| | Of Those, Who is in Service? | 10/48 (20.8%) | 17/170 (10%) |
| | Meet Full Diagnostic Criteria? | 14/48 (29.2%) | 16/170% (9.4%) |

Anxiety: According to child report, 39 of the 4210 children (0.9%) fulfilled our requirements for the overall anxiety indicator. Of these 39 children, 12 of them (30.8%) were currently in service use. Thus, as shown in the lowa data set, about 70% of the children who met diagnostic criteria for the anxiety disorders, thus presenting a need, were not in services. Since our criteria for the indicator included the need for diagnostic criteria, all 39 children met full criteria for an anxiety disorder. The child report for the anxiety indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Overall Anxiety |
|-----------|------------------------------|----------------------------|
| Child | “Yes” to Indicator | 39/4210 (0.9%) |
| | Of Those, Who is in Service? | 12/39 (30.8%) |

Panic: According to the child report, 11 of the 4210 children (0.3%) fulfilled our requirements for our panic indicator. Of these 11 children, 9 of them (81.8%) were currently in service use. Remembering that we did not need full criteria for panic disorder to be picked up by our indicator, it seems that Chris Lucas’s observations that a panic attack denotes the need for psychiatric services is true in this population. The child report for the panic indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Panic |
|-----------|------------------------------|------------------|
| Child | “Yes” to Indicator | 11/4210 (0.3%) |
| | Of Those, Who is in Service? | 9/11 (81.8%) |

Aggression: According to the child report, 67 of the 4210 children (1.6%) in this sample fulfilled our aggression requirements, which included multiple fight initiation or weapon use but no impairment. Of these 67 children, 7 of them (10.4%) were currently in service. Thus, 90% of the children that met our criteria for the aggression indicator were not in service. Of the 67 children that we picked out with the indicator, 32 of them (47.8%) of them met full diagnostic criteria for conduct disorder. This child report for the aggression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Physical Aggression |
|-----------|--------------------------------|--------------------------------|
| Child | “Yes” to Indicator | 67/4210 (1.6%) |
| | Of Those, Who is in service? | 7/67 (10.4%) |
| | Meet Full Diagnostic Criteria? | 32/67 (47.8%) |

Eating Disorders: According to the child report, 13 out of the 4210 children (0.3%) fulfilled our requirements for our multiple binging indicator, while 25 of the 4210 children (0.6%) fulfilled our requirements for our vomiting and/or laxative use indicator. Out of the 13 that met the binging requirement, 2 of them (15.4%) were currently in service. Out of the 25 that met the vomiting/laxative requirement, 4 of them (16%) were currently in service. Interestingly, 2 of the 13 that met the binging requirement had a diagnosis for eating disorders, the same amount of children that were currently in service. Likewise, 4 of the 25 that met the vomiting/laxative requirement had a diagnosis for eating disorders, the same amount of children that were currently in service. Although we are not sure of the overlap, it seems that the children currently in service have an eating disorders diagnosis. The child report for the eating disorders indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Multiple Binging | Indicator: Vomiting/Laxative Use |
|-----------|--------------------------------|--------------------------------|-------------------------------------|
| Child | "Yes" to Indicator | 13/4210 (0.3%) | 25/4210 (0.6%) |
| | Of Those, Who is in Service? | 2/13 (15.4%) | 4/25 (26%) |
| | Meet Full Diagnostic Criteria? | 2/13 (15.4%) | 4/25 (16%) |

Bronx (H. Bird):

With a sample size of 234, the Bronx data set was examined on five of our six indicators, with the exclusion of eating disorders. Parent, child, and combined reports were available (*See APPENDIX V for description of data set*).

Depression: According to the combined report, 5 of the 234 children (2.1%) fulfilled the requirements for our depression indicator. Of these 5 children, four of them were currently in service (80%). Four of the five children met diagnosis criteria for major depression. Thus, the majority of the children that we picked up were in service and had a diagnosis of major depression. The combined report for the depression indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Depression with Impairment |
|-----------|--------------------------------|---------------------------------------|
| Combined | "Yes" to Indicator | 5/234 (2.1%) |
| | Of Those, Who is in service? | 4/5 (80%) |
| | Meet Full Diagnostic Criteria? | 4/5 (80%) |

Suicide: According to the combined report of both parents and youth, 6 out of 234 children (2.6%) had a suicidal plan according to our indicator, while 8 of the 234 children (3.4%) had actually attempted suicide in the last year. Of the six with a plan, two of them (33.3%) were currently in services. Of the eight that had attempted suicide, two of them (25%) were currently in services. Thus, more than two-thirds of the children that had planned OR attempted suicide in the last year according to combined report were not receiving any mental health treatment. According to the diagnostic criteria for major depression, one of the six (16.7%) planners fulfilled the diagnosis, while two of the eight (25%) attempters fulfilled the diagnosis. The combined report for the suicidal indicator is illustrated in the table below.

| Informant | Analytic Items | Indicator: Suicidal Plan | Indicator: Suicidal Attempt |
|-----------|--------------------------------|-----------------------------|--------------------------------|
| Combined | "Yes" to Indicator | 6/234 (2.6%) | 8/234 (3.4%) |
| | Of Those, Who is in Service? | 2/6 (33.3%) | 2/8 (25%) |
| | Meet Full Diagnostic Criteria? | 1/6 (16.7%) | 2/8 (25%) |

Anxiety: According to the combined report of both parents and youth, 15 out of 234 children (6.4%) fulfilled our requirements for the overall anxiety indicator. Of these 15 children, four of them were currently in services (26.7%). Thus, over 70% of the children who met diagnostic criteria for the anxiety disorders, thus presenting a need, were not in services. Since our criteria for the indicator included the need for diagnostic criteria, all 15 children meet full criteria for an anxiety disorder. The combined report is illustrated in the table below.

| Informant | Analytic Items | Indicator: Overall Anxiety |
|-----------|------------------------------|----------------------------|
| Combined | "Yes" to Indicator | 15/234 (6.4%) |
| | Of Those, Who is in Service? | 4/15 (26.7%) |

Panic: According to the combined report of both parents and youth, 11 of the 234 children (4.7%) met our indicator criteria for panic. Of these 11 children, two of them (18.2%) were currently in service use. Thus, over 80% of the children showing symptoms of panic were not currently being seen. The combined report is illustrated in the table below.

| Informant | Analytic Items | Indicator: Panic |
|-----------|------------------------------|------------------|
| Combined | "Yes" to Indicator | 11/234 (4.7%) |
| | Of Those, Who is in Service? | 2/11 (18.2%) |

Aggression: The prevalence of this indicator in the sample was too small to analyze. Only two of the 234 children were in service or had a diagnosis of aggression. According to combined report, none of the children fulfilled our criteria for aggression. This is mostly due to the overall small sample size of only 234 children.

NOTE: The Bronx data set did not include any questions on eating disorders, so this indicator has been omitted.

NLSY- Canada (K. Bennett): Analyses Pending.

Gender and Age Analyses:

For these analyses all youth responses from the MECA, Texas and Iowa samples were first combined forming a total sample size of 6348, which was then broken out by gender and age group (according to the median age): (9-13) and (14-17).

Similarly, parent responses were combined across MECA and Iowa samples to give a total sample size of 2138, which was then broken out by gender and age group (according to the median age): (9-11) and (12-17).

Depression: According to the Youth reports, younger males may be slightly more likely (0.51%) to endorse our depression indicator (severe depression plus impairment) than females (0.30%). Among adolescents there is the expected much higher depression rates but the gender effect reverses with the males less likely (1.58%) to endorse our depression indicator than females (2.45%). The parental report has approximately the

same overall depression rate (1.15% vs. 1.45%) but parents report much higher depression in the younger females (1.47%) and do not report an increase in depressive rate as females enter adolescents (1.73%). This contrasts sharply with the youth reports in which females report their rate jumping 7 fold from (0.30% to 2.45%). On the other hand for males the parents report much higher adolescent rate (2.39%) than is endorsed by the males (1.58%). Whether this represents gender bias underreporting of depression by parents or a greater tendency for depressed males than depressed females to deny their depression is unclear. However the disagreements here between parents and youth are striking and were reflected in the focus group opinions as well.

Suicide: According to the youth reports young males are more likely than the females to have a suicide plan (1.52% vs. 0.79%) and to make an attempt (2.25% vs. 2.13%) but this reverses in adolescents with females more likely to have a plan (1.90% vs. 1.58%) and twice as likely to report having made an attempt (6.11% vs. 3.16). Parents report approximately 1/3rd of the suicide plans that their children endorse (0.56% vs. 1.43%) and about 1/7th the attempts (0.47% vs. 3.32%)! While parents report that adolescent females have three times the rate of suicide plans vs. males (1.30% vs. 0.48%), contrary to known statistics they do not report higher rates of attempts for their female adolescent children (0.72% vs. 0.43%). The under recognition by parents of suicidal behavior is striking and again is supported by focus group opinion. Clearly a great deal of focus will have to go to the suicidal behavior indicator, which is so sorely needed.

Anxiety: The rates of anxiety by youth report are remarkably consistent across age and gender all cells having about 1.92% of all youths having some anxiety disorder. Parents report anxiety levels nearly twice as high for the young females (3.57%) and for all adolescents (4.55% vs. 3.90%). Anxious youths may be more clinging and dependant bringing these disorders more to parental attention. The question for this project becomes whether one needs to frame indicators and public messages differently for cases where parents under-recognize vs. over-recognize an emotional problem.

Aggression: On the items of physical aggression and fighting with/without weapon the adolescent females are close to males and only seem very different in the category of fighting and weapon use taken together (2.38% vs. 3.23%). Otherwise females, both pre-teens and adolescents are almost as likely as males to be overly aggressive (1.09% vs. 1.51%). Parents on the other hand see the females as more aggressive than males both as children (0.84% vs. 0.64%) and as adolescence (1.08% vs. 0.48%)

Eating Disorders: According to the youth reports, younger males and females are about equally unlikely to engage in severe eating disorder patterns. But as adolescents, females are more likely than males to binge (1.02% vs. 0.62%), or vomit (1.02% vs. 0.27%). Parents reporting on these behaviors seemed to be unaware of any such behaviors, which are known to often be kept secretive, even at great cost.

Overall results suggest that the indicators identify both genders approximately equally, with somewhat more older youth than younger children being identified. Additional

analyses of other data sets (NLSCY-Canada) are pending, in order to determine which types of profiles or indicators might best characterize younger children.

Analyses of Any Indicator with Service Use

Parent Sample: For these analyses, all parent responses from the MECA and Iowa samples were first combined forming a total sample size of 2138, and then broken out by gender and age group (according to the median age): (9-11) and (12-17). The data was examined for the presence of any indicator with service use items, as well as how unmet need changes when a child has 1, 2, 3, or more indicators. The results are shown in the tables below (*See APPENDIX IV for results of data analyses*).

Regarding any indicator, the number and percentage of children (as reported by a parent) having any of the six indicators (depression, suicide, anxiety, panic attacks, aggression, and eating disorders) is shown below. On average, about 6% of the population demonstrated the presence of at least one indicator, with the range being from 4.4% to 8.4%.

| | Have Any of the Indicators | |
|-----------|----------------------------|-----------|
| | Male | Female |
| Age 9-11 | 34 (4.4%) | 34 (7.1%) |
| Age 12-17 | 35 (8.4%) | 33 (7.1%) |
| Total | 136 (6.4%) | |

The data was then examined for service use. According to parent report, of the children reported to be positive on at least one indicator, approximately 30% were currently in services. There were still 70% of children that were not currently in services despite the presence of a severe indicator, and parental awareness.

| | Have Any of the Indicators With Service Use | |
|-----------|---|---------------|
| | Male | Female |
| Age 9-11 | 3/34 (8.8%) | 13/34 (38.2%) |
| Age 12-17 | 11/35 (31.4%) | 10/33 (30.3%) |
| Total | 37/136 (27.2%) | |

In addition to examining “any indicator” status across the service use items, the data was analyzed according to how unmet need changes when a child has 1, 2, 3, or more indicators. With one exception, the percentage of children receiving services increased with the number of indicators, as expected. Nevertheless, even when three indicators were present more than half of the children with were not currently receiving treatments and this was true by both parent and, as indicated below, child report. (Note: According to parent data, no children had over three indicators combined. The slight decrease in service use by parent report for three indicators is probably not significant as the number of children in this category by parental report is so low. Thus, if just one more child from this group were in treatment the expected increase in percentage would hold, as $3/5 = 60\%$.)

| | One Indicator with Service Use | | Two Indicators With Service Use | | Three Indicators with Service Use | |
|-----------|--------------------------------|---------------|---------------------------------|------------|-----------------------------------|----------|
| | Male | Female | Male | Female | Male | Female |
| Age 9-11 | 2/30 (6.7%) | 11/32 (34.4%) | ¼ (25%) | 2/2 (100%) | -- | -- |
| Age 12-17 | 8/28 (28.6%) | 3/21 (14.3%) | ¼ (25%) | 7/10 (70%) | 2/3 (66.7%) | 0/2 (0%) |
| Total | 24/111 (21.6%) | | 11/20 (55%) | | 2/5 (40%) | |

Child Sample: For these analyses all youth responses from the MECA, Texas and Iowa samples were first combined forming a total sample size of 6348, which was then

broken out by gender and age group (according to the median age): (9-13) and (14-17). The data was examined on the presence of any indicator with service, as well as the indicators in increasing numbers (such as meeting criteria for one indicator with service use, two indicators with service use, etc.) The results are shown in the tables below (*See APPENDIX IV for results of data analyses*).

Regarding any indicator, the number of children that said “yes” to having any of the six indicators ranged from 6.3-12.8%, with the average being approximately 9%. Overall, the prevalence of indicators increased with age and was higher in females.

| | Have Any of the Indicators | |
|-----------|----------------------------|-------------|
| | Male | Female |
| Age 9-13 | 111 (6.3%) | 105 (6.4%) |
| Age 14-17 | 144 (9.9%) | 189 (12.8%) |
| Total | 549 (8.6%) | |

The data was then examined for service use. According to the child report, only 15% of the children that said “yes” to an indicator were currently in services, remarkably half of what the parents reported. Thus, approximately 85% of children that expressed severe symptoms also reported that they were not receiving any treatment.

| | Have Any of the Indicators with Service Use | |
|-----------|---|----------------|
| | Male | Female |
| Age 9-13 | 13/111 (11.7%) | 12/105 (11.4%) |
| Age 14-17 | 22/144 (15.8%) | 34/189 (18.0%) |
| Total | 81/549 (14.8%) | |

In addition, the data was analyzed according to how unmet need changes when a child has 1, 2, 3, or more indicators. As predicted, the percentage of children receiving services increased with the number of indicators that they presented. Notice, however, that as with parental report, even children with a combination of three indicators are been seen by professionals less than 50% of the time.

| | One Indicator with Service Use | | Two Indicators With Service Use | | Three Indicators with Service Use | |
|-----------|--------------------------------|----------------|---------------------------------|--------------|-----------------------------------|-------------|
| | Male | Female | Male | Female | Male | Female |
| Age 9-13 | 10/83 (12.1%) | 9/89 (10.1%) | 3/23 (13.0%) | 2/12 (16.7%) | 3/3 (100%) | 1/3 (33.3%) |
| Age 14-17 | 12/113 (10.6%) | 16/146 (11.0%) | 3/21 (14.3%) | 9/29 (31.0%) | 5/8 (62.5%) | 5/10 (50%) |
| Total | 47/431 (10.9%) | | 17/85 (20%) | | 11/24 (45.8%) | |

| | Four Indicators with Service Use | | Six Indicators with Service Use | |
|-----------|----------------------------------|------------|---------------------------------|------------|
| | Male | Female | Male | Female |
| Age 9-13 | 0/2 (0%) | 0/1 (0%) | -- | -- |
| Age 14-17 | 2/2 (100%) | 3/3 (100%) | -- | 1/1 (100%) |
| Total | 5/8 (62.5%) | | 1/1 (100%) | |

Analyses of Any Indicator with Diagnosis

Parent Sample: For these analyses, all parent responses from the MECA and Iowa samples were first combined forming a total sample size of 2138, and then broken out by gender and age group (according to the median age): (9-11) and (12-17). Combining all the indicators, the data was examined for how likely a child was to have a DSM-IV diagnosis when he/she met criteria for any of the indicators. The results are rather

striking – according to parent report, almost 70% of the children that had any indicator met criteria for a DSM-IV diagnosis. Thus, the indicators had well over a 50% positive predictive value (PPV). The results of these analyses are shown in the table below (*See APPENDIX IV for results of data analyses*).

| Parent Report | Any Diagnosis / Any Indicator | |
|---------------|-------------------------------|-------------------------|
| | Male | Female |
| Age 9-11 | 28/39 = 71.8% | 26/36 = 72.2% |
| Age 12-17 | 21/37 = 56.8% | 22/36 = 61.1% |
| Total | 97/148 = 65.5% | |

Child Sample: For these analyses, all child responses from the MECA, Texas and Iowa samples were first combined forming a total sample size of 6348, which was then broken out by gender and age group (according to the median age): (9-13) and (14-17). As explained above with the parent sample, the data was examined for how likely a child was to have a DSM-IV diagnosis when he/she met criteria for any of the indicators. Although not as striking as the parent report, it is still remarkable that these results indicate that 50% of the children that had any indicator met criteria for a DSM-IV diagnosis (approximately 50% PPV). The results of these analyses are shown in the table below (*See APPENDIX IV for results of data analyses*).

| Child Report | Any Diagnosis / Any Indicator | |
|--------------|-------------------------------|--------------------------|
| | Male | Female |
| Age 9-13 | 58/126 = 46.0% | 54/117 = 46.2% |
| Age 14-17 | 99/181 = 54.7% | 96/214 = 44.9% |
| Total | 307/638 = 48.1% | |

Additional Indicator Analyses

After various feedback from focus groups and advocacy/consumer organizations, additional analyses were performed looking at indicators related to severe symptoms of either ADHD and substance use. Each of the four data sets (MECA, Iowa, Texas, and Bronx) was examined separately for these two indicators. Note that the Iowa and Bronx data sets did not examine substance use, so this indicator has been omitted (*See APPENDIX IV for results of the data analyses*).

MECA:

ADHD: According to the combined report of both parents and youth, 71 of the 1285 children (5.5%) said yes to our indicator. Of these 71 children, 21 of them were currently in service use (29.6%). Thus, 70% of the children that often got into a dangerous situation because of not thinking were currently not in services. 18 of the 71 children (25.3%) had a diagnosis of ADHD.

| Informant | Analytic Items | Indicator: ADHD, dangerous situation |
|-----------|----------------|--------------------------------------|
| | | |

| | | |
|----------|--------------------------------|----------------|
| Combined | "Yes" to Indicator | 71/1285 (5.5%) |
| | Of Those, Who is in service? | 21/71 (29.6%) |
| | Meet Full Diagnostic Criteria? | 18/71 (25.3%) |

Substance Use: According to the combined report of both parents and youth, 29 of the 1285 children (2.3%) had used a substance more than 6 times in the last year. Of these 29, 6 were currently in service (20.7%), and 2 of the 29 had a diagnosis of substance abuse. The miss school indicator was not applicable to this data set. 2 of the 1285 children met criteria for the marijuana indicator (0.2%), however none of the children were in service or had a diagnosis.

| Informant | Analytic Items | Indicator: Other Substances | | Indicator: Marijuana |
|-----------|--------------------------------|-----------------------------|-------------|----------------------|
| | | Substance Use | Miss School | |
| Combined | "Yes" to Indicator | 29/1285 (2.3%) | N/A | 2/1285 (0.2%) |
| | Of Those, Who is in Service? | 6/29 (20.7%) | N/A | 0% |
| | Meet Full Diagnostic Criteria? | 2/29 (6.9%) | N/A | 0% |

IOWA:

ADHD: According to the combined report of both parents and youth, 22 of the 853 children (2.6%) met our criteria for the ADHD indicator of being in a dangerous situation. Of these 22, 9 of them were currently in services (40.9%). The rest of the children, over 50%, were not being seen by any professional. Of the 22, 8 of them had a diagnosis of ADHD (36.4%).

| Informant | Analytic Items | Indicator: ADHD, dangerous situation |
|-----------|--------------------------------|--------------------------------------|
| Combined | "Yes" to Indicator | 22/853 (2.6%) |
| | Of Those, Who is in service? | 9/22 (40.9%) |
| | Meet Full Diagnostic Criteria? | 8/22 (36.4%) |

TEXAS:

ADHD: According to the child report, 73 of the 4210 children (1.7%) met the criteria for the ADHD indicator. Of these 73, 18 of them were currently in service (24.7%). 14 of the 73 met full diagnostic criteria (19.2%) for ADHD. See the tables below.

| Informant | Analytic Items | Indicator: ADHD, dangerous situation |
|-----------|--------------------------------|--------------------------------------|
| Child | "Yes" to Indicator | 73/4210 (1.7%) |
| | Of Those, Who is in service? | 18/73 (24.7%) |
| | Meet Full Diagnostic Criteria? | 14/73 (19.2%) |

Substance Use: According to the child report, 35 of the 4210 children (0.8%) had used a substance more than 6 times in the last year. Of these 35, 1 was currently in service (2.9%), and 9 of the 35 had a diagnosis of substance abuse. Thus, 8 children who met full diagnostic criteria for not currently in services. The miss school indicator was present in 4 of the 4210 children (0.1%). $\frac{1}{4}$ of these children were in services, and 25% of them had a diagnosis of substance abuse. 5 of the 4210 children met criteria for the marijuana indicator (0.1%). Three of these five children were currently in services and one child met diagnostic criteria for marijuana abuse.

| Informant | Analytic Items | Indicator: Other Substances | | Indicator: Marijuana |
|-----------|--------------------------------|-----------------------------|---------------------|----------------------|
| | | Substance Use | Miss School | |
| Child | "Yes" to Indicator | 35/4210 (0.8%) | 4/4210 (0.1%) | 5/4210 (0.1%) |
| | Of Those, Who is in Service? | 1/35 (2.9%) | $\frac{1}{4}$ (25%) | 3/5 (60%) |
| | Meet Full Diagnostic Criteria? | 9/35 (25.7%) | $\frac{1}{4}$ (25%) | 1/5 (20%) |

BRONX:

ADHD: According to the parent report, 3 of the 234 children (1.3%) met the criteria for the ADHD indicator. Of these three children, none of them were in service and one had a diagnosis of ADHD (33.3%). Thus, our indicator picked up one clinically diagnosed child that should be getting professional help for ADHD.

| Informant | Analytic Items | Indicator: ADHD, dangerous situation |
|-----------|--------------------------------|--------------------------------------|
| Child | "Yes" to Indicator | 3/234 (1.3%) |
| | Of Those, Who is in service? | 0/3 (0%) |
| | Meet Full Diagnostic Criteria? | 1/3 (33.3%) |

Task IV

Stakeholder Engagement: As the conceptual framework evolved, the team engaged a broad range of relevant stakeholders by organizing a number of focus groups to obtain feedback and input to ensure credibility of the framework, and usability of the proposed indicators. Ultimately the focus groups should include youth and families, educators, healthcare providers, child care providers, scientists from various disciplines, professional organizations, and mental health advocates.

The first major activity designed to engage stakeholders occurred at the meeting of the Carter Center in November 2001. At that meeting, it was agreed that the following issues needed to be addressed by the SC's efforts, if indicators were to serve a useful purpose:

CRITICAL QUESTIONS FOR STAKEHOLDERS CONCERNING USE OF INDICATORS

How can mental health messages and indicators best enhance identification of mental health problems and avoid the possibility of increasing stigma or profiling?

To what extent should indicators focus on children and youth who have undeniable severe and current mental illness, in order to improve their identification and assistance in obtaining care? Alternatively, to what extent should indicators focus on children with little or no impairment, but who may be at risk for eventually developing a severe mental disorder?

What are the advantages/disadvantages of developing indicators to focus on children and youth with severe, persistent and current mental disorders and impairments vs. a focus on children with little or no impairment, but who are at risk for developing severe mental health problems? What are the risks/benefits of creating messages aimed at identification/detection of current problems vs. early identification and prevention?

What are the advantages/disadvantages of developing indicators to focus on severe, persistent, and current mental disorders (i.e., 5% of youth) vs. a focus on youth with more moderate levels of disorders (i.e., 20%)?

How might the risks and benefits of focusing on the 5% vs. the 20% of youth vary with the target audience, e.g., with the general public vs. with primary care providers? Is there a strategy where the advantages and strengths of focusing on both approaches can be obtained, while still minimizing the limitations of each?

What considerations must be taken to ensure that messages are culturally appropriate and understood within the target audience? Are there special concerns and cautions with the use of indicators with already stigmatized groups? If so, what are they, and how can these concerns be addressed?

Should messages concerning mental health indicators be used for very young children (e.g., ages 2-5)? If so, how can indicator messages balance the public health concerns of identifying early risk factors with a focus on the continued potential for positive growth and development?

Should messages reflect potential differences between boys and girls, or would it be preferable to have a smaller, more consistent set of messages that apply to both genders?

What consensus signs and symptoms and indicators can we propose, and how would a public mental health approach to surveillance enter into a redesign of children's mental health system.

Specific recommendations emerged out of this meeting for each of these questions, and have since been refined by the SC in the course of its activities, have guided the overall conceptual approach described earlier, and have framed the SC's final Phase I recommendations.

One important component of our stakeholder engagement strategy, recommended by the Carter Center participants and also agreed upon as within the scope of work for this project, was seeking the input of a range of focus groups. These activities and their outcomes are described below.

Initial Focus Groups: Thus far our focus groups have included parents, teachers, adolescents, and mental health advocates, and further focus groups are planned with pediatricians, pre-school teachers, and child care providers. We have attempted to have these groups generally representative of the potential users of the final document, including participants representing ethnically and culturally diverse populations and settings.

Two different forms of open-ended questionnaires to guide discussion in the focus groups were developed (*See APPENDIX VI for focus group questionnaires*). In both forms the six indicators are presented as brief vignettes. For example, the depression indicator is stated as:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

On the questionnaire, each group was asked three main questions:

1. *Is this individual's problem severe and in need of an evaluation?*
2. *How would you describe this individual? What language would you use?*
3. *What additional indicators are we missing?*

During the first two focus groups, the parents were also given a list of possible phrases to describe this situation and were asked for their preference of these phrases. For example, for the depression indicator:

What terms would most accurately characterize this child?

- *Severe depression with impairment*
- *Severe and persistent sadness that doesn't go away*
- *Serious unhappiness that is problematic*
- *Extreme sadness that interferes with the child's life*

However, as we were concerned that the list of alternative phrasings for the indicators might limit the groups' creativity with message creation, an alternative form for the focus group handout did not include these, and this form was given to the last four of six focus groups. In addition, all groups were given the list of indicators developed by Christopher Lucas, M.D., and asked to comment on these as well.

Lastly, the groups were asked to describe appropriate ways to present these mental health messages:

1. *What other behaviors should parents be on the lookout for?*

2. *What is the best way to identify mental health problems in children without labeling or stigmatizing the child?*
3. *How could we make these messages culturally appropriate and understood within each target audience?*
4. *Should these mental health messages be used for very young children (ages 2-5)?*

Descriptions of Focus Groups:

- Parent Advocate group in the Bronx, New York (May 22, 2002).
 - This group consisted of 10 parents, mostly of Hispanic origin, from a low-income neighborhood.
- Parent Advocate groups (2) in Rockville, Maryland (May 28 and 29, 2002).
 - We had two focus groups with this group. The first group consisted of 15 parents and the second had 3 parents. Most participants had children with mental health problems and were familiar with many disorders.
- Middle School Teachers from Mamaroneck, New York (June 3, 2002).
 - This group consisted of 8 adults who taught ages 10-13. This school is located in an upper-middle class neighborhood.
- High School Teachers from Mamaroneck, New York (June 5, 2002).
 - This group consisted of 17 high school teachers, in the same neighborhood as the middle school.
- High School Students from Mamaroneck, New York (June 12, 2002).
 - This group consisted of 14 high school students, grades 9 through 12.
- Parents from Washington Heights, New York (July 1, 2002).
 - This group consisted of 12 parents from the Washington Heights area that were recruited through flyers.

The feedback from all of the focus groups combined are organized below according to each of the six indicators, followed by general comments regarding additional indicators and formats for presentation:

1. Depression Indicator:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

- Language:
 - "Sadness" is a more appropriate word than depression
 - "Extreme" and "long term" are good ways to describe the sadness
 - If it is from the parent's perspective, can not say "child who feels sad" – instead say "child who is sad"
 - "Unhappy" may be a better word than sadness because it can also denote anger
 - "Unhappy" is problematic because it is common among teenagers
 - Instead of "severe" sadness, might be better to say "persistent," especially because children can show different emotions in different environments
- Behavior:
 - Any changes in behavior, such as isolation or withdrawal
 - Does not have to be change, could be persistence
 - Extreme tiredness, lethargic, apathy
 - Disconnected, detached, vacant expression
 - Loss of interest in friends/hobbies, such as school play

- Excessively happy for no apparent reason
- Additional Comments:
 - It is necessary to state the timing or length of the sadness
 - Teachers are most likely to see apathy rather than sadness – it is more socially acceptable
 - An important problem is deciphering between the internal (ex. sadness) and external (ex. tiredness) symptoms
 - Know it's a problem when hear it from different sources (even if it's not a sudden change)
- Key Phrases for Indicator:
 - "Persistent sadness that doesn't go away and affects the child's life."
 - "Extreme sadness and/or emotional detachment"
 - "Extreme mood change that continues"

2. Suicide Indicator:

Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

- Language:
 - The word "suicidal" is age sensitive (parents would not apply this word to younger children)
 - Some teachers liked the word "kill" since it was upfront and strong, but others thought that this word may scared other parents/teachers away
 - Most agreed that "kill" was better than "suicide"
- Behavior:
 - Talks about hurting or killing themselves
 - Talks frequently about methods of suicide
 - Says that he/she doesn't want to live anymore
 - Writes suicidal notes—that could be more serious than just talking
 - Self-mutilation or harming themselves (such as through cutting) to release their inner pain
 - Seems happy all of a sudden for no apparent reason
- Additional Comments:
 - Does not have to be a suicidal attempt to warrant attention
- Key Phrases for Indicator:
 - "Tried to hurt or kill himself, and doesn't seem to want to live anymore."
 - "Wanting to harm and/or kill yourself"

3. Anxiety Indicator:

Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

- Language:
 - Anxiety is not a good word to use
- Behavior:
 - Extreme fear or worries debilitating to the child's life
 - Isolation, loss of interest in activities
 - Terror that prevents him/her from doing things they normally would
- Additional Comments:
 - This indicator is too general
 - Should separate "school phobia" – the children that are too scared to even show up to school
 - These symptoms are more noticeable at home than at school
- Key Phrases for Indicator:
 - "Extreme worries or fears that prevents the child from doing things that he/she needs or should do (things that their peers do)."
 - "Extreme fear that interferes with daily activities"

- “Severe anxiety inappropriate to the situation”

4. Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

- Language:
 - Child thinks he/she is going “crazy”
 - Use of the word “panic” should be avoided
 - “Panic attack” is a good term and understood by teachers
- Behavior:
 - “Frozen,” as if they are trying not to die at that moment
 - Immobilizing
 - Unable to rationally reason with oneself
- Additional Comments:
 - Should include the length of time (a.k.a. 10 minutes)
- Key Phrases for Indicator:
 - “Sudden, overwhelming sense of fear for no apparent reason, which could be associated with physical symptoms including a racing heartbeat and shortness of breath.”
 - “Sudden overwhelming fear for no apparent reason - that could be accompanied physical symptoms (a rapid heartbeat, shortness of breathe, etc.).”
 - “Physiologic panic attack lasting (time limit) that comes out of the blue”

5. Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

- Language:
 - Could be described as outbursts, physical aggression, acting out
 - Persistent physical or verbal outbursts
- Behavior:
 - Unable to stop fighting
 - Desire to harm others
 - Uncontrolled anger
 - No fear of authority
 - Inappropriate, out of control, persistent anger
- Additional Comments:
 - The biggest problem for the parent would be to decipher between what is a discipline problem and what is actually a mental health issue
 - Not necessary to have impairment part of indicator
 - This child will get attention because of the nature of the illness, however he/she will usually not be considered mentally unhealthy
 - Child does not necessarily have to start the fight
- Key Phrases for Indicator:
 - “Extreme physical aggression, almost always angry”
 - This indicator could be split into two:
 - 1) “Frequent and severe loss of control that harms or threatens to harm others or self” (Lost of control with unrestrained anger)
 - 2) “Initiates multiple fights in the last year, with and without the use of weapons” (Frequently starts fights and has a desire to harm others)

6. Eating Disturbance Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child’s eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

- Language:
 - No Comments
- Behavior:
 - Vomiting, bingeing, or using laxatives
 - Dramatic weight loss
 - Extreme preoccupation with food, body image, exercise and losing weight
 - Obsessive behavior that endangers one's health
 - Frequent bathroom use immediately after meals
- Additional Comments:
 - These children should be described by what is missing, not by what they have done. In other words, parents and/or friends may not be aware of certain behaviors, such as vomiting, but they could notice missing meals.
 - Must account for the fact that bingers are not necessarily thin
 - This could easily go unrecognized by adults for various reasons (parents don't want to see it, child is very secretive)
 - No longer are children covering it up with big clothing – in fact, the style is to show off their skinniness, being thin is popular
- Key Phrases for Indicators:
 - "Extreme preoccupation with food, body image, and losing weight" AND/OR
 - "Vomiting, bingeing, and/or using laxatives to lose weight."
 - "Obsession with food, exercise, and/or weight loss that endangers one's health"

7. Additional Indicators and Comments:

- Additional Indicators:
 - Rejected and unable to make relationships with peers
 - Change in personality, behavior, or sleeping habits
 - Substance abuse
 - Inappropriate sexual behavior
 - Attention problems, out of control behavior
 - Mania, mood swings
- Presentation:
 - Use different formats for different audiences (for example, one-liners for parents, cartoon images for children)
 - 1) Cartoons (perhaps drawn by children)
 - 2) Story format with examples
 - 3) Posters to hang in classroom
 - 4) Checklist for parents
 - 5) Show statistics ("not one in a million")
 - 6) Show happy, well-adjusted children rather than depressed ones
 - Language Possibilities
 - 1) Your Child's Health: Healthy Body and Healthy Mind. Both are equally important – here are some health issues that parents should know about, etc. If your child has shown any of these behaviors, help is available, and you are not alone.
 - 2) "Healthy physically, healthy emotionally"
 - 3) Need to stress that if anyone has these symptoms or has a friend that does, get help (tell a teacher or counselor)
 - 4) Also stress that it's OKAY to get help, you are not alone
- Additional Factors:
 - Idea of "School Readiness" rather than mental health for younger children
 - Cultural appropriateness
 - Economic appropriateness
 - All indicators have common elements:
 - Inappropriate behavior for your child
 - Extreme behavior
 - Happens over a long period of time
 - Unusual for the situation

Details of the findings from each individual focus group are included in the appendices (See APPENDIX VII).

Additional Focus Groups: After these initial focus groups, the feedback was applied and changes were made to the chosen indicators. In particular, indicators for substance use and ADHD were added due to concerns from various individuals and professional organizations (See APPENDIX VI for third version of handout). The newly phrased indicators are as follows:

ADHD-related Indicator (severe inattention/hyperactivity)

- Imagine a child that almost always seems restless and whose behavior has become “out of control.” This behavior causes him/her to become involved in dangerous situations that may harm or already has harmed him/herself or others.

Substance Use Indicator

- Imagine a child that has used illegal substances, such as heroin or PCP, more than six times during the past year.

In addition, we are examining three other indicators, namely uncontrollable behavior, mood swings, and drastic changes in personality. However, since these indicators were unable to be analyzed using the DISC items, we did not include them on the official handout given out to the focus groups. Also note that the Eating Disorder indicator has been separated into Laxative Use/Vomiting and Losing Weight/Body Image in response to focus group feedback. Thus, in all, we have decided on 12 general topics for our indicators, and they are as follows:

1. Depression/Sadness
2. Suicide
3. Anxiety
4. Panic
5. Frequent Fights
6. Laxative use/Vomiting
7. Losing Weight/Body Image
8. Substance Use
9. Severe Inattention/Hyperactivity
10. Out of Control Behavior
11. Mood swings
12. Drastic Changes in Personality

See Appendix IX for an overall, consolidated summary of the final phase I study indicators, along with a description of their scientific/psychometric characteristics, to be carried forward for further study and/or modifications in Phase II. See discussions of Phase II in Task VI below.

Descriptions of Additional Focus Groups:

- Preschool Teachers from New York, NY (October 15, 2002)

- This group consisted of 8 teachers who teach at the same school on the Upper West side of Manhattan. They teach toddlers through kindergarten.
- Pediatric Residents from New York, NY (October 18, 2002)
 - This group consisted of 8 pediatric residents from the Mount Sinai Adolescent Health Clinic in Manhattan, New York.

The feedback from these additional two focus groups was combined and listed below according to the new indicators, followed by general comments:

1) ADHD Indicator:

Imagine a child that almost always seems restless and whose behavior has become “out of control.” This behavior causes him/her to become involved in dangerous situations that may harm him/herself or others.

- Language:
 - Tuned out
 - Inability to engage
- Behavior:
 - Unable to sit still
 - Hyperactive
- Additional Comments:
 - Contextually inappropriate to pediatricians because teachers are more likely to observe these problems
 - Teachers are unlikely to push a diagnosis, will try to engage in any way possible first
 - Once diagnosed, still a battle to find the right dosage that will last
 - Parents are very aware of this disorder – guiltless and easily remedied
- Key Phrases for Indicator:
 - “Inability to sit still”
 - “Excessive talking”
 - “Tuned out”

2) Substance Use Indicator:

Imagine a child that has used illegal substances, such as heroin or PCP, more than six times during the past year.

- Language:
 - Should be developed by according to each substance
- Behavior:
 - Failure to respond and improve after medical advice
- Additional Comments:
 - Not applicable for young children
 - Referral system for adolescents is not too stringent
 - Child’s developmental stage should be considered
 - Parents are a huge barrier against referral

3) General Comments:

- Young Children (Ages 2-5):
 - Depression
 - Seen as withdrawal more than sadness
 - Unable to engage
 - Must last long time – young kids go through many phases
 - Suicide
 - Not common with younger children
 - Anxiety
 - Very common and serious, especially social phobia

- Parents do not take it seriously
- Panic
 - Not common with younger children
- Aggression
 - Very common with young boys
 - Need to look for lack of remorse
- Eating Disorders
 - Not common with younger children
 - More of a parental issue of control
- Inattention/Hyperactivity
 - Well known with parents and teachers
 - Diagnoses are not always favored
- Substance Use
 - Does not occur with younger children
- Additional Indicators
 - Hurtful with no remorse
 - Inability to relate to anyone
 - Paralyzing shyness
- Stigma is a major problem
 - Parents do not want to label child, especially young child, as “mentally ill”
 - Parents do not understand that an intervention is a “tune-up” that could be helpful to any child
- Teachers are good indicators
 - Witness child interacting in different environments
 - More objective than parents

Details of the findings from each individual focus group are included in the appendices (*See APPENDIX VII*).

Additional Stakeholder Engagement Activities: As a further means of obtaining stakeholder input and “buy-in” during Phase I, the Phase I document, indicators and proposed language have been provided to key advocacy organizations and professional associations, for additional input and feedback.

STAKEHOLDER ORGANIZATIONS AND ASSOCIATIONS REQUESTED TO
PROVIDE INPUT TO PHASE I DOCUMENT AND POTENTIAL INDICATORS

Advocacy/Consumer Organizations

Child and Adolescent Bipolar Foundation
Federation of Families for Children's Mental Health
CHADD (Children and Adults with Attention Deficit Disorder)
National Alliance for the Mentally Ill (NAMI)
National Mental Health Association
National Depressive and Manic-Depressive Association

Professional Associations

American Academy of Child & Adolescent Psychiatry
American Academy of Pediatrics
American Academy of Family Practice
American Psychological Association
Society for Developmental and Behavioral Pediatrics

Each organization has been asked to review the draft indicators document, with especial attention on the indicators themselves, the language to describe them, and the recommended approaches to present them to various target audiences. In addition, each organization has been asked for recommendations for critical additional indicators, and whether it can provide tentative endorsement of these indicators. The input from these organizations received as of October 31, 2002, is collated and presented with the final Phase I document (*See APPENDIX VIII for their input*).

Task V

Preparation of Draft Phase I Document: Based on the above data analyses and findings and recommendations from the various focus groups and stakeholders, the contractor together with the SC has developed this working document describing the overall framework for the initial development of indicators, and recommendations for further testing and deployment of indicators. In addition, in Appendix VIII we present a brief outline of an Indicators Guide, with notations concerning the kinds of materials that must be developed in order to reach the different target audiences, including educators, pediatricians and other primary care practitioners, parents and youth. Also outlined in this document is a description of the need for a technical assistance capacity designed to assist users to utilize finally agreed-upon indicators, and to guide users in actions end-they should take to address concerns that may arise in the use of indicators (resource lists, web sites, provision of camera ready copy of materials, questions to ask, etc.).

Task VI

Future Recommendations: Phase II and III. The SC has developed a set of recommendations that should be carried out as a part of the Phase II and III activities agreed-upon earlier by CMHS and NIMH project officers. These are listed below in roughly the chronological order that they should be accomplished:

Phase II.

- **Additional Data Sets.** Examine the extent to which each of the indicators can be identified in additional data sets, and the extent to which these indicators characterize children most often not receiving needed mental health services. Possible additional data sets include those by Rolf Loeber, Jane Costello, and perhaps the control group of the preschool Head Start program.
- **Publications.** A number of the results obtained in thus far are both surprising and unknown to the scientific research and the utilization research communities. Prepare scientific papers for publication in professional journals based on significant analysis conducted in Phase I.
- **Additional Focus Groups.** Additional focus groups will be conducted involving pediatricians, high-risk parents, and perhaps a group known to journalists as Person on the Street (POS), that is a sample of persons who will ultimately be the consumers of public service announcements or other social marketing tools that emerge from the project. In collecting such a group one hopes to over sample the less sophisticated audience in order to insure the broad acceptability of the public messages. For example we have discussed sampling New York City Taxi drivers as representative POS.

- **Preliminary Practical Testing.** Begin testing by introducing selected indicator(s) in a pediatric setting. In this setting a number of important factors could be determined regarding the best ways to apply the indicators in real-world settings. For example: determine how pediatricians use the indicator(s) and how they communicate with youth and parents about the indicators, how parents understand indicators, how well the indicators function in case-finding against clinical diagnosis, how clinicians, parents, and youth respond when an indicator is positive, and how well indicators becomes incorporated into daily work-process of a clinical practice.

Phase III.

- **Expanded Prospective Testing.** After initial testing (as described above) clarifies modalities for applying the indicators, each of the indicators will be tested with other major target audiences. In each of these contexts the indicators will be evaluated to determine if they are understood and applied appropriately, and how well they identify or characterize children or youth with significant mental health needs. In addition comprehension and applicability can be evaluated within each of these contexts by presenting each indicator to a target audience, along with 3-4 vignettes of a child with symptoms, and then determining whether the target audience properly associates the indicator with the vignettes deemed to warrant clinical evaluation and intervention by a group of seasoned expert clinicians. Finally it will be important to determine if the indicators induce behavior change in a variety of caregivers and or gatekeepers, e.g. do pediatricians change the way they evaluate and manage mental disorders within their practice after they have absorbed the indicators. If it can be shown that the indicators are serving their intended purpose with educational, professional, and advocacy organizations, then a broader deployment of the indicators via a public media campaign can be developed.
- **Assess Indicators for Predictive Potential.** While we have focused on current un-met need, further studies can be designed determine the extent to which these indicators can help PREDICT future and persistent mental health needs across various age and gender groups.
- **Develop Dissemination Tools and Materials.** After field-testing has established the most useful ways of utilizing these indicators, tools and materials will be developed that are specific to the major professional and advocacy organizations that are likely to apply the indicators. Such tools might include the following:

- For Advocacy Organizations:
 - Briefing kits for presenting the indicators and related stories to local media, business, etc. (slides, videotape with youth and parent telling their own personal story how the illness affected the youth, handouts)
 - Carefully vetted text that can accompany the indicators if more information is desired
 - Recommendations/suggestions for further spread and use of the indicators
- For Health Professional Organizations
 - Training materials for presentation at annual meetings
 - Speakers bureau of experts who can speak about the indicators to primary care providers
 - Materials to assist the health professional in his/her practice, such as screening checklists, office brochures, pocket cards with indicators and appropriate interview questions, etc.
- For Educational Organizations
 - Training materials for presentation at teacher in-service and other meetings (videotape, handouts, etc.)
 - Speakers bureau of experts who can speak about the indicators to teachers students
 - Materials to assist the educator in the classroom, such as posters, lesson materials, tailored to different age groups.
- Ongoing Support Institution. Federal agencies or private foundations should fund the development of a technical assistance center to provide advice and support to organizations and associations seeking to deploy the indicators to their own target populations. This center should also provide copies of indicator materials to parties that request them, maintain an information and assistance website, and address questions from the press.

BIBLIOGRAPHY

- Achenbach, T. M., Howell, C. T., Quay, H. C., & Conners, C. K. (1991). National survey of problems and competencies among four- to sixteen-year-olds: parents' reports for normative and clinical samples. *Monographs of the Society for Research in Child Development*, *56*, 1-131.
- Amsel, L., & Mann, J. J. (2001). Suicide risk assessment and the suicide process approach. In *Understanding Suicide Behavior: The Suicide Process Approach to Research and Treatment*, Kees van Heeringen (Editor).
- Bennett, K. J., Lipman, E. L., Brown, S., Racine, Y., Boyle, M. H., & Offord, D. R. (1999). Predicting conduct problems: Can high-risk children be identified in kindergarten and grade 1?. *Journal of Consulting and Clinical Psychology*, *67*, 470-480.
- Bennett, K. J., Lipman, E. L., Racine, Y., & Offord, D. R. (1998). Do measures of externalizing behaviour in normal populations predict later outcomes? Implications for targeted interventions to prevent conduct disorder. *Journal of Child Psychology and Psychiatry and Applied Disciplines*, *39*, 1059-1070.
- Bennett, K. J., & Offord, D. R. (2001). Screening for conduct problems: does the predictive accuracy of conduct disorder symptoms improve with age?. *Journal of the American Academy of Child & Adolescent Psychiatry*, *40*, 1418-25.
- Foundations and Agencies Network for Children's Mental Health (FAN) (2000). *Off to a good start: Research on the risk factors for early school problems and Selected federal policies affecting children's social and emotional development and their readiness for school*. Chapel Hill: University of North Carolina, FPG Child Development Center.
- Friedman, R. M., Katz-Leavy, J. W., Manderscheid, R. W., & Sondheimer, D. L. (1998). Prevalence of serious emotional disturbance in children and adolescents. An update. In R. W. Manderscheid & M. A. Sonnenschein (Eds.), *Mental health, United States, 1998* (pp. 110-112). Washington, D.C.: U.S. Government Printing Office.
- Huffman, L. C., Mehlinger, S. L., & Kerivan, A. S. (2000). Risk factors for academic and behavioral problems at the beginning of school. In *Off to a good start: Research on the risk factors for early school problems and selected federal policies affecting children's social and emotional development and their readiness for school*. Chapel Hill: University of North Carolina, FPG Child Development Center.

- Jensen, P. S. (2002). Health provider decision-making and interventions to change provider behaviors. Report on Emotional and Behavioral Disorders in Youth, 2, 53-79.
- Jensen, P. S., Hinshaw, S. P., Kraemer, H. C., Lenora, N., Newcorn, J. H., Abikoff, H. B., March, J. S., Arnold, L. E., Cantwell, D. P., Conners, C. K., Elliott, G. R., Greenhill, L. L., Hechtman, L., Hoza, B., Pelham, W. E., Severe, J. B., Swanson, J. M., Wells, K. C., Vitiello, B., Wigal, T. (2001). ADHD comorbidity findings from the MTA study: Comparing comorbid subgroups. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 147-58.
- Lochman, J. E. (1995). Screening of child behavior problems for prevention programs at school entry. The Conduct Problems Prevention Research Group. *Journal of Consulting & Clinical Psychology*, 63, 549-59.
- MTA Cooperative Group (1999). A 14-month Randomized Clinical Trial of Treatment Strategies for Attention Deficit Hyperactivity Disorder. *Archives of General Psychiatry*, 56, 1073-1086.
- MTA Cooperative Group (1999). Moderators and Mediators of Treatment Response for Children with Attention-Deficit/Hyperactivity Disorder. *Archives of General Psychiatry*, 56, 1088-1096.
- Murray, C. J., & Lopez, A. D. (1996). Evidence-based health policy--lessons from the Global Burden of Disease Study. *Science*, 274, 740-3.
- Puig-Antich, J., Kaufman, J., Ryan, N. D., Williamson, D. E., Dahl, R. E., Lukens, E., Todak, G., Ambrosini, P., Rabinovich, H., & Nelson, B. (1993). The psychosocial functioning and family environment of depressed adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 32, 244-53.
- U.S. Department of Health and Human Services (1999). Chapter 3: Children and mental health and Chapter 8: A vision for the future. In *Mental health: A report of the Surgeon General*.

APPENDIX I:
MINUTES FOR STEERING COMMITTEE MEETINGS

October 16, 2001

3:00-4:00 pm Conference call

Present on call: Dan Offord, Jane Costello, Peter Jensen, and Robin Nemeroff

Steering Committee

Minutes/discussion summary (1):

Peter began by describing the background of the CMHS/NIMH “Indicators/Early Warning Signs” project: 1) to identify those indicators or warning signs most predictive of mental health services need, based on data derived from selected data sets; 2) to work with consumers and various focus groups to determine the most useful, understandable, and acceptable messages that can be derived from these data, in order to develop a common set of messages across consumer groups and various stakeholders and to improve identification of children in need of mental health services.

General discussion centered on the following points:

- the difficulties entailed in accurately predicting later mental health need - prediction is usually quite poor, though somewhat better with older children than younger children
- it might make sense to start from “cases” (i.e., those who are significantly impaired, medical necessity, etc.) and work backwards.
- in addition to careful consideration of analyses by age and gender, possible differences by ethnicity should be explored at the outset (example: obesity related to depression in Caucasian females, but not in African American or Native American females).
- We might want to be relatively conservative, and attempt to predict only to serious problems/impairment (3-5%), rather than the larger group (perhaps 20% of the population?) with some symptoms of mental disorder. In addition, it was noted that warning signs perhaps ought to be developed only to problems for which we have an intervention. Thus, for endpoints to which we would want to predict, the criteria might be: “Is it really serious, and can we treat it?”
- Discussion of contextual factors suggested that this category could be a problematic, in terms of their usefulness as warning signs. This could lead to labeling and stigmatization of persons who may be in a high risk group, but do not in fact have any signs of mental illness. A goal of the overall approach should be to minimize false positives and avoid stigmatization. One means of accomplishing this would be to ensure that warning signs are *persistent* and noted *over time*, and show a *critical number* and *range*.
- Relatedly, the “primary prevention of secondary disorder” approach described by Ron Kessler might be a useful approach to some of the data. Also, a chronic disease model and disease management approach might be a useful way to couch warning signs and the overall project.

Optimal characteristics of data sets might include:

- North American
- Good endpoint data available, since we want to work backwards from the endpoints to the predictors. Endpoints might include services need/use, impairment, severe symptoms, medical necessity, disorder with impairment, etc.
- Good age range coverage (0-18 years)...starting as young as possible
- low refusal rates
- multiple informants
- power/size of the sample

It was agreed that the following would occur in preparation for the next call:

- Jane will fax or email to Peter/Robin some work she did previously for NIDA in describing the characteristics of various data sets

- Peter will contact Kathleen Bennett, who has done several relevant papers and analyses on a nationally representative Canadian sample, Statistics Canada (24,000 children, ages 0-11, followed every 2 years, with 3 waves now completed).
- Next call will be Tuesday, October 23rd, 11am Eastern.
- Robin has started on a table of the various data sets, and if we are far enough along by next week, that draft will be sent around.

Peter Jensen

October 23, 2001
 11:00-12:00 am Conference call
 Present on call: Dan Offord, Jane Costello, Peter Jensen, and Robin Nemeroff

Steering Committee
 Minutes/discussion summary (2):

Initial discussion centered around the implications of the discussions of the first meeting, namely whether it made best sense to develop indicators/warning signs to identify the most severely impaired 5%, of whom only 1 in 4 is identified and receives services, or to attempt to develop indicators/warning signs for the additional 15% of children who may have somewhat milder conditions. One potential benefit of restricting the efforts of the indicators initiative to the most impaired 5% is that indicators for this group of children need not be predictive of **future** mental health services need, since these children presumably would need services **now**. Thus, the problems of the generally low power of prediction, and the possible problems of mis-identifying/labeling children who do not eventually develop significant problems, could be circumvented. Simply focusing on better indicators of the three quarters of the 5% who are currently not being identified and not receiving services could be of great assistance, and would be much less likely to do harm. While this approach would then not enable public efforts at early identification and prevention, one might argue that “we can only do so much,” so lets pick a strategic objective that we can achieve, and go for more difficult targets once we have success with more easily achievable objectives.

It was agreed that if we consider taking this approach, it would be important to clarify the following unresolved issues:

- 1) Is it true that even among the more severely impaired kids (5%), still only 1 in 4 gets identified and treated? Or is this less likely to be true, and apply only to less impaired kids (the 5-20th% percentile)? Analyses must be done to address this question.
- 2) Would it make sense to conduct one set of analyses for indicators of current mental health need re: the severely impaired 5% (perhaps via indicators and messages to mental health providers, special educators, primary care providers, etc.), so that these professionals would be more attuned to the “primary prevention of secondary disorders” and a disease management approaches, while another set of analyses/indicators and resulting messages might be developed for the general public, either around this same 5%, or around the less severely impaired 5-20%?
- 3) It was noted that this activity could get quite ambitious, but Peter noted that the activity was framed as a multi-phase project, and that we might outline some activities, analyses, and objectives that would only be completed in the context of a subsequent contract. This suggests the importance of prioritizing our activities, proceeding on the basis of “first things first,” and identifying future activities that the federal government should pursue.

Further discussion centered on the following points:

- depending upon the decision re: the top 5% or the top 20% (or both), it may be necessary to require current significant psychopathology, as well as the subsequent prediction to later bad/accumulating outcomes. This would further severely limit the available databases to those

- with robust measures of psychopathology and impairment, but would also allow the use of some cross-sectional data bases (e.g., MECA, etc.).
- Jane indicated the merits of using some other public health relevant endpoints, e.g., school dropout, teen pregnancy, etc., instead of only psychopathology, and this was generally agreed upon.
 - Robin reviewed the list of data sets that had been identified to date. Peter indicated the wish to stay within North America, and to restrict the data sets to those with at least one sampling period that is relatively more current (1990 and forward). These qualifications were augmented by additional suggestions from SC members.
 - Some general discussion of the merits of using clinical data sets (where denominators are not known) followed. Although it is true that there may not be sufficient power to address some questions from epidemiologic community-based samples, it was generally agreed that inferences from such clinical samples would be problematic. Further, there should be sufficient power in the available data sets to still address broad areas of focus with substantial public health relevance and to develop likely useful indicators.
 - Next call will be Tuesday, October 30th, 11am Eastern.
 - Robin Nemeroff is compiling a table of the various relevant data sets, and she will distribute the draft for review by the SC by the end of this week. .
 - Note: Since the call, Bob Friedman has agreed to join the SC, and he will be invited to join the next call.
 - Note: Peter contacted Kathryn Bennett, who sent her latest papers (published and in press) re: predictions of later impairment and psychopathology from a nationally representative Canadian sample Kathryn was quite interested and willing to participate with relevant analyses, if so determined by the SC.

Peter Jensen

November 14, 2001
11:00-12:00 am Conference call
Present on call: Dan Offord, Jane Costello, Bob Friedman, and Peter Jensen
Development of Children's Mental Health Indicators
Steering Committee
Minutes/discussion summary (3):

Because this was the first call that Bob Friedman could join, the background, rationale, and the current status of the project was reviewed. Dan Offord briefly summarized the Carter Center presentations, and noted that Peter's presentation reflected the intent and previous input of the Steering Committee. In terms of the scope of the Steering Committee's work, Peter noted that we should be able to shift from weekly to bi-weekly calls, eventually getting them down to every three weeks or so, plus one or two face-to-face meetings.

After some general discussion, questions were raised about whether the "product" would actually be a set of public messages based on scientifically derived indicators, or whether actual scales or measures would be developed. Peter pointed out that the current project is the former (public messages based on scientifically derived indicators) rather than the latter. This might seem to untie our hands somewhat, since the kinds of psychometric work and testing of a measure across multiple settings may not be required.

However, Jane cautioned us, noting that with a simple list of indicators, in the real world someone, somewhere, would probably make up a "scale" based on the list. This does suggest that as we develop potential indicators, we should also have our eye on recommendations about future scale development, so that valid tools for screening or assessment purposes might be thoughtfully developed rather than just arise on an ad hoc basis.

To Do At Next Call. As a means of proceeding, it was agreed to pick and work through some specific examples of possible behaviors/indicators, to determine how a given indicator would practically play out, and to determine if there are other variables that we need to consider to actually consider the merits of a given indicator. One example might be the fact that an indicator might reflect a particular disorder for which we have nothing to offer and no effective treatments – should it not be a candidate for these reasons?

Once we have played out several indicators, it will be more possible to determine whether there are any other considerations that we must take into account before we begin to narrow down the selection of potential data sets. Peter suggested that by the end of the next call, it would be a reasonable goal to narrow the list of 40-50 data sets down to 10.

Date of Next Call: For our next call, it was agreed to pick two dates, so that Barbara Huff might have a range of options to choose from. Two dates were tentatively selected, Tuesday Dec 5th, 11am, and Dec 6th, 11am. Peter will check with Barbara to determine

if/whether either of these dates will work, and then will email folks for the conference call details.

December 6, 2001
11:00-12:00 am Conference call
Present on call: Barbara Huff, Dan Offord, Jane Costello, Bob Friedman, and Peter Jensen

Development of Children's Mental Health Indicators
Steering Committee
Minutes/discussion summary (4):

Barbara Huff was able to join the call. Peter briefly reviewed past discussions pertaining to the overall task of identifying "indicators" of unmet service need. Bob expressed some concerns initially that the group's current focus on severely ill children, juvenile justice outcomes, etc., might miss children for whom there are opportunities for early intervention. However, it was clarified that our task must include the examination of indicators across 3 general age groups: infants/preschoolers, elementary school-aged children, and adolescents. Given this clarification, the SC member unanimously concurred that the development of indicators for current unmet need, if it included unmet need in these younger age groups, would be an appropriate approach to addressing this issue.

Based on the discussion from the last call (Nov. 14th), the SC attempted to work through an example of a condition for which we would want to develop some indicators, and for which we do have an effective treatment, where treatment is associated with improved outcomes. As an example of one such condition, we began with ADHD. In this case, perhaps an indicator might be "severe and prolonged difficulties with attention that affect school work." In such an instance, if the indicator demonstrated 1) appropriate sensitivity and PPV to DSM-IV ADHD with impairment among children not currently being served (e.g., the "unmet need" group), and/or 2) appropriate sensitivity and PPV to some threshold for symptomatic impairment regardless of ADHD status (to be decided) among children not currently being served (unmet need), we would regard it as appropriate and a possible candidate for a final indicator to be recommended. (NB: these criteria were identified as two of the three criteria identified on Nov. 14th of conditions for which we should consider developing indicators. The third criterion is noted in the last paragraph below).

We then worked through a second example: a child, age 5, with severe tantrums, depression, mood swings, and irritability, possibly bipolar disorder. In this example, there may be no known effective treatment, as there is for ADHD. But given this severe constellation of symptoms and impairment, is this a child we should be concerned about, or that we would want our indicators not to miss, even though we may not know that we have an effective treatment to offer? In this case, the community standard among clinicians would suggest that such a child is in need of services, even though we don't know of a specific efficacious service, and even if all we can do is simply to ensure the child's immediate safety, support the family, attempt to reduce risk for abuse or neglect, and/or possibly prevent subsequent high risk behaviors (running into the street).

In this second example, the group agreed that we *should indeed* develop indicators for such children, but we need to be more cautious in such instances, because the risk-benefit ratios may be different, since we would be less certain that identifying such children leads to a positive outcome.

Such an instance would likely fit the third category of behavior or condition we agreed upon on November 14th, i.e., “a behavior constitutes an ethical imperative (based on the community standard of practice), such that any child with that behavior should get a MH assessment (e.g., suicidal plan or behavior, other imminently dangerous behaviors, etc. ‘Gray’ issues might include multiple contacts with police, school expulsion, runaway behavior, etc.).”

Our next call will be Thursday, Dec. 13th, 11:00-12:30. Josey, who works with Peter will distribute the 800 call-in number and code # in the next day or so. On the next call we will work through another example or two, and then turn our attention to the identification of optimal data sets.

Peter Jensen

January 15, 2002
4:30-5:30 pm Conference Call
Present on call: Jane Costello, Bob Friedman, Dan Offord, Peter Jensen, and Maura
Crowe
Development of Children's Mental Health Indicators
Steering Committee
Minutes/discussion summary (5):

Peter began the call by stating that although the next step must be to identify the most appropriate data sets, he felt it was necessary to review his previous conversation with Jane. During that December call, Jane raised some concerns regarding the premise of the project, namely 1) can the analyses be useful, 2) is the process of developing indicators worthy, and 3) can it be done. Peter countered these concerns by reinforcing the fact that this is, at minimum, a two-stage project. One potential outcome of the first stage will be to present the findings to the government, however ask them not to act on these preliminary results. Although the findings from the analyses will not be incredibly new, they will have scientific roots and provide a level to frame the positioning of public messages.

In response to Peter's argument, Jane asserted that there is a large difference between clinical samples and what can ethically and responsibly be said to them on the basis of data sets. She was concerned about raising expectations on the policy level. What if the expectations cannot be met on all different levels, thus creating false hopes? On the other hand, as Bob pointed out, this project may be a necessary step in order to continue the education process. We are already in a situation of unmet need due to financial barriers, lack of services, and lack of effective interventions. We should not hide from pointing out the needs.

We then discussed how the initiative should be about heightening awareness in the general public so that they do a better job of identifying mental illness. The most important person regarding the health of a child is the parent, and it is necessary to heighten their awareness. The conversation led to a questioning of a conclusion that was drawn at an earlier conference call, specifically whether something should be done when a child is in need. Peter asked the group whether that was a bad premise. Could we truly say that it is a bad thing to help parents identify a suicidal child, for example, and put them in treatment?

It was agreed that the final indicators would have to be very severe and specific, so that parents do not overemphasize symptoms. Dan's threshold point brought up an interesting idea—we could identify a set of indicators and then study the effects of these indicators and their outcomes in prospective studies. Another issue was the effects of the law on the indicators, and we worked through an example. If parents bring a child into an ER with suicidal intentions, and the ER dismisses the symptoms, then the parents have a potential lawsuit if the child's symptoms increase. On the other hand, if the ER does an entire work up (which the parents find unnecessary), the parents have a very small chance of winning a lawsuit. In other words, it is better to provide too much care than too little.

Another aspect to consider is the effect the public will have on the indicators. As Dan stated, the public will distort the properties of the indicators. A future study would be to study these effects and whether or not they lead to an increase in false positives. It will be necessary to lay out criteria for a very few selective indicators and see their effects. In terms of public education, Dan brought up a previous study regarding blood pressure. In this example, a man, who felt healthy and had a diastolic pressure of 90, was told by his doctor that he had hypertension. The result of this information caused the man to drink heavily and eat poorly, in effect making him unhealthy. Thus, the lesson learned was that an intervention could change behaviors for the worse.

After much discussion, it was concluded that if someone we loved had signs of a mental illness, we would do what we could to get them appropriate, effective treatment. We should apply this common outlook to the initiative. We will stay on the side of safety (before the public, studies, etc.), but it would be wrong to be ineffective given the current state of unmet need. As the devil's advocate, Jane brought up the example of Anthrax. People were told the symptoms, and as a result they are now suffering more from the effects of treatment rather than the illness. Her knowledge gained from the project in Ann Arbor indicated that it takes a very detailed and sophisticated interview to cut down on the number of false positives. In addition, one of David Shaffer's studies showed that only a few children who did not already have a mental illness (for which they were being treated for) reached the treatment level. Thus, it was questioned whether or not we were on the wrong level, and should be focusing on the professionals rather than the general public.

At the conclusion of the call, Dan's recommendation for balance revolved around four principles: 1) begin with a very serious symptom and unmet need, 2) use careful wording of the indicator, 3) assess people's understanding of the indicator, and 4) plan a prospective study in which we study how people act upon receiving the information. We will begin with these four principles on the next conference call, which Maura will schedule for next week.

February 6, 2002

2:30-3:30 Conference call

Present on call: Jane Costello, Barbara Huff, Dan Offord, Peter Jensen, and Maura Crowe

Development of Children's Mental Health Indicators
Steering Committee

Minutes/discussion summary (6):

Peter began the discussion by summarizing the previous conference call. During that call, we had a discussion about the potential benefits and harm of public messages, coming to the conclusion that the development of indicators should be based on certain conditions. 1) the child has severe symptoms of a mental-disorder-related condition, 2) there is current unmet need, 3) the impact and understanding of possible indicators and related public messages be prospectively tested, and 4) the effort is initially restricted to providers. Barbara agreed with these conclusions, and suggested that we consult the Bright Futures materials for providers done by Maternal and Child Health. Peter will ask Kelly Kelleher for these materials.

Further discussion concerned the possible data sets and their requirements. It had previously been agreed that the data sets should 1) be rich in psychopathology measures, 2) longitudinal or cross-sectional, 3) determine if the child is currently receiving services, and 4) take place in North America. Before Jane left the call, she offered a suggestion of using a newsletter format for the indicators, such as done by the Harvard Women's Health Newsletter. She will circulate that example before the next call.

Dan noted that there were two ways of proceeding with this study. We could either go forward, mining the data sets to see if they will yield a good set of predictors/indicators, or we could look a priori define a set of situations/conditions that we felt would be incontrovertible as possible indicators.

The group brain-stormed about what symptoms or behaviors would meet such an "incontrovertible" criterion for needing to be brought to the attention of providers, if such children were not currently in the service system:

- 1) Suicidal Ideation + Plan
 - Suicidal Ideation + Severe Depression
 - Suicidal Ideation + Recent Suicidal Behavior
- 2) Depression + Severe Impairment (i.e. absent from school, failing grades, etc.)
- 3) Anxiety + Severe Impairment (i.e. absent from school, inclusive of panic attacks)
- 4) Physical aggression to people or animals (could be accompanied by repeated school expulsions)
- 5) Eating Behaviors (i.e. severe weight loss, severe increase in exercise, taking laxatives, etc.)

In addition to these behaviors, Peter suggested two other behaviors to be discussed during the next call, namely impulsivity and mood instability. Barbara also suggested PTSD,

however there is a possibility that these symptoms/behaviors may overlap with those already mentioned (i.e. depression and/or anxiety).

Upcoming Goals:

- Review current list of symptoms/behaviors
- Consider including impulsivity, mood instability, and/or PTSD
- Consider running our developing list by a clinician focus group, and getting their input on the list
- Examine datasets and pick out the top choices, based on what would be needed to determine children meeting the “incontrovertible” criteria above.

The next call is tentatively scheduled for Friday, February 15th, from 11-12 PM. If there are any changes with that time or date, Maura will contact you via e-mail.

Prepared by: Maura Crowe

February 15, 2002
 11:00-12:00 pm Conference Call
 Present on call: Dan Offord, Rolando Santiago, Peter Jensen, and Maura Crowe

Development of Children's Mental Health Indicators
 Steering Committee
 Minutes/discussion summary (7):

At the beginning of the call, Peter summarized for Rolando the purpose of the Steering Committee and our progress up to this point. Rolando will be participating in the conference calls from now on, in addition to Judy Katz-Levy and Jane Pierson from CMHS.

During the last call, five potential indicator criteria for children were established for inclusion in our study, namely 1) Suicidal Ideation + Plan / Severe Depression / Recent Suicidal Behavior, 2) Depression + Severe Impairment, 3) Anxiety + Severe Impairment, 4) Physical aggression to people or animals, and 5) Eating Behaviors with Severe Impairment. To be considered, datasets need to 1) be North American, 2) from 1990 or later, 3) have a large community-represented sample, and 4) include service utilization data. Countries other than the United States and Canada are not initially being considered because of cultural factors and different systems of care. For inclusion in the unmet need category, it is necessary for the children to have service use beyond primary care, unless that provider is offering mental health services.

Peter, Dan, and Rolando then looked over the dataset tables and choose the top candidates. Listed according to priority, the following datasets are of top interest:

1. Great Smoky Mountain Study - Costello, E. Jane
2. Pittsburgh Youth Study - Loeber, R.
3. Oregon Adolescent Depression Project - Lewisohn, Peter M.
4. National Comorbidity Study in U.S. and Canada - Kessler, R.C. (w/ Ontario Health Supplement)
5. MECA – Bird, H.

The next step will be to contact the key architects of these datasets for information. In addition, the indicators need to be operationalized, with the criterion written out more explicitly.

To Do:

- Peter will call the dataset architects
- Maura will obtain specific information and variables in each of the relevant data sets
- Peter will operationalize the indicators and service use requirements
- One or more focus groups with providers need to be formed. These providers will comment on our previous work and provide new suggestions for indicators.

Prepared by: Maura Crowe

February 26, 2002
 9:00-10:00 am Conference Call
 Present on call: Barbara Huff, Robert Friedman, Jane Costello, Maura Crowe, and Peter Jensen

Development of Children's Mental Health Indicators
 Steering Committee
 Minutes/discussion summary (8):

At the beginning of the call, Peter summarized for Barbara and Bob what had been discussed during the last call. Last week, Dan, Rolando, and Peter had decided on the top five datasets, and these datasets with references were circulated before the call. A meeting was scheduled for next Monday, March 4th, at 7:15 am in Tampa. Barbara, Bob, Rolando, Peter, and Judy Katz-Levy will be attending this meeting.

When the top datasets were examined, it was realized that none of them focus on children younger than age 8. Although it will be harder to find severe indicators in young children, it was decided that they couldn't be ignored. One thought was to take the top 5% of a sample (e.g., NLSY Canada) with severe symptoms and examine which of these children are in care. In that way, we could come up with an estimate of unmet need. Even though year-to-year persistence does not necessarily occur in this young age group, that should not prevent us from gathering information to guide future efforts. Jane suggested a few datasets that may be helpful with the younger age group. Her HMO study used the DISC to interview 300 7-11 year olds from 1984-1987. In addition, John Lavigne and Sally Horwitz did two separate primary care samples, consisting of children age 3 and up.

The next step will be to contact the key architects of the top eight datasets. These datasets are 1) Great Smoky Mountain Study, 2) Oregon Adolescent Depression Project, 3) National Comorbidity Survey, 4) MECA, 5) Pittsburgh Youth Study (may not be useful since the sample is only boys), 6) Jane's HMO study, 7) John Lavigne's study, and 8) Sally Horwitz's study, and 9) NLSY-Canada. Our goal will be to choose four of the eight datasets and form focus groups to review analyses to be conducted by the extended July deadline. Jane raised practical concerns regarding the time expected of these key architects, including herself, and the funding that will be necessary for involvement. We will proceed by contacting all architects, facing other hurdles as they arise.

The next call is scheduled for Tuesday, March 19th, at 9 AM (EST). Just like the last call, the dial-in number is 1-800-820-4690 and the participant code is 7076345 #.

To Do:

- Peter will contact the key architects and determine their willingness to participate
- Maura will add the younger datasets to the chart, as well as the NLSY Canadian study
- Meeting in Tampa is set for Monday, March 4th at 7:15 AM

April 10, 2002

12:00 – 1:00 pm Conference Call

Present on call: Peter Jensen, Barbara Huff, Robert Friedman, Dan Offord, Larry Amsel, and Maura Crowe

Development of Children's Mental Health Indicators

Steering Committee

Minutes/discussion summary (9):

Before the call, Maura faxed the steering committee depression and suicide excerpts from various measures used in the datasets. The call began with a discussion of these measures, namely the DISC, DICA, K-SADS, CAPA, and two utilization measures (SURF and CASA). In addition, Peter welcomed Larry Amsel to the group. He is a professor at Columbia University and will assist in taking the initiative to the next level.

The first questions examined in the DISC focused on the child's sadness. The main issue was what questions (if answered positively) would meet the criteria for severe depression and/or suicidality. It was decided that the reasons for depression are less important (i.e. if the depression was situational) than the symptoms themselves. After reviewing the items, it seems like the DISC will allow us to operationalize both 1) suicide ideation + plan and 2) depression + severe impairment.

As we went through the measures, two issues arose. The first was deciding how current the symptoms need to be. Various measures phrase their symptom questions according to different time periods, such as in the past month (DICA), 3 months (CAPA), or 6 months (DISC). However, since parents usually answer questions according to the last month, regardless of whether they were asked about 3 or 6 months, the time differences may not be that crucial. The second issue involved the criteria for service use with suicidality. Suicidal thoughts did not meet the criteria for inclusion. However, thoughts plus a plan, severe depression plus impairment, and any suicidal attempt did qualify for inclusion.

After looking through all the measures, it seems as if the process of identifying kids according to our risk factors will be feasible. The next step will be to talk with the principle investigators of the top datasets (NLSCY, Great Smoky Mountain Study, OADP, NCS, MECA, and possibly the Pittsburgh Youth Study). We will work with each investigator to operationalize the construct of a case that should be identified and assessed. The group decided to put June 10th, 13th, and 14th on hold for face-to-face meetings with these key architects and the committee.

The next call is scheduled for Tuesday, April 30th, from 3:00 – 4:00 PM (EST). Just like the last call, the dial-in number is 1-800-820-4690 and the participant code is 7076345 #.

To Do:

- Peter will contact the key architects and determine their willingness to participate, as well as work with them to organize data charts to send to the committee.
- Maura will fax members of the steering committee aggression excerpts from selected measures that will be discussed during the next conference call.

April 30, 2002
3:00 – 4:00 pm Conference Call
Development of Children's Mental Health Indicators
Steering Committee
Minutes/discussion summary (10):

Present on call: Peter Jensen, Wei Li, Barbara Huff, Robert Friedman,
Dan Offord, Larry Amsel, Maura Crowe

The call began with a discussion of statistical analyses performed by Wei on the MECA data. The results illustrated that our developed indicators are capable of identifying children that are severely depressed and/or suicidal, who have also not been seen by a mental health professional. By examining the children that were identified, we may be able to develop new, better indicators from their characteristics.

Since we seemed to be on the right track, we continued to analyze the measures. Before the call, Maura faxed the steering committee aggression excerpts from various measures used in the datasets, namely the DISC, DICA, K-SADS, and CAPA. When examining the DISC, the items that seemed promising were those involving severe fights (occurring several times within the last year) and weapon use. Items that seemed to lie in the "gray" area included those about physical cruelty, hurting animals, suspensions, and expulsions. Since these items are rather ambiguous, we decided not to include them.

In addition to the aggression excerpts, Maura faxed the group the OCHS scale that was used in the NLSCY dataset. Dan walked us through the scale, and we decided that the strength of this dataset would be in identifying externalizing disorders.

Peter raised some promising news regarding other datasets that may be applicable to our project. Rand Conger has a dataset from the rural Midwest that contains information on 1000 youth. In addition, Prudence Fischer has a few datasets of interest, including one HMO study by Bob Roberts.

The next call will either be on Friday, May 17th between 9 and 11:30 AM or Tuesday, May 21st between 1 and 3 PM. As soon as the time is decided, Maura will confirm via e-mail. Just like the last call, the dial-in number will be 1-800-820-4690 and the participant code will be 7076345 #. In addition, Friday, June 14th, is currently on hold for a face-to-face meeting with the scientists.

To Do:

- Peter, Larry, and Maura will continue going through the measures to find items that fit our inclusion criteria. They will do this for symptoms of aggression, anxiety, and eating disorders, and then present their results to the group during the next call.
- Maura will track down information on the additional datasets and include them in our overall chart.
- Wei will send the group the results of her statistical analyses on the depression/suicidal items.
- Larry and Maura will continue to work on setting up focus groups for the end of May with parents, pediatricians, and teachers.

May 21, 2002
 2:00 – 3:00 pm Conference Call
 Development of Children’s Mental Health Indicators
 Steering Committee
 Minutes/discussion summary (11):

Present on call: Peter Jensen, Wei Li, Jane Costello, Robert Friedman,
 Larry Amsel, Maura Crowe

Before the call, Maura e-mailed the group the updated dataset table, as well as the chosen items from the DISC 2.3 and 4. The call began with Peter informing Jane of our work during the past few meetings. Jane felt comfortable with the group’s progress, and will need to look over the materials before she commits to any analyses of her data.

Wei updated the group with some of the analyses that she has done on the MECA data regarding suicidal cases. Although she has only analyzed the MECA data at this point, we will be expanding into various other datasets, including those done by Rand Conger and Bob Roberts, within the next few weeks. Both of these datasets used the DISC IV. We will also be examining the NLSCY of Canada with the help of Kathy Bennett, however it may be difficult to pull out internalizing disorders from this dataset.

Regarding all datasets, once we figure out how many children meet our chosen criteria for a certain indicator, we can construct two denominators: 1) the number of children that meet our chosen criteria, and 2) the number of children that meet our chosen criteria who also meet full criteria for the disorder.

The focus groups with pediatricians, teachers, and parents are planned to take place in the next few weeks. Our goal with these groups is to determine if our chosen indicators are in agreement with their thoughts. One method of working with the focus groups is for them to see where our indicators fit into their pre-chosen vignettes of severity. Also, we can find out what other types of kids they think should be in service. Two parent groups are scheduled for May 28th and 29th in Washington, D.C., and the teacher groups are scheduled for June 3rd and 5th. The pediatrician group will be decided shortly.

The face-to-face meeting with the scientists is scheduled for Friday, June 14th, from 10AM to 3PM in New York City. Our next conference call is scheduled for June 4th from 4:00 - 5:30 PM. As always, the dial-in number will be 1-800-820-4690 and the participant code will be 7076345 #.

TO DO:

- Peter, Larry, and Maura will be attending focus groups within the next few weeks, and will update the group during the next conference call on June 4th.
- Maura will circulate Wei’s statistical analyses of the MECA data.
- Peter will contact Bob Roberts and seek to get his permission to use his HMO data.

June 4, 2002
4:00 – 5:30 pm Conference Call
Development of Children’s Mental Health Indicators
Steering Committee
Minutes/discussion summary (12):

Present on call: Peter Jensen, Wei Li, Barbara Huff, Robert Friedman,
Prudence Fisher, Larry Amsel, Maura Crowe

Peter began the call by updating the group regarding the focus groups as well as the datasets. We had several exceptional focus groups with parents and teachers in New York and Maryland, and we plan on having a few more within a month with pre-school teachers and pediatricians. Before the call, Maura sent the committee the notes from all of these groups, as well as analyses performed by Wei on the MECA and Texas datasets.

The most striking comment that we heard at the focus groups was to use “common sense” language, such as “sadness” instead of depression and “extreme fear” instead of panic. They also suggested breaking up a few of the indicators into several different ones. Other indicators to think about including were 1) loss of control with a desire to hurt others, 2) emotional withdrawal and detachment, and 3) severe mood swings. In several groups, we noticed that the phrase “mental health” was viewed negatively. Instead, they suggested using words such as “emotional health” or “healthy mind,” and include these thoughts in the overall context of the child’s health.

Prudence arranged for access to two new datasets, namely Rand Conger’s Iowa dataset and Bob Robert’s Texas HMO dataset. Wei has already begun analyses on this data, and we will send the final results to the group by next Thursday.

Wei discussed her analyses of the child data from the Texas study. In addition to these analyses, she will find out which children that fulfill our criteria also meet full criteria for their disorder, and separate the children according to gender and age. We may need to loosen up some of the criteria, specifically for eating disorders, to pick up more children.

The face-to-face meeting with the scientists is scheduled for next Friday, June 14th, from 9 am to 3 pm in New York. Maura and Josey will be working on arranging flights and hotels for those involved, and will be in touch this week. By next Thursday, we will be sending the group the updated draft of our report to CMHS, including the notes from the focus groups and the analyses on the datasets, as well as an agenda to the meeting.

To Do:

- Maura and Josey will be in touch to make flight and hotel arrangements for Bob, Barbara, Dan, and Kathy.
- Peter, Larry, and Maura will prepare the CMHS draft to send to the steering committee, scientists, as well as to CHADD, MHA, NAMI, and the FFCMH, by next Thursday.
- Wei will finish her analyses of the Texas and Iowa datasets.

June 14, 2002
9:00 – 3:00 PM Indicators Scientists Meeting
Beacon Hotel, New York City
Development of Children’s Mental Health Indicators
Minutes/discussion summary:

Present: Peter Jensen, Barbara Huff, Dan Offord, Larry Amsel, Maura Crowe, Wei Li,
Kimberly Hoagwood, Prudence Fisher, Eliot Goldman, and Kathryn Bennett

Introduction: The meeting began with a warm welcome from Peter, as well as introductions of all participants. Peter then gave a brief background and timeline of the project to get everyone up to date with our progress thus far.

Overall Focus: The initial conversation focused on the purpose of this project and our future goals. One concern regarding the future implications of these indicators was that they should be tightly linked with a plan for service, such as an evidence-based list of supports. However, these supports may not be appropriate for the general public. Instead, stating that the child should “get an evaluation” may be more appropriate.

All agreed that this project is a huge endeavor, and our chances at success are highest if we narrow down our work by focusing on one particular indicator that has shown good evidence of meeting diagnosis and finding children who need services, but that also has good evidence-based treatments (such as depression). In this way, we will be making sure that we do more good than harm (“receptor capacity”).

As for reaching the providers, it was suggested that we should start with where the doctors are right now – a.k.a. a practice they are in the habit of performing – and add to it so that they feel comfortable. An example of this would be to incorporate our indicators into their “prescription pad.” Although some felt that the school system might be better prepared for evaluations, it was decided that it is necessary to go through both avenues (the school and the providers) in order to reach the most children.

Data Analyses: The most striking result from the data analyses was the amount of unmet need for these severe indicators. Peter went through each table summarizing the results that Wei presented. Next, we will analyze the data according to each indicator across any service item, and vice versa (service question across any indicator).

Once the analyses are finished, what is the next step? If we give this message to primary care physicians, we will need to determine if they are identifying more children. We need to test out how the data plays out in a pediatric setting. One consideration is that the indicators we have chosen are embedded within a large interview format (the DISC). Will they behave the same in identifying children when they stand alone? One way to test that would be to give the interview to the child, blind to the pediatrician. Then the pediatrician could ask the indicator alone, and we could compare to see if the results match (interview and indicator).

It was concluded that there are three primary goals when working with primary care physicians: 1) Find out if the indicator works, 2) See if more children are identified by the physician, and 3) Determine if the doctors instill the “right” message to the children and families, and not just identify. Another mentioned result would be to see the extent to which the referral is followed through (how many children reached treatment based on our indicators). Although this is desired, it was decided that this aspiration is not “real-world” and not the purpose of this project. The largest reason for children not reaching the referral step of their treatment seems to be stigma, although when and where the services are held is also a hindrance. The hope would be that we change the clinician’s behavior first, instead of concentrating on trying to change the behaviors of patients.

Focus Groups: Next on the agenda was to discuss the feedback and work with the focus groups. The group decided that any suicidal attempt, whether it was low or high-risk, was an indicator. We will be having two additional focus groups before the deadline of July 15th – one with physicians and one with pre-school teachers. In addition, we may have supplementary groups of adolescents, parents, and taxicab drivers. We are sending this draft to organizations such as NAMI and CHADD, as well as professional associations, such as the American Academy of Child and Adolescent Psychiatry.

NLSCY: After lunch, Kathryn discussed her study and how it may possibly fit into the indicators project. The National Longitudinal Study of Children and Youth (NLSCY) consists of over 20,000 children within three cycles, ages 0-15, beginning in December of 1994. The strengths of this data are the suicide, aggression, and service items. The only problem with the service items is that they do not state why they saw the professional. Thus, they could have seen a pediatrician for their mental health problem. One way to get around this would be to look at both suicidal and non-suicidal children and compare their methods of utilization.

After going through the items, it was clear that this data set would be an excellent addition to the indicators project. However, Kathryn noted that in order to obtain access to the master file of data, she will need to submit documentation and it could take up to four weeks to process. Peter was still optimistic of the use of the data set, especially because of its unique wording of items, and will ask for a no-cost extension of the grant. Kathryn will separate the age groups as follows: 4-5, 6-7, 8-10, 11-13, and 14-15.

Future Recommendations: Dan pointed out that we have excellent unmet need data, and this data could stand alone in a scientific paper. It was decided that Phase II would be split up into Phase II and Phase III. During the new Phase II, we will analyze additional data sets, have several more focus groups, submit scientific papers to be published, and test out 2 or 3 indicators in various environments. Possible additional data sets include those by Rolf Loeber, Hector Bird, Jane Costello, and perhaps the control group of the preschool Head Start program. For the next focus groups, we plan to include preschool teachers, doctors, high-risk parents, and even taxicab drivers. Once we know that the indicators “work,” Phase III will consist of testing them with pediatricians, and seeing if the providers’ behaviors change.

To Do:

- Peter, Larry, and Maura will work to re-craft the draft, incorporating our agreed-upon future recommendations, and will send this draft to the SC and scientists for input
- The Steering Committee will begin to prepare a scientific paper regarding the unmet need findings from our data sets
- Kathryn will work on operationalizing the NLSCY data to our indicators
- Barbara will follow-up on the preschool teacher survey
- Wei will analyze the MECA, Iowa, and Texas data sets for each indicators across any service item and vice versa

Maura will be in touch via e-mail to set up the next SC call

July 8, 2002
2:00 – 3:00 pm Conference Call
Development of Children’s Mental Health Indicators
Steering Committee
Minutes/discussion summary (13):

Present on call: Peter Jensen, Wei Li, Barbara Huff, Robert Friedman, Kathy Bennett, Dan Offord, Jane Costello, Larry Amsel, Maura Crowe

Peter began the meeting by reviewing the discussions held during our face-to-face meeting in New York on June 14th. The analyses of the data sets revealed that approximately 1% of the population had the indicators, and this was equally distributed across age and gender (except for suicide). We have not examined ethnicity at this point, but we have analyzed “any indicator” status across the service use items, as well as how unmet need changes when a child has 1, 2, 3, or more indicators (analyses distributed earlier).

The feedback from the various focus groups was reviewed. From several parent focus groups two additional indicators we identified that we should look at – namely, severe mood swings and impulsive out of control behavior, though it may be difficult to construct these indicators from the data. CHADD noted that we should include an ADHD-related indicator, considering how prevalent it is among youth. The hesitation for including this indicator from the start was the risk of false positives, as well as the assumption that most of these children would have been seen by professionals. This will be explored further in the data sets.

Last week Peter met with the Federal Interdepartmental Group, which consisted of the NIMH and CMHS, as well as the Juvenile Justice department, HRSA, and the CDC. He presented the last four pages of our Phase I document, and there was a good deal of excitement about the project across the board. NIMH would like the project to continue via some grant funding mechanism, but there has been some internal confusion over whether the project was intended to develop a psychometric measure (rather than serve as the foundation for evidence-based messages). This confusion was only partly clarified with NIMH staff, though several folks seem to have lingering concerns, perhaps still some confusion. NIMH had several good possible funding suggestions, such as partnering with a social marketing agency to test the public’s perception using an SBIR (small business grant mechanism), or a conference grant. It appears that the other federal agencies will want to continue the study prospectively with direct support via contract, however.

For the NLSCY data set, although there is no school readiness measure for the younger children, it may be possible construct signs of kids in difficulty in kindergarten that would predict the children that need services. Kathy will do descriptive runs of the frequency of certain items at age 4 for both girls and boys.

The Phase I document is due on July 15th, however Peter requested a no-cost extension until mid-October. We will modify the document by adding the agreed-upon next steps of Phase II and III, as well as integrating the feedback of the focus and advocacy groups, and then get further feedback from the Steering Committee.

To Do:

- Peter, Larry, and Maura will work on modifying the Phase I document and will send it out next Monday, July 15th.
- Kathy will test the frequency of certain items at age 4 in the NLSCY data set.
- Maura will set up the next call via email. It will be held in 3 to 4 weeks.

July 31, 2002
3:00 – 4:00 pm Conference Call
Development of Children’s Mental Health Indicators
Steering Committee
Minutes/discussion summary:

Present on call: Peter Jensen, Wei Li, Barbara Huff, Robert Friedman, Kathy Bennett, Bob Roberts, Maura Crowe

Peter introduced Bob Roberts to the group, who is the principal investigator of the Texas data set. Prior to the call, Bob read the Phase I Document and felt that the majority of the results were consistent with his findings in Texas. The only inconsistency was the suicidal attempts versus the suicidal plans. He will check on that contradiction and get back to us during our next call. In addition, he informed us that the parents in his study were only administered externalizing modules.

Kathy has submitted the proposal for access to the NLSCY data, and should receive a reply within three to four weeks. Once they have approval, they are going to examine suicidal and aggressive symptomatology. For the three-year old age group, the data is based on temperament scales, since the OCHS scales begin at age 4. The codebook for the data is located on the Stats Canada website, which Peter and Maura will track down.

Bob Roberts noted large ethnicity differences in the Texas data set, especially regarding the minority reports of parents and children. He suggested that we conduct future focus groups in the Southwest. Wei is going to reexamine the data for ethnicity breakdowns.

In addition to the indicators that we have already examined, a few more have emerged throughout our research and collaborations with advocacy groups. Specifically, the next step is to look at substance use and ADHD. Both the NLSCY and Texas data sets contain information on substance use. Substance use will be examined according to age, severity, and frequency. As for ADHD, we are unsure if we will be able to show medical necessity based on the DISC items, but we will take a look before the next call. The selected DISC items will be faxed to the committee, along with an article by Peter.

The next conference call is scheduled for Friday, September 6th, at 10 AM (EST). The dial-in number is 1-800-820-4690 and the participant code is 7076345 #.

To Do:

- Wei will analyze the Texas, Iowa, and MECA data sets according to ethnicity.
- Peter, Larry, and Maura will examine the DISC-IV and pull out the relevant items for ADHD, substance use, and, if possible, mood swings; these will be faxed to the group.
- Kathy will examine the temperament scales for aggression, and will fax these to Maura for distribution. Maura will also re-distribute the OCHS scales.
- Peter and Maura will track down the Stats Canada codebook, and examine it for additional possible variables, such as “external validators” and send to the group.
- Maura will fax Peter’s paper on external validators to the group.

- Bob Roberts will re-check his data regarding suicidal plans versus attempts. He will also clean data sets to Peter and Wei so they can redo the analyses here

September 6, 2002
10:00 – 11:00 am Conference Call
Development of Children’s Mental Health Indicators
Steering Committee
Minutes/discussion summary:

Present on call: Peter Jensen, Wei Li, Larry Amsel, Robert Friedman, Bob Roberts, Jane Costello, Maura Crowe, Barbara Huff, and Kathy Bennett

The agenda for today’s meeting was to review the faxed materials regarding ADHD and substance use, as well as go over the analyzes performed by Wei. As a reminder, Peter mentioned that these particular areas were of concern to several consumer groups.

Our initial hesitations with examining ADHD as an indicator revolved around the problem of showing medical necessity. Given the consumer need, we reexamined the DISC IV and chose severe items related to hyperactivity and harmful situations. The first developed indicator involved cross-situational symptoms (a.k.a. restlessness at home and school) along with impairment (a.k.a. problems with schoolwork). The second indicator looked at dangerous situations with impairment. The group agreed that combining both the items for restlessness and for dangerous situations would reduce the false positives.

Bob suggested using datasets that have different instruments, however Jane noted that although there is different wording in the various instruments, they are all basically the same items since they are all based on the DSM-IV. Thus, the underlying issue that was highlighted was whether or not the DSM-IV focuses on the right items. This coincides with the public’s opinion that various symptoms are not specified in these items, such as mood swings.

The developed indicators for substance use were split into alcohol, other substances, and marijuana. Given the high percentages of use and of comorbidity with substance use, this area was not initially considered by the Steering Committee. However, it was discovered that it might be interesting to map substance use to any diagnosis. In the same light, we can map any of the indicators to any diagnosis. Although the indicators are concerned with medical necessity rather than diagnosis, we need to be careful when using the phrase “medical necessity,” since that usually implies that a treatment is available.

The next conference call is scheduled for Monday, September 30th, at 2:30 PM (EST). The dial-in number is 1-800-820-4690 and the participant code is 7076345#.

To Do:

- Wei will continue analyzing the data sets, focusing on combining the ADHD symptoms and mapping the indicators to any diagnosis.
- Bob R. will call Wei on Monday to discuss further analyzes.
- Peter, Larry, and Maura will rework the draft to include the idea of “zero tolerance” for substance use, as well as the notion that “medical necessity” does not necessarily denote available treatments.

Minutes from Today's Call

9/30/02

Present on call: Bob Friedman, Barbara Huff, Peter Jensen

Data from Wei's recent analyses for substance use and hyperactivity w/physical risk or injury were reviewed and discussed. These analyses suggest that we can in fact obtain roughly 1% of kids who meet these criteria.

How to word substance use and alcohol abuse indicators was discussed further. One possibility would be to separate them from the main indicators, with an additional separate paragraph, with caveats, e.g., "Parents should be aware that brief experimentation with substances occurs unfortunately all too commonly in youth. All substance and alcohol use is to be strongly discouraged in youth, being both illegal and dangerous, even one-time experimentation. Repeated use (more than 1-2 times) of illegal substances should be taken extremely seriously, and is an important warning sign of the need for further medical and mental health evaluation." Peter agreed to contact Sybil Goldman, to see if she had SAMHSA contacts that could advise us on language/communication issues, since we don't want crisp warning signs to somehow indicate that experimentation is okay.

Further discussion followed on the extent to which the indicators are "evidence-based." After some discussion, three levels of evidence were proposed and agreed upon:

Level of Examination for Scientific Evidence and Public Acceptability/Interpretability for Indicators of Unmet Need.

Level Description

- 1 = Acknowledged psychological symptom or profile in standard texts, such as DSM listed symptom or behavior. Unclear whether language is interpretable or applicable across various stakeholders, settings, ethnic groups, gender, age.
- 2 = Level 1, plus: Language and understandability of specific terms have been vetted through multiple focus groups and stakeholders, including parents, teachers, providers, different ethnic groups, etc. Widespread agreement that each indicator conveys a severe, face-valid, widely recognized behavior that should warrant further evaluation and possible intervention.
- 3 = Levels 1 and 2, plus: indicator examined in multiple epidemiologic (community based, non-referred sample) data sets, and frequency determined to approximate 1%, and be present across ethnic, gender, and age groups. Most youth who have the indicator are not receiving services.

Following these criteria, of the current 12 indicators, nine meet level 3 criteria, and three meet level 2 criteria. This framework will be incorporated into the final draft, due on October 31st.

Two more focus groups are being planned, and should be done by mid-October (one doctors, one pre-school teachers).

Peter provided an update from Judy Katz-Leavy and Rolando Santiago, who both were optimistic that this should continue to be funded into phase II. There is also a possibility that the Foundations and Agencies Network will provide some partial, modest support for the activity.

Further comments and analyses will be incorporated into the next draft, to be reviewed at the next meeting, October 28th, 10-noon.

To Do:

- Larry/Maura will send out latest draft week of Oct 21st, integrating latest analyses, new indicators, final two focus groups, and level of evidence template.
- Peter will contact Sybil Goldman re: SUD/alcohol indicators language suggestions from SAMHSA.

Peter Jensen

October 28, 2002
10:00 – 12:00 pm Conference Call
Development of Children’s Mental Health Indicators
Steering Committee
Minutes/discussion summary:

Present on call: Peter Jensen, Wei Li, Barbara Huff, Robert Friedman, Kimberly Hoagwood, Larry Amsel, Maura Crowe

The call began with an explanation of the documents sent via email. The first document was the entire Phase I draft while the second document was an excerpt of this draft, namely Appendix IX, that contains a crisp summary of the project and future plans.

Although we initially began with six indicators, the list has expanded to 12, and 9 of these 12 meet the highest level of review (3). It is important to state that these 12 are not the final list of indicators – more could be added in Phase II, such as school failure. Three crucial findings regarding the indicators are that they map onto diagnosis on an average of 30-70%, they all meet criteria for unmet need, and they work across various ethnic groups and genders.

Larry and Maura gave a summary of the focus groups held during the past few weeks. They met with 8 preschool teachers from the upper west side of Manhattan. Despite the fact that these teachers and parents were quite informed of mental health issues, stigma was still a major problem. They commented that the parents worried about the child’s school record and did not view an evaluation as a “tune-up,” as the teachers had encouraged. Two major parental fears were that of medication and of blame. The teachers felt that they were the key to this age group, for they saw the children behaving in various environments. There is a need for more focus groups with this age group, and Barbara suggested her “Starting Early, Starting Smart” group for Phase II of the project.

In addition, Larry met with 8 pediatric residents from the Mt. Sinai Adolescent Health Clinic. They were very positive about this project and the need for indicators. However, there were concerns about stigmatizing the adolescents or being too invasive. At the clinic, the residents preferred to handle the children as much as possible without referring out, and they even had pediatricians specializing in disorders such as anorexia. As for individual indicators, they felt that panic manifested itself in physical symptoms, such as stomach aches. Also, on the whole, they had a smaller tolerance for violence than the other focus groups, yet they had a higher tolerance for drug use.

After discussing various changes regarding the wording of certain indicators, Peter commented that the Phase I document would be finished by Thursday for submission and circulation amongst the Steering Committee. One future project includes submitting a scientific paper for publication in JAMA. Maura will be setting up a future call, possibly in December, to discuss the first draft of this paper and the funding for Phase II of this project. Peter thanked everyone for their hard work throughout the year.

APPENDIX II:
TABLE OF DATA SETS WITH BIBLIOGRAPHY

Longitudinal Studies with Representative Community Samples

| Dataset (untitled if no name) | PI or First Author | Outcomes | Symptom Measures | Functional Measures, Risk Factors | Sample Total number (subsample percentages); community or clinical | Age at T1 | Sex %M, %F (at T1) | Ethnicity | Time Increments # of waves (if one follow-up, then 2 waves), every how many years? | Refusal Rate |
|--|--------------------|--|--|--|--|--|--------------------|---|--|--|
| Great Smoky Mountain Study ^{1,5,6} | Costello, E. Jane | Comorbid substance use and behavioral disorders; association between poverty & psychiatric diagnosis | CBCL, CAPA, CGAS, CASA | CAPA, Child and Adolescent Functional Assessment Scale, Social Interactions Survey | 1015 public school children; Parallel Study: 323 American Indian children; community | Ages 9, 11, and 13 yrs | | 90% white, 8% black, 1% mixed race, 1% Hispanic and Asian | 4 waves, 1 yr. | |
| Oregon Adolescent Depression Project ¹⁶ | Lewisohn, Peter M. | Depression and comorbidity | K-SADS, LIFE | N/A | 1709; community | 14-18 yrs Mean = 16.6 | 47% M, 53% F | 91% white, 9% other | 3 waves; T1, T2 (1 year later), and T3 (mean age 24) | 12% at T2 |
| Pittsburgh Youth Study ¹⁷ | Loeber, R. | Co-morbid substance use & ADHD; persistent delinquency; persistent mood disorders | CBCL, DISC, TRF, Substance Use Scale, drug use and internalizing disorder measures | SRD, Antisocial Behavior Scale, persistent delinquency measure | 2550 at T1 (850 boys in each grade), 750 at T2 (250 boys in each grade); community | Grades 1, 4, and 7 (Mean ages 7, 10, and 13 yrs, respectively) | 100% M, 0% F | 50% white, 50% black | Grade 1: 8 waves Grade 4: 6 waves Grade 7: 7 waves Every 6 mos. | Average throughout study: 4% for Grade 1 3% for Grade 4 6% for Grade 7 |
| Untitled ⁴ | Costello, E. J. | Behavioral and emotional disorders, serious emotional disturbance (SED) | DISC, version 1.3 (parent and child). Follow-up: DISC, version 2.1. CBCL | N/A | 300 from 2 pediatric clinics in a large urban HMO | 7-11 yrs | 48% M, 52% F | 19% black, 81% other | 2 waves, 5 yrs | 24% of families initially selected refused to participate, leaving a total of 300 children |
| Untitled ² | Horwitz, S. M. | Psychiatric disorders | DISC, CBCL | N/A | 1060 (final group) | 5-9 yrs | 51% M, 49% F | 82% white, 10% black, 6% Hispanic, 2% other | 2 waves, 1 yr | 17% at T1 |
| Untitled ^{12,13,14,15} | Lavigne, John V. | Disruptive, emotional (including phobia), adjustment, and other disorders | CBCL, DICA, PSI, C-GAS | RABI, FES, LES | 510 from 68 Chicago-based pediatric practices | 2-5 yrs | 60% M, 40% F | 67% white, 19% black, 7% Hispanic, 7% other | 3 waves; T1, T2 (1-3 yrs later), T3 (additional 12-28 months later) | 23% at T1 |

| | | | | | | | | | | |
|---|-----------------|---|--|---|-------------------------------|-------|--------------|--|-----------------------|--|
| National Longitudinal Survey of Children and Youth ³ | Offord, D. | Prevalence of various biological, social, and economic characteristics and risk factors | OAK scales | School and social functioning measures | 22,831 | 0-11 | | | Every 2 yrs to age 25 | |
| Antisocial Behaviors in US and Island Puerto Rican Youth RO-1 MH56401 | Bird, Hector | Disruptive, mood, anxiety, and substance abuse | DISC-IV, FHE (Myrna), KBIT, prime MD schedule for maternal MDD (Spitzer) | SAMHSA service use questionnaire, CGAS, Elliot scales | 1125 children, 14,000 parents | 5-13 | 60% M, 40% F | 100% Puerto Rican | 3 waves, 1 yr apart | |
| Iowa-Georgia Rural Minority MH48165 | Conger, Rand | Disruptive, mood, anxiety, and substance abuse | DISC-IV | | 897 | 10-12 | 46% M, 54% F | 94% black, 6% other | 2 waves, 2 yrs apart | |
| Texas HMO MH49764 | Roberts, Robert | Disruptive, mood, anxiety, substance abuse, eating disorders | DISC-IV, CAPA suicidal model, Beck Suicidal Intent Scale | Interpersonal Support Evaluation List (ISEL), CGAS, UCLA Loneliness Scale | 4200 | 11-17 | 51% M, 49% F | 36% white, 36% black, 25% Hispanic, 3% other | 2 waves, 1 yr apart | |

Other Population-based Studies – Cross-sectional

| Dataset | PI | Outcomes | Symptom Measures | Functional Measures | Sample | Age | Sex | Ethnicity | Refusal Rate |
|---|------------------------------|---|-----------------------------------|---|--------------------------------|---|-----------------|--|--------------|
| National Comorbidity Survey ^{9, 10} | Kessler, R.C. | Affective, Anxiety, and Substance use Disorders & other disorders | CIDI, based on DSM-III-R criteria | N/A | 8,098; community | 22% 15-24 yrs; 32% 25-35 yrs; 28% 35-44 yrs; 18% 45-54 yrs | 48% M, 53% F | 75% white, 13% black, 9% Hispanic, 3% other | 18% |
| The NIMH Methods for the Epidemiology of Child and Adolescent Mental Disorders Study (MECA) ^{7, 8, 11} | Lahey, Benjamin B. (et. al.) | Mental Disorder and Service Utilization | DISC (2.3), FHE | SURF, PDS, APGAR, PMS, PDPS, DAS, LEC, ISCS | 1523 eligible youth; community | 9-17 yrs | 53% M, 47% F | 51% white, 15% black, 28% Hispanic, 6 % other | 16% |

References:

1. **Angold, A.**, Messer, S. C., Stangl, D., Farmer, E. M. Z., **Costello, E. J.**, & Burns, B. J. (1998). Perceived parental burden and service use for child and adolescent psychiatric disorders. *American Journal of Public Health, 88*, 75-80.
2. Briggs-Gowan, M. J., **Horwitz, S. M.**, Schwab-Stone, M. E., Leventhal, J. M., & Leaf, P. J. (2000). Mental health in pediatric settings: Distribution of disorders and factors related to service use. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 841-849.
3. Canada's National Longitudinal Survey of Children and Youth. (n.d.). Retrieved April 9, 2002 from <http://www.hrdc-drhc.gc.ca/arb/conferences/nlscyconf/flyer-e.shtml>
4. **Costello, E. J.**, Angold, A., & Keeler, G. P. (1999). Adolescent outcomes of childhood disorders: The consequences of severity and impairment. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 121-128.
5. **Costello, E. J.**, **Angold, A.**, Burns, B. J., Stangl, D. K., Tweed, D. L., Erkanli, A., & Worthman, C. M. (1996). The Great Smoky Mountains Study of Youth: Goals, design, methods, and the prevalence of DSM-III-R Disorders. *Archives of General Psychiatry, 53*, 1129-1136.
6. Federman, E. B., **Costello, E. J.**, **Angold, A.**, Farmer, E. M. Z., & Erkanli, A. (1997). Development of substance use and psychiatric comorbidity in an epidemiologic study of white and American Indian young adolescents: The Great Smoky Mountains Study. *Drug and Alcohol Dependence, 44*, 69-78.
7. Flisher, A. J., Kramer, R. A., Hoven, C. W., King, R. A., Bird, H. A., Davies M., Gould, M. S., Greenwald, S., **Lahey, B. B.**, Regier, D. A., Schwab-Stone, M., & Shaffer, D. (2000). Risk behavior in a community sample of children and adolescents. *Journal of the American Academy of Child and Adolescent, 39*, 881-887.
8. Goodman, S. H., Hoven, C. W., Narrow, W. E., Cohen, P., Fielding, B., Alegria, M., Leaf, P. J., Kandel, D., Horwitz, S. M., Bravo, M., Moore, R., & Dulcan, M. K. (1998). Measurement of risk for mental disorders and competence in a psychiatric epidemiologic community survey: The National Institute of Mental Health Methods for the Epidemiology of Child and Adolescent Mental Disorders (**MECA**) study. *Social Psychiatry, 33*, 162-173.
9. **Kessler, R. C.**, Molnar, B. E., Feurer, I. D., & Applebaum, M. (2001). Patterns and mental health predictors of domestic violence in the United States: Results from the national comorbidity survey. *International Journal of Law and Psychiatry, 24*, 487-508.

10. **Kessler, R. C.**, McGonagle, K. A., Zhao, S., Nelson, C. B., Hughes, M., Eshleman, S., Wittchen, H. U., & Kendler, K. S. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: Results from the National Comorbidity Survey. *Archives of General Psychiatry, 51*, 8-19.
11. **Lahey, B. B.**, Flagg, E. W., Bird, H. R., Schwab-Stone, M. E., Canino, G., Dulcan, M. K., Leaf, P. J., Davies, M., Brogan, D., Bourdon, K., Horwitz, S. M., Rubio-Stipec, M., Freeman, D. H., Lichtman, J. H., Shaffer, D., Goodman, S. H., Narrow, W. E., Weissman, M. M., Kandel, D. B., Jensen, P. S., Richters, J. E., & Regier, D. A. (1996). The NIMH Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) Study: Background and methodology. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 855-864.
12. **Lavigne, J. V.**, Arend, R., Rosenbaum, D., Binns, H. J., Christoffel, K. K., & Gibbons, R. D. (1998). Psychiatric disorders with onset in the preschool years: I. Stability of diagnoses. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 1246-1254.
13. **Lavigne, J. V.**, Arend, R., Rosenbaum, D., Binns, H. J., Christoffel, K. K., & Gibbons, R. D. (1998). Psychiatric disorders with onset in the preschool years: II. Correlates and predictors of stable case status. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 1255-1261.
14. **Lavigne, J. V.**, Arend, R., Rosenbaum, D., Binns, H. J., Christoffel, K. K., Burns, A., & Smith, A. (1998). Mental health service use among young children receiving pediatric primary care. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 1175-1183.
15. **Lavigne, J. V.**, Binns, H. J., Arend, R., Rosenbaum, D., Christoffel, K. K., Hayford, J. R., & Gibbons R. D. (1998). Psychopathology and health care use among preschool children: A retrospective analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 262-270.
16. **Lewinsohn, P. M.**, Rohde, P., & Seeley, J. R. (1998). Major depressive disorder in older adolescents: Prevalence, risk factors, and clinical implications. *Clinical Psychology Review, 18*, 765-794.
17. **Loeber, R.**, Stouthamer-Loeber, M., & White, H. R. (1999). Developmental aspects of delinquency and internalizing problems and their association with persistent juvenile substance use between ages 7 and 18. *Journal of Clinical Child Psychology, 28*, 322-332.

APPENDIX III:
ITEMS FROM THE DISC 4

DISC 4 ITEMS RELATED TO INDICATORS

(For all of the following, assume yes=1, no=0, and missing=0.

In addition, the “CROSSTAB” function refers to answering the service question if the child adhered to the criteria and impairment formula.)

1. DEPRESSION WITH SEVERE IMPAIRMENT

- a. (SUM(1b, 1d)=2) AND (SUM(27a, 28a, 29a)>=2).
CROSSTAB to 32.

Depression text (page 1):

- #1b. Would you say that (he/she) seemed that way for most of the day?
- #1d. In the last year, were there two weeks in a row when (he/she) seemed sad or depressed almost every day?

Impairment text (page 18):

- #27a. How often did being this way keep (him/her) from doing things or going places with (you (or (his/her) family)/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #28a. How often did being this way keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #29a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because (he/she) was this way? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 19):

- #32. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) was (sad or depressed/acting like nothing was fun/grouchy)?

2. SUICIDAL IDEATION AND PLAN OR ANY SUICIDAL ATTEMPT

- a. 21b=1
CROSSTAB to 32.

Suicidal plan text (page 13):

- #21b. In the last year, did (he/she) say that (he/she) had a plan for exactly how (he/she) would kill (himself/herself)?

Service text (page 19):

- #32. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) was (sad or depressed/acting like nothing was fun/grouchy)?

b. 22=1.

CROSSTAB to 32.

Suicidal attempt text (page 14):

- #22. Has (he/she) ever, in (his/her) whole life, tried to kill (himself/herself) or made a suicidal attempt?

Service text (page 19):

- #32. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) was (sad or depressed/acting like nothing was fun/grouchy)?

3. ANXIETY WITH SEVERE IMPAIRMENT

a. Social Phobia

- (DSM-IV Criteria) AND (SUM(19a, 20a, 21a)>=2).
CROSSTAB to 24.

Impairment text (page 5):

- #19a. How often did feeling that way keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #20a. How often did feeling that way keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #21a. How bad were the problems (he/she) had with (his/her) schoolwork/work) because (he/she) was like that? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 6):

- #24. In the last year - that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a

hospital or a clinic or at their office because (he/she) was nervous around other people?

b. Separation Anxiety

- (DSM-IV Criteria) AND (SUM(16a, 17a, 18a) \geq 2). CROSSTAB to 21.

Impairment text (page 16):

- #16a. How often did (worrying like that/doing these things) keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #17a. How often did (worrying like that/doing these things) keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #18a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because (he/she) (worried like that/did these things)? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 17):

- #21. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) (worried about being away from (you/(attachment figure)) or about being away from home/(NAME () SYMPTOMS IN Q1-12 AND NOTES 1-4))?

c. Panic

- ((SUM(1 AND box a)=2) OR (SUM(2 AND box b)=2) OR (SUM 3 AND box c)=2)) AND (SUM(14a, 15a, 16a) \geq 2). CROSSTAB to 19.

Panic text (pages 27, 28, and 30):

- #1. In the last year – that is, since ((NAME EVENT)/(NAME CURRENT MONTH) of last year) – has ____ had an attack when all of a sudden (he/she) felt very afraid or strange?
- Box a: If 2 or more * responses were coded in D-R, continue.
- #2. In the last year, has ____ had a time when (he/she) suddenly seemed like (he/she) was suffocating or (he/she) couldn't breathe?
- Box b: If 1 or more * responses were coded in E-R, continue.

- #3. In the last year, has _____ had a time when (he/she) said (his/her) heart suddenly started to beat very fast?
- Box c: If a * response was coded in A or B, continue.

Impairment text (page 36):

- #14a. How often did these attacks keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #15a. How often did these attacks keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #16a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because of these attacks? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 37):

- #19. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) had these attacks of feeling very afraid or strange?

d. Agoraphobia

- (DSM-IV Criteria) AND (SUM(7a, 8a, 9a) \geq 2).
CROSSTAB to 12.

Impairment text (page 44):

- #7a. How often did (this fear/these fears) keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #8a. How often did (this fear/these fears) keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #9a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because of (this fear/these fears)? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 45):

- #12. In the last year – that is, since ((NAME EVENT)/(NAME CURRENT MONTH) of last year) – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) was afraid of (traveling (in a car/on a bus/on a train)/being (on bridges/in tunnels)/being in a crowded place/leaving the house by (himself/herself))?

e. Generalized Anxiety

- (DSM-IV Criteria) AND (SUM(16a, 17a, 18a) \geq 2).
CROSSTAB to 21.

Impairment text (page 53):

- #16a. How often did worrying like that keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #17a. How often did worrying like that keep (him/her) from doing things or going places with other (children/people (his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?
- #18a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because (he/she) worried like that? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 55):

- #21. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) worried about a lot of different things?

f. Post Traumatic Stress Disorder

- (DSM-IV Criteria) AND (SUM(37a, 38a, 39a) \geq 2).
CROSSTAB to 42.

Impairment text (page 84):

- #37a. How often did being like that keep (him/her) from doing things or going places with (you or (his/her) family/(his/her) family)? Would you say: a lot of the time, some of the time, or hardly ever?
- #38a. How often did being like that keep (him/her) from doing things or going places with other (children/people

(his/her) age)? Would you say: a lot of the time, some of the time, or hardly ever?

- #39a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because (he/she) was like that? Would you say: very bad, bad, or not too bad?

NOTE: Answering “a lot of the time,” “some of the time,” “very bad,” or “bad” denotes a “yes” to the question.

Service text (page 86):

- #42. (In the last year/Since (TRAUMATIC EVENT)), has (he/she) been to see someone at a hospital or a clinic or at their office because of the way (he/she) felt or acted after ((TRAUMATIC EVENT/it happened))?

NOTE: Combine ALL anxiety disorders into one and test for criteria and service use.

4. SEVERE PHYSICAL AGGRESSION WITH SEVERE IMPAIRMENT

a. Physical Fighting and Impairment

- (27f=1).
CROSSTAB to 41.

Physical fighting text (page 50):

- #27f. Has (he/she) started a physical fight more than once in the last year?

Service text (page 61):

- #41. In the last year (that is, since (NAME CURRENT MONTH) of last year), has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) did these things?

b. Weapon Use and Impairment

- (29f=1) OR (29u=1).
CROSSTAB to 41.

Weapon Text (page 52):

- #29f. Has (he/she) threatened someone with a weapon in the last six months (that is, since (NAME EVENT/MONTH))?
- #29u. In the last year, has (he/she) threatened someone with a weapon?

Service text (page 61):

- #41. In the last year (that is, since (NAME CURRENT MONTH) of last year), has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) did these things?

5. EATING BEHAVIORS WITH SEVERE IMPAIRMENT

a. Recent multiple binges

- (12e=1).
CROSSTAB to 29.

Binging text (page 4):

- #12e. Did (he/she) have eating binges at least twice a week for as long as three months?

Service text (page 14):

- #29. In the last year – that is, since (NAME CURRENT MONTH) of last year – has ____ been to see someone at a hospital or a clinic or at their office because (he/she) (NAME <> AND () SYMPTOMS IN Q10-19 AND NOTE 5)?

b. Vomiting

- (14a=1).
CROSSTAB to 29.

Vomiting text (page 5):

- #14a. Has (he/she) made (himself/herself) throw up to lose weight or to keep from gaining weight?

Service text (page 14):

- #29. In the last year – that is, since (NAME CURRENT MONTH) of last year – has ____ been to see someone at a hospital or a clinic or at their office because (he/she) (NAME <> AND () SYMPTOMS IN Q10-19 AND NOTE 5)?

c. Laxatives

- (15c=1).
CROSSTAB to 29.

Laxative text (page 6):

- #15c. Did (he/she) take medication at least twice a week for as long as three months?

Service text (page 14):

- #29. In the last year – that is, since (NAME CURRENT MONTH) of last year – has ____ been to see someone at a hospital or a clinic or at their office because (he/she) (NAME <> AND () SYMPTOMS IN Q10-19 AND NOTE 5)?

NOTE: After complete these analyses, test to see if chosen children meet criteria for full disorder (specifically for depression, conduct disorder, and eating disorders).

6. OTHER ITEMS TO FLAG

- Conduct Disorder
- (#8=1).
 - Has (he/she) ever held someone up or attacked somebody to steal from them?
- (#25e=1).
 - Did (he/she) do this more than five times in the last year?
- (#28e=1).
 - Did (he/she) do this more than five times in the last year?

DISC IV ITEMS RELATED TO INDICATORS

(For all of the following, assume yes=1, no=0, and missing=0.

(Very bad=1, bad=1, not too bad=0, refuse to answer=0, don't know=0)

In addition, the "CROSSTAB" function refers to answering the service question if the child adhered to the criteria and impairment formula.)

1. SEVERE INATTENTION/HYPERACTIVITY

- a. (SUM(33D AND 33E)>=1).
CROSSTAB to 44 OR 45.

Symptom text (page 14):

- #33d. When (he/she) was at home, did (he/she) often get (him/herself) into a dangerous situation because (he/she) wasn't thinking?
- #33e. How about when (he/she) was (at (school/work) or) other places?

Service text (pages 18 and 19):

- #44. In the last year, has (he/she) taken any medicine for being overactive, being hyperactive, or having trouble paying attention?
- #45. In the last year – that is, since (NAME CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) was overactive, hyperactive, or had problems paying attention?

2. ALCOHOL USE WITH SEVERE IMPAIRMENT

- a. (SUM(2A AND 21A)>=1) AND (#26A=1).
CROSSTAB to 42.

Symptom text (pages 2 and 6):

- #2a. Did (he/she) miss (school/work) more than once because of drinking?
- #21a. Has this happened more than once (a.k.a. couldn't remember things that were done while drinking)?

Impairment text (page 9):

- #26a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because of this? Would you say: very bad, bad, or not too bad?

Service text (page 12):

- #42. Did (he/she) ever see a doctor, counselor, or some other person like that because of (his/her) drinking?

3. MARIJUANA USE WITH SEVERE IMPAIRMENT

- a. (SUM(2A AND 9A) \geq 1) AND (SUM(24A AND 30A) \geq 1).
CROSSTAB to #27, 40, OR 41.

Symptom text (pages 26 and 27):

- #2a. Did (he/she) miss (school/work) more than once to get high on marijuana?
- #9a. Did this happen more than once (a.k.a. get in trouble with the police)?

Impairment text (pages 31 and 33):

- #24a. How bad were the problems (he/she) had with (his/her) (schoolwork/work) because of this? Would you say: very bad, bad, or not too bad?
- #30a. Did (he/she) have a problem more than once because (he/she) was using marijuana?

Service use text (pages 32 and 34):

- #27. In the last year – that is, since (NAME EVENT/CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she)(NAME RESPONSES IN Q2-17)?
- #40. Did (he/she) ever see a doctor, counselor, or some other person like that because (he/she) was using marijuana?
- #41. Did (he/she) go to a group meeting like “NA” because (he/she) was using marijuana?

4. OTHER SUBSTANCE USE

- a. (SUM(4C, 5D, 6C, 7D, 8D, 9D, 10C, AND 11D) \geq 1).
CROSSTAB to 70 OR 83.

Symptom text (pages 40, 42, 43, 44, 45, 46, 47, and 48):

- #4c. Has (he/she) used heroin six or more times in the last year?
- #5d. Has (he/she) used (SUBSTANCE FROM A - opiates) six or more times in the last year?
- #6c. Has (he/she) used PCP six or more times in the last year?

- #7d. Has (he/she) used (SUBSTANCE FROM A - hallucinogens) six or more times in the last year?
- #8d. Has (he/she) used (SUBSTANCE FROM A – nitrate) six or more times in the last year?
- #9d. Has (he/she) used (SUBSTANCE FROM A – inhalants) six or more times in the last year?
- #10c. Has (he/she) used steroids six or more times in the last year?
- #11d. Has (he/she) used (SUBSTANCE FROM A – any other substances) six or more times in the last year?

Service use text (pages 60 and 63):

- #70. In the last year – that is, since (NAME EVENT/CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) (NAME RESPONSES IN Q12-27)?
- #83. Did (he/she) ever see a doctor, counselor, or some other person like that because (he/she) used (NAME SUBSTANCES)?

- b. 12A=1.
CROSSTAB to 70 OR 83.

Symptom text (page 49):

- #12a. Did (he/she) miss (school/work) more than once because of using (NAME SUBSTANCES IN Q 1-11)?

Service use text (pages 60 and 63):

- #70. In the last year – that is, since (NAME EVENT/CURRENT MONTH) of last year – has (he/she) been to see someone at a hospital or a clinic or at their office because (he/she) (NAME RESPONSES IN Q12-27)?
- #83. Did (he/she) ever see a doctor, counselor, or some other person like that because (he/she) used (NAME SUBSTANCES)?

APPENDIX IV:
RESULTS OF DATA ANALYSES
(SEE EXCEL FILE)

APPENDIX V:
DESCRIPTION OF FOUR MAJOR DATA SETS

MECA Description

The NIMH Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) Study was performed in order to develop methods for surveys of mental disorder and service utilization in unselected population-based samples of children and adolescents. Four universities, namely Columbia University in New York City, Emory University in Atlanta, Georgia, the University of Puerto Rico in San Juan, Puerto Rico, and Yale University in New Haven, Connecticut, collaborated to conduct this methodological study. The MECA study had eight primary aims: 1) to determine whether lengthy interviews conducted in the subjects' homes were acceptable to respondents and could obtain adequate response rates in diverse populations, 2) to provide information on the psychometric properties of diagnostic interviews, 3) to develop strategies to combine information from various interviews, 4) to develop and assess the psychometric properties of impairment measures, 5) to develop and test utilization measures, 6) to develop and test demographic and family history measures, 7) to develop expertise in the organization and conduct of a multi-site epidemiological survey with a common protocol, and 8) to provide tentative estimates of the prevalence of disorders in children.

The sample was drawn from the four geographic areas that were selected based on socioeconomic, cultural, and ethnic diversity. The target population was all youth ages 9 through 17 residing in a housing unit. A total of 7,527 sample housing units were enumerated across the four sites, and 20% of these contained at least one eligible youth, for a total of 1,523 youths. Of these, 1,253 pairs of youths and adult caretakers were interviewed with the NIMH DISC, Version 2.3, and the Service Utilization and Risk

Factors Interview (SURF). These instruments examined a range of anxiety disorders, mood disorders, disruptive behavior disorders, and miscellaneous disorders, such as anorexia and bulimia, as well as service use. Results indicated that large-scale epidemiological survey of mental disorders and service use involving lengthy interviews in the homes of unscreened population-based samples of youths and their adult caretakers were acceptable to the community and could achieve good response rates.

Texas Description

This study, officially named “Depression and Anxiety, Minority Youth, and Primary Care,” contained a prospective random sample of 11- to 17-year-olds enrolled in 1 of 2 large HMOs in Texas during a 1-year period of March 1998 to February 1999. The sample was stratified by ethnicity. The principal investigator of this study is Robert Roberts, and the HMOs involved are the MacGregor Medical Association and the Kelsey-Seybold Clinic. The DISC-IV was administered twice, one year apart, to both youth and parent informants. The sample size was approximately 4,200 during wave 1 of the study, and 3,150 during wave 2, during which face-to-face interviews were conducted. Gender breakdowns were approximately 50-50 during both waves. The ethnicity of the sample during wave 1 was as follows: 36% white, 36% black, 25% Hispanic, and 3% other. Funding from NIMH has been received to conduct a third wave assessments in 2003-2004, providing data on a three-wave cohort of 2,250 youths who will be 15-21 in the third wave. In Wave 1 - Wave 2, 17 DSM-IV disorders were examined, including disruptive behaviors, mood disorders, anxiety disorders, substance use, and eating disorders. Two papers have been published thus far, one examining the prevalence and correlates of bullying and the other prevalence and consequences of insomnia. Two more papers have been submitted, one examining ethnic differences in parent reports of youth mental health problems and the other ethnic differences in parent-child agreement on mental health problems among youths.

Grant Number: MH49764

Iowa Description

The Iowa-Georgia Rural Minority Study, performed by Rand Conger at the Center for Family Research in Rural Mental Health, consisted of 897 children, ages 10-12, that were recruited from schools, parents, teachers, pastors, youth groups, and community organizations in rural communities of Iowa and Georgia. Inclusion criteria included age and specific ethnicity (African-American). The sample was 54% female and 46% male. The DISC-IV was administered twice in face-to-face interviews, two years apart, to both youth and parent informants. Disorders examined included major depression, disruptive behavior disorders, some anxiety disorders, such as general and separation anxiety, and substance use. Results have not yet been published.

Grant number: MH48165

Bronx Description

This study, officially named “Antisocial Behaviors in US and Island Puerto Rican Youth” contained a sample of 1125 children of 5- to 13- year-olds. The sample was 100% Puerto Rican and the gender breakdown was 60% male, 40% female. The DISC-IV was administered three times, one year in between each wave. For our analyzes, the sample size was 234 children at baseline. The Principle Investigator, Hector Bird, was interested in examining disruptive, mood, anxiety, and substance use problems in Puerto Rican children and adolescents.

APPENDIX VI:
QUESTIONNAIRES FROM FOCUS GROUPS

Questions Guiding Focus Groups' Discussion of Indicators for Children's Mental Health (First Version)

1. Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

How would you categorize this child?

- Severe depression with impairment
- Severe and persistent sadness that doesn't go away
- Serious unhappiness that is problematic
- Sadness with interference in daily activities

2. Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

How would you categorize this child?

- Suicidal in need of immediate help
- Severely depressed and does not want to live anymore
- Extreme sadness with no regard for life

3. Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected their schoolwork.

How would you categorize this child?

- Nervous and afraid of other children
- Scared to be alone, and feels ill when away from attachment figures
- Unable to get over their worries and interact appropriately with others

4. Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breathe.

How would you categorize this child?

- Very nervous and frightened, undergoing a panic attack
- Panicked for no apparent reason
- Very agitated and unable to control emotions

5. Imagine a child that has started multiple fights within the last year, with and without the use of weapons. These fights have interfered with relationships at home and at school, and have had bad effects on his/her schoolwork.

How would you categorize this child?

- Very aggressive and quarrelsome
- Bullying behavior that has badly impacted various parts of his/her life
- In need of immediate help for fear of the lives of those around him/her

6. Imagine a child that has been trying to lose weight even though they are not overweight, and has gone as far as to binge and vomit their food. The child's eating behaviors have affected relationships with family and friends as well as badly affected their schoolwork.

How would you categorize this child?

- Severe eating problems with unnecessary vomiting
- Problematic eating behaviors with excessive dieting
- Problem with how they see their own body, that has affected other various parts of his/her life

QUESTIONS:

1. What other behaviors should parents be on the lookout for?
2. What is the best way to identify mental health problems in children without labeling or profiling the child?
3. How could we make these messages culturally appropriate and understood within each target audience?
4. Should these mental health messages be used for very young children (ages 2-5)?

Questions Guiding Focus Groups' Discussion of Indicators for Children's Mental Health (Second Version)

1. Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.
2. Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.
3. Imagine a child that seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.
4. Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.
5. Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.
6. Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors have affected relationships with family, and have caused concerns at school and with friends.

QUESTIONS:

1. What other behaviors should parents be on the lookout for?
2. What is the best way to identify mental health problems in children without labeling or stigmatizing the child?
3. How could we make these messages culturally appropriate and understood within each target audience?
4. Should these mental health messages be used for very young children (ages 2-5)?

Other Possible Indicators

Potential Indicators (Based on Youth Reports)

- Nervous or uncomfortable in a group
- Often feeling nervous when in front of other people
- Getting very sick or upset when away from parents or attachment figures
- Afraid of the dark (9-17 year olds)
- Ever having a panic attack
- Afraid to go out of house for fear of panic attack
- Tense, difficult to relax
- Wetting self during day after age 5
- Thinking serious about killing self
- Hard to keep mind on things
- Stolen from others
- Lied to get money
- Broken into house, building, or car
- Expelled from school
- Getting into arguments with family/friends due to drinking
- Used marijuana 6 or more times
- Used cocaine/crack in past year
- Used Opiates in past year

Potential Indicators (Based on Parent Reports)

- 1) Getting very sick or upset when away from parents or attachment figures
- 2) Afraid of bridges or tunnels, or going out of the house alone (9-17 year olds)
- 3) Ever having a panic attack
- 4) Thinking seriously about killing self
- 5) Belief that one has special powers or abilities
- 6) Often cannot do things that require attention
- 7) Hard to keep mind on things
- 8) Refuses to do what told to do by adults
- 9) Getting even by hurting or messing up people
- 10) Doing mean things on purpose
 - Lied to get money
- 11) Broken into house, building, or car

Questions Guiding Focus Groups' Discussion of Indicators for Children's Mental Health (Third Version)

1. Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.
2. Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.
3. Imagine a child that seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.
4. Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.
5. Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.
6. Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors have affected relationships with family, and have caused concerns at school and with friends.
7. Imagine a child that almost always seems restless and whose behavior has become "out of control." This behavior causes him/her to become involved in dangerous situations that may harm him/herself or others.
8. Imagine a child that has used illegal substances, such as heroin or PCP, more than six times during the past year.

Main Questions:

- Does this child need professional help?
- How would YOU say this indicator (specific wording)?
- Are we missing any other important indicators of children's mental health problems?

APPENDIX VII: SUMMARIES FROM FOCUS GROUPS

FOCUS GROUP NOTES
CHAMP Collaborative Board, Bronx, NY
May 22, 2002

Participants: 10 Parents

Main Questions: How would you say it? What are we missing?

- Depression Indicator
 - “Sadness” is a more appropriate word than depression
 - It is necessary to state the timing or length of the sadness
 - “Extreme” and “long term” are good ways to describe
 - Another thing to look for would be any changes in behavior, such as isolation or withdrawal

- Suicidal Indicator
 - The word “suicidal” is age sensitive (parents would not apply this word to younger children)
 - A child that always talks about death (but doesn’t necessarily seem sad) could be at risk

- Panic Indicator
 - Possible way to describe child would be “extreme fear for no good reason”
 - Another description is “frozen,” as if they are trying not to die at that moment
 - “Anxiety attack” is a more commonly used phrase
 - One symptom of the panic could be that the child thinks he/she is going “crazy”

- Aggression Indicator
 - “Extreme physical aggression, almost always angry”
 - Child is unable to stop fighting, and in need of help
 - The biggest problem for the parent would be to decipher between what is a discipline problem and what is actually a mental health issue

- Eating Behavior Indicator
 - These children should be described by what is missing, not by what they have done. In other words, parents and/or friends may not be aware of certain behaviors, such as vomiting, but they could notice missing meals.

- Major warning signs: lying about eating, refusing to eat, hiding food, and/or constant extreme weight loss
 - Since dieting is so common with teenagers, the requirements must be extreme (multiple behaviors trigger need for service)
-
- Final Thoughts
 - A “checklist” format may be most appropriate for parents
 - When asked to describe a news segment regarding this information, parents said the best way would be:
 - “Your Child’s Health: Healthy Body and Healthy Mind. Both are equally important – here are some health issues that parents should know about, etc. If your child has shown any of these behaviors, help is available, and you are not alone.

FOCUS GROUP NOTES**Potomac Ridge Behavioral Health, Rockville, MD****May 28, 2002****Participants: 15 Parents****Main Questions: How would you say it? What are we missing?**

1. Depression Indicator:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- Sadness does not communicate the severity, need to say “extreme sadness or depression that doesn’t go away”
- “Extreme mood changes” also works.
- Its not just sadness its withdrawing from life from activities

2. Suicide Indicator:

Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- “Tried to kill himself, ”
- “A child that does not want to live and tries to hurt himself”
- “Wants to hurt himself”

3. Anxiety Indicator:

Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- “A child that withdraws because he/she is scared”
- “Extreme social withdrawal”
- “Shunned by peers”

4. Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- “Just a panic attack,” is something you would say to reassure someone!
- “Physiological attack of heart pounding intensity and shortness of breath”

- “No apparent reason,” OR “out of proportion to the situation.”
- “For no good reason.”

5. Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- “Frequently starts fights and reacts aggressively”
- The teachers need help with this they see it as a disciplinary problem. Zero Tolerance Policy
- “Unprovoked severe aggression”
- “Unpredictable unprovoked violence”

6. Eating Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child’s eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

- This is more accepted but also there is more publicity about the problem on TV and in papers
- Need to use modifiers “extreme” or “severe” to distinguish from socially accepted forms of dieting
- The new “00” sizes and the increasing desire to be very thin

7. Other Indicators to Consider:

- Extreme social withdrawal
- Inability to have or keep friends
- Shunned by peers -- extreme rejection by peers
- Extreme mood swings

8. How to sell message

- Parents still feel blamed
- Frame within overall good health including Mental Health
- No fault disorders
- Comic strip depictions
- Have a child with mental illness act as spokesperson
- Use celebrities who have Mental Illness or have children with Mental Illness

FOCUS GROUP NOTES**Potomac Ridge Behavioral Health, Rockville, MD****May 29, 2002****Participants: 5 Parents****Main Questions: How would you say it? What are we missing?**

1) Depression Indicator:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- If it is from the parent's perspective, can not say "child who feels sad" – instead say "child who is sad."
- Kids may show disinterest or detachment instead of sadness.
- "Unhappy" may be a better word than sadness because it can also denote anger.
- Problem with "unhappy" is that it is not severe, and it is common among teenagers.
- Instead of "severe" sadness, might be better to say "persistent," especially because children can show different emotions in different environments.
- Final thought: "Persistent sadness that doesn't go away and affects the child's life."

2) Suicide Indicator:

Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- Talks about hurting or killing themselves
- A child that says that he/she doesn't want to live anymore
- A child that writes suicidal notes—that could be more serious than just talking
- Any act of self-mutilation could indicate suicidal behavior.
- Final thought: "Tried to hurt or kill himself, and doesn't seem to want to live anymore."

3) Anxiety Indicator:

Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- Children that avoid doing things that they are supposed to do
- Extreme fear or worries
- If the anxiety or fear is debilitating to the child's life
- Final thought: "Extreme worries or fears that prevents the child from doing things that he/she needs or should do (things that their peers do)."

4) Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- Unreasonable panic out of the blue
- Eminent fear that you're going to die
- A specific sudden episode of overwhelming fear
- Use of the word "panic" should be avoided
- The attack could be triggered but is nothing to be panicked about
- Final thought: "Sudden, overwhelming sense of fear for no apparent reason, which could be associated with physical symptoms including a racing heartbeat and shortness of breath."

5) Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- Main issue is clarifying to the parents that this could be a mental disorder
- Severe aggression instead of just fights
- Could be described as outbursts, physical aggression, and/or acting out
- Persistent physical or verbal outbursts
- Final thought -- this indicator could be split into two:
 - "Frequent and severe lost of control that harms or threatens to harm others or self."
 - "Initiates multiple fights in the last year, with and without the use of weapons."

6) Eating Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

- Extreme preoccupation with food, body image, and losing weight
- Determined or obsessed with losing weight
- Include behaviors such as vomiting, bingeing, or using laxatives which could stand alone as indicators
- Final thought -- this indicator could be split into two:
 - “Extreme preoccupation with food, body image, and losing weight” AND/OR
 - “Vomiting, bingeing, or using laxatives.”

7) Other Indicators to Consider:

- Can not make or maintain friendships
- Rejected and unable to make relationships with peers
- Change in personality or behavior

FOCUS GROUP NOTES**Hommocks Middle School, Mamaroneck, NY****June 3, 2002****Participants: 8 Teachers****Main Questions: How would you say it? What are we missing?**

1. Depression Indicator:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- Must include a time limit (a.k.a. 2 weeks or longer)
- Vacant expression, extreme tiredness, lethargic
- Persistent sadness, hopelessness
- Disconnected, detached
- Loss of interest in friends/hobbies
- Final thought: “Extreme sadness and/or emotional detachment”

2. Suicide Indicator:

Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- Harming themselves (such as through cutting) to release their inner pain
- Does not have to be a suicidal attempt to warrant attention
- Final thought: “Wanting to harm and/or kill yourself”

3. Anxiety Indicator:

Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- This indicator is too general
- Anxiety is not a good word to use
- Isolation, loss of interest in activities
- Extreme fear or worries
- Final thought: “Extreme fear that interferes with daily activities”

4. Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- Incapacitating fear
- Unable to function
- Unable to rationally reason with oneself
- Overwhelming fear which could lead to physical symptoms such as a racing heart and/or shortness of breathe
- Final thought: “Sudden overwhelming fear for no apparent reason - that could be accompanied physical symptoms (a rapid heartbeat, shortness of breathe, etc.)”

5. Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- Desire to harm others
- Uncontrolled anger
- Not necessary to have impairment part of indicator
- Split this into two indicators:
 - i. “Frequently starts fights and has a desire to harm others”
 - ii. “Lost of control with unrestrained anger”

6. Eating Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child’s eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

- Excessive interest in food, exercise, and weight loss
- Dramatic weight loss
- Must account for the fact that bingers are not necessarily thin
- Any vomiting and/or laxative use
- Obsessive behavior that endangers one’s health
- Split this into two indicators:
 - i. “Vomiting and/or using laxatives to lose weight”
 - ii. “Obsession with food, exercise, and/or weight loss that endangers one’s health”

7. Other Comments:

- Use different formats for different audiences (for example, one-liners for parents, cartoon images for children)
- Cartoons could be drawn by the children themselves, with several images for each indicator
- Story format is a good way to catch people's attention
- Skits/acting is not a good format because children tend to not take it seriously
- A good way to present would be a poster format that teachers could explain to the children and post in their classrooms
- Should be presented as "Healthy physically, healthy emotionally"
- Need to stress that if anyone has these symptoms or has a friend that does, get help (tell a teacher or counselor)
- Also stress that it's OKAY to get help, you are not alone
- A powerful technique would be to show the statistics of these disorders (a.k.a. "you're not one in a million, you're one in four.")

FOCUS GROUP NOTES**Mamaroneck High School, Mamaroneck, NY****June 5, 2002****Participants: 17 Teachers****Main Questions: Do these children need services? How would you say it? And what are we missing?**

1) Depression Indicator:

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- Sudden change in behavior that persists
- Does not have to be a change in behavior – could be persistence
- Other symptoms include apathy, tiredness, and withdrawal
- Child could also be excessively happy for no apparent reason
- Teachers are most likely to see apathy rather than sadness – it is more socially acceptable
- An important problem is deciphering between the internal (ex. sadness) and external (ex. tiredness) symptoms.
- For impairment, should also include that the “sadness” affects activities that they normally like, such as being in the school play
- “Extreme mood change that continues”

2) Suicide Indicator:

Imagine a child who has expressed a specific plan of how they would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- This is a no-brainer – child definitely needs some professional help
- Seems happy all of a sudden for no apparent reason
- Should look for pre-suicidal behavior, such as harming oneself
- Some teachers liked the word “kill” since it was upfront and strong, but others thought that this word may scared other parents/teachers away
- Most agreed that “kill” was better than “suicide”
- Look out for children that talk frequently about methods of suicide
- “Cutting” is very common with adolescents – and those that cut repeatedly with the intention to hurt themselves should be seen professionally

3) Anxiety Indicator:

Imagine a child whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition,

these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- Should separate “school phobia” – the children that are too scared to even show up to school
- These symptoms are more noticeable at home than at school
- This indicator is too general – includes too many children (anxiety is normal for teenagers)
- Must be extreme to warrant attention – with inclusion of impairment
- “Severe anxiety inappropriate to the situation”
- Parents are often unsure of what is “normal”
- Must note that children behave differently in different environments

4) Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- Immobilizing
- “Panic attack” is a good term and understood by teachers
- Should include the length of time (a.k.a. 10 minutes)
- “Physiologic panic attack lasting (time limit) that comes out of the blue”

5) Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- This child will get attention because of the nature of the illness, however he/she will usually not be considered mentally unhealthy
- As in the history of alcohol abuse, society needs to change from punishing these aggressors to helping them
- Inappropriate, out of control, persistent anger
- Child does not necessarily have to start the fight
- Victims should also be watched, but must be careful not to stigmatize
- No fear of authority
- No control internally or externally

6) Eating Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

- Need to stress the possible results of this behavior (such as death)
- This could easily go unrecognized by adults for various reasons (parents don't want to see it, child is very secretive)
- No longer are children covering it up with big clothing – in fact, the style is to show off their skinniness, being thin is popular
- Look for excessive exercise
- Look for use of laxatives, diet pills, and dangerous new herbal products
- Look for change in diet or eating behavior
- Look for frequent bathroom use immediately after meals
- Preoccupation with body image, food, exercise, and weight
- Important to keep in mind that overweight children also have eating disorders
- This is a control issue – everything revolves around food

7) Additional Comments:

- Other indicators to consider:
 - Substance abuse
 - Isolated, unable to make friendships
 - Change in sleeping habits
 - Inappropriate sexual behavior
 - Mania
- Very important to recognize cultural appropriateness
 - Examples
 - one generalization is that it will be harder for white parents to recognize eating disorders because many have them themselves
 - Europeans have a harder time recognizing alcohol abuse
- Very important to recognize economic affects on these indicators
 - Examples
 - One generalization is that rich parents feel the need to have “perfect” children, and place this extreme pressure on their kids
 - Parents with less money may have less time to notice this mental health indicators
- Illustrating examples of children that exhibit these indicators, such as with cartoon images, is a good way to catch people's attention.

FOCUS GROUP NOTES

Mamaroneck High School, Mamaroneck, NY

June 12, 2002

Participants: 14 Students

Main Questions: Do these adolescents need services? How would you say it? And what are we missing?

1) Depression Indicator:

Imagine a friend who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork or after school activities.

Comments:

- Withdrawal, distant
- Change in lifestyle and behaviors (i.e. quit job, drinking, overly cleanly)
- Depressed, not happy with oneself
- Should take notice when you think they could endanger their life
- There are different signs for different people

2) Suicidal Indicator:

Imagine a friend who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- All commented that this person needed professional help, but then many knew of friends that had attempted suicide and did not go into service (they did not tell adults of attempt)
- Suicide and kill both work for the language
- “Cutters” are “psycho” and need immediate help, but piercers are normal
- Many would go consult other friends about someone in trouble, rather than tell adults, in case it’s not serious
- Children felt that they could tell how serious a situation was for a friend
- Some feel that telling an adult will not necessarily help

3) Anxiety Indicator:

Imagine a friend whom seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the person from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- Very quiet
- Don’t like themselves
- Want to be accepted

4) Panic Indicator:

Imagine a friend that, at certain times, has been very panicked or frightened, expressing physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- Frequency of attacks dictates whether they should be in service
- Panic is like “stress,” very common among teenagers

5) Aggression Indicator:

Imagine a friend that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- These people need anger management, not necessarily mental health treatment
- Hostile, mad at the world
- Wants attention
- These friends may need mental health treatment AND discipline from cops

6) Eating Indicator:

Imagine a friend that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further the weight loss. This person’s eating behaviors have affected relationships with family, and have caused concerns at school and with friends.

Comments:

- The children need professional help
- Uncomfortable with self
- Doesn’t have to be dramatic weight loss

7) Other Comments:

- Mental health issues are stigmatized because children “do it to themselves”
- Higher sensitivity to cutting than suicide attempt
- Poor communication between parents/teachers and children
- Parents are likely to over or under react
- Ambivalence over whether people who attempt suicide need to be seen
- Ambivalence over what friends should do in that situation
- Distrust of mental health professionals
- Many suicidal attempts never came to adult’s attention
- Children can avoid parents and teachers...attempts can go unnoticed

FOCUS GROUP NOTES

Parents from Washington Heights, New York

July 1, 2002

Participants: 12 Parents

Main Questions: Are these serious? How would you say it? What are we missing?

- **Depression Indicator:**

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- This problem definitely deserves medical attention
- Sudden change in personality
- Know it's a problem when hear it from different sources (even if it's not a sudden change)
- After two weeks of sadness, would turn to services if child doesn't open up to parents
- Time period is not definite – things can creep up on you
- Final thought: "Unusually sad for a long time"

- **Suicide Indicator:**

Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- Definitely needs to be seen by professional
- This is always serious regardless of the age
- Some children would express the idea that they wished they were dead – but this is not necessarily true with young children
- Any plan or attempt is a definite indicator
- Verbally saying it could be enough also, even if it is a cry for help (better to be safe than sorry)

- **Anxiety Indicator:**

Imagine a child who seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- In extreme cases this warrants professional help

- Child that keeps to himself
 - Overly clingy for an extended period of time
 - Child in terror – terrified look – that prevents him/her from doing things they normally would
 - Extreme nervousness when not appropriate (for no good reason)
- Panic Indicator:

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

 - Sudden, extreme anxiety
 - Mind blurs, skin is cold, heart races, blood pressure changes
 - Final thought: “Sudden feeling of overwhelming fear accompanied by racing heart”
- Aggression Indicator:

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

 - Constant/frequent excessive unprovoked fighting
 - Bullying and intimidation
 - Extreme hyperactivity and out of control behavior
- Eating Indicator:

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child’s eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

 - This condition is very severe and needs immediate help
 - Any vomiting or laxative use stands alone as an indicator
- Other Comments:
 - All indicators have common elements:
 - Inappropriate behavior for your child
 - Extreme behavior

- Happens over a long period of time
- Unusual for the situation
- Inability to register sadness or anger when there is reason (ex. laughing when things are not funny)
- Unusual appetite, sleep patterns, or bowel movement patterns
- How to present:
 - Don't ask what is wrong – ask if there is some way to help
 - Would child's life be easier if he/she did not have these issues?
 - Change child's life for the better
 - Illustrate happy well-adjusted kids (instead of depressed kids)

FOCUS GROUP NOTES

Preschool Teachers from New York, New York

October 15, 2002

Participants: 8 Teachers

Main Questions: Are these serious? How would you say it? What are we missing?

• *Depression Indicator:*

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

Comments:

- Withdrawn
- Unable to be engaged – young children are not interested in grown-ups, toys, or other children
- “Sad” – not a good word, not all children are sad when they are depressed, in fact many have a “lack of emotion”
- “Miserable” or “hopeless” may be better descriptors than sad.
- “Two weeks” is a problem phrase – too specific
- Sustained mood change

• *Suicide Indicator:*

Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.

Comments:

- Suicide is very rare in young children
- Many kids say “I’m going to kill you”
- For young children, death is not a reality or an end

• *Anxiety Indicator:*

Imagine a child who seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

Comments:

- This is a serious problem, even with young children, although it depends on the degree of severity
- Kids can go through phases that don’t necessarily need help
- Parents usually do not take the anxiety seriously – they are resistant because of fears:

- Fear of medication
- Fear of being blamed for problem
- Parents do not understand what treatment interventions for young children consist of – they are afraid that it will go on the child's permanent record
- This indicator could be divided into two for young kids:
 - Social Phobia
 - General Anxiety

- *Panic Indicator:*

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath.

Comments:

- Very rare with young children
- If anything, they have different anxiety symptoms – shivering or biting
- Racing heartbeat is so common with little kids

- *Aggression Indicator:*

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

Comments:

- Common behavior in boys
- A mental health issue when there is no remorse for the violence or harm caused – or the child is oblivious to having caused havoc

- *Eating Indicator:*

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child's eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

Comments:

- Not very applicable to younger children
- More of a parent issue than child issue – want extreme control over food intake – important that we address parents on this issue
- Early awareness of bodily image – as early as 3 years old

- *ADHD Indicator:*

Imagine a child that almost always seems restless and whose behavior has become “out of control.” This behavior causes him/her to become involved in dangerous situations that may harm him/herself or others.

Comments:

- Parents are very aware of this disorder – and look for it since there is no guilt (not their fault) and it can be easily remedied (with medication)
- Teachers look to see if there is anything that will engage the child
- Sometimes more “tuned out” than hyperactive
- Schools are unlikely to make ADHD diagnosis, although it starts as early as Preschool
- For kids that are diagnosed, it’s hard to find the right med dosage – and once they do, it will need to be readjusted after a period of time

- *Substance Use Indicator:*

Imagine a child that has used illegal substances, such as heroin or PCP, more than six times during the past year.

Comments:

- Not applicable to young children

- *Other Comments:*

- Our chosen indicators are common in young children – not a problem unless persists for long period – all children go through phases
- Recap of chosen indicators:
 - Depression seen as withdrawal more than sadness, unable to engage, need to make sure it persists for long period of time because all kids go through phases
 - Suicide is not common in little kids
 - Anxiety, especially social phobia, is a serious problem with young children that most parents do not take seriously because of various fears
 - Panic is not common in young children
 - Aggression is very common with young children especially boys, needs to be taken seriously when there is a lack of remorse
 - Eating disorders are not common in younger children, more of an issue for parents and their need to control
 - ADHD is well known among parents, and received well. Teachers are unlikely to push a diagnosis. It could be seen more as “tuned out” than hyperactivity
 - Substance use does not occur with young children
- Other more obvious indicators at a young age:
 - Hurtful with no remorse

- Inability to relate to anyone
- “Parallelizing shyness”
- Indicator is children do not respond cognitively and emotionally
- Stigma is a major problem with young children
 - Parents resistant to labeling child with “mental health” problem
 - Do not understand that every child would benefit from an intervention – a “tune-up” - need to reassure parents that their child is going through a stage but need to work at it
- Teachers are very good at distinguishing what is a problem and what is just a phase
 - See the child interacting in different environments
 - More objective than parents
 - Observe over a period of time
 - “Teachers are the indicators at this age”

FOCUS GROUP NOTES**Pediatric Residents from Mount Sinai Adolescent Health Center, NY, NY**
October 18, 2002**Participants: 8 Residents****Main Questions: Are these serious? How would you say it? What are we missing?****.1. Depression Indicator:**

Imagine a child who feels very sad almost every day for at least 2 weeks or longer, and whose sadness gets in the way of their relationships with family and friends, as well as affects their schoolwork.

- Many agreed that they needed more information about the child's life events, for example, a death in the family, or another reason for sadness. According to the indicators in #1, they were not sure they would refer the child for professional help.
- The group wanted a specific definition of "professional help". Larry asked them to think of it as the next step of psychological assessment. Given that this particular group is very psychologically oriented, they might consider the next step to just be extra sessions with them (the pediatrician).
- One argument was that the child's psychological stage (early, mid-, or late adolescent) would make a difference in the decision to refer. But in and of itself, #1 would not be enough to grounds to make a referral.
- There was a lot of concern about how mental problems, depression in particular, could be missed in adolescents because of how the general public attributes certain behaviors to "normal" adolescent development.
- When asked specifically how they would change the wording of #1, many agreed that the length of time that the child showed depressed behavior would have to be longer than 2 weeks. The group agreed that "more than 2 weeks" would constitute a definite problem and not a stage.
- Some suggested that an acute behavior change should be measured in something like "loss of interest in activities". Others added that an emphasis should be placed on the child's relationships with his/her friends as opposed to the family. Adolescents tend to rely on their friends whereas family problems are not uncommon.
- Others suggested that "frequent crying" should be an indicator, although the pediatrician should expect that adolescent males might not readily admit to crying. Also, the inability to sleep was agreed on as a good indicator for depression.

- 2. *Suicide Indicator:*

Imagine a child who has expressed a specific plan of how he/she would like to kill themselves, or has actually attempted suicide at some point.

- The group in general thought that this was a “no-brainer”. But when asked about specific wording, they thought that doctors should be careful about using strong wording for suicide to prevent the child from retracting in fear of admitting his/her feelings. There was some disagreement on whether asking if a child “tries to hurt him/herself” was an adequate basis for suicide risk because a child may cut or bruise him/herself to get attention, but may not necessarily be making an attempt on his/her life. In general, the group agreed that there is a wide range of risk of self-injury. The wording “kill” is the strongest, but there should be other ways to determine potential harm.
- One suggestion was to have doctors ask general to more specific questions in order to make the child feel comfortable and to assess risk at the same time.

- 3. *Anxiety Indicator:*

Imagine a child who seems very anxious, afraid, and worrisome of social situations, other people, or being separated from his/her parents. In addition, these feelings have kept the child from doing things with family and friends, and have badly affected his/her schoolwork.

- Many in the group agreed that “school phobia” might be a more accurate indicator for children. Specifically the group suggested “not going to school”, “not socializing”, and “fear of going out” as indicators. One suggestion was to have attendance records as a more concrete indicator. Others suggested that questions about what the child does with his/her free time would be very useful.
- This led to some concern that doctors will not be the first to observe problems of social phobia in children because teachers and parents are more likely to see problems in school or at home. In general, the group felt that these indicators were not likely to be looked out for in the clinical setting.

- 4. *Panic Indicator:*

Imagine a child that has expressed symptoms of very panicked or frightened, along with physical symptoms of a racing heartbeat and shortness of breath

- The doctors unanimously agreed that these were indicators that they see often in the clinical setting because of the physical manifestations of the illness. They feel more experienced associating physical symptoms with panic attacks and referring children to a social worker or mental health professional for these problems.

- Problems they often see include “nausea, headache, unexplained cardiac problems, and GI problems”.
- They said that their patients often say “I couldn’t breathe” or “I thought I was going to die” when explaining a panic episode. Patients will often explain the events surrounding their panic attack, but not the anxiety they felt. Children in particular do not complain of “anxiety” as they are more likely to point out physical problems.
- In general, the group agreed that children who experience panic attacks would show concrete physical symptoms that are “non-medically based”. They feel these physical complaints can be differentiated from complaints associated with hypochondria because of the discrete physical change associated with panic attacks.

- 5. *Aggression Indicator:*

Imagine a child that has started multiple fights within the last year, with or without the use of weapons. These fights have caused serious problems at home, at school, and with peers.

- The group felt that being involved in fights was a strong enough indicator for aggression problems. Some felt that it was not necessary to include the second sentence of #5.
- The group added that it would be useful to include violence to pets/animals and property as an indicator.

- 6. *Eating Indicator:*

Imagine a child that has been trying to lose weight even though he/she is not overweight, and has gone as far as to binge and vomit his/her food, or use laxatives to further lose weight. The child’s eating behaviors has affected relationships with family, and has caused concerns at school and with friends.

- The group agreed that they were definitely on the lookout for indications of eating disorders in the clinical setting, but there was a lot of disagreement on how strong of an indicator should be used.
- On argument was that the second sentence is not needed if it was used to indicate severity. Some thought that to vomit after eating is enough for concern, even if it was done only 2 times, and they didn’t want to miss children using a “stronger” indicator.
- Other argued that to use “vomiting” as an indicator would lead to over-diagnosing children. (Note: most of the discussion was lead by eating disorders specialist, Dr. Stephen Sondike.) Specific indicators like “repeated vomiting”, “repeated use of laxatives”, and an “inappropriate body-image” all over “a period of time” were suggested.

- 7. *ADHD Indicator:*

Imagine a child that almost always seems restless and whose behavior has become “out of control.” This behavior causes him/her to become involved in dangerous situations that may harm him/herself or others.

 - The group suggested that indicators like “inability to stay in seat/keep still” and “excessive talking” during school as opposed to during playtime would be useful.
 - In general, the group thought that this indicator was “contextually inappropriate” as teachers are more likely to observe these problems.

- 8. *Substance Use Indicator:*

Imagine a child that has used illegal substances, such as heroin or PCP, more than six times during the past year.

 - Several people in the group felt that adolescent health professionals were more “liberal” and not too stringent in their referral system for drug problems. For example, if a child does well in school and at home and may smoke marijuana at parties would not be referred for a drug problem.
 - Some thought that the child’s development stage should be considered. Many adolescents go through an “experimental phase” that should not warrant a referral for drug problems.
 - Many agreed that indicators should be developed by substance. Each substance has different concerns and the context in which the drugs are used is important.
 - After the meeting, Dr. Stephen Sondike shared that he generally tries to observe a patient’s drug habits throughout many doctor visits before deciding whether or not to make a referral. When he observes drug use, he advises against it. He feels that the strongest indicator for a drug problem is when a child is unable to stop using the drug despite advice. “Failure to respond and improve after medical advice” is his personal indicator for a drug problem.
 - Regarding the referral system in general, Dr. Sondike explained that there is confidentiality regarding adolescent patients at Mt. Sinai. Parents are mostly not notified of drug-problems, pregnancy, or STD’s, for example. However, in private practice, it is difficult to maintain confidentiality if a child needs help outside of primary care. He feels that parents are a huge barrier to making referrals for adolescents.

APPENDIX VIII:
STAKEHOLDER FEEDBACK

Feedback from CHADD (Children and Adults with Attention Deficit Disorder)

From: DrCBJones@aol.com [mailto:DrCBJones@aol.com]
To: Clarke Ross
Date: 6/13/02 11:57PM
Subject: Re: Please Comment by July 3 - Surgeon General's Indicator's Project

Clarke

I am amazed by this document both in length and perception! As a diagnostician who daily works with students who are misdiagnosed and mistreated, I see a document of this magnitude being extremely helpful. Evaluators are looking for succinct guidelines with well documented theory. This seems to answer those needs. I know that we are often asked to endorse things at CHADD and I have been highly critical, as have others, of playing that role. This however is not a product but a guideline. I heartily add my endorsement to these statements.
 Clare B. Jones, Ph.D.

From: "Clarke Ross" <clarke_ross@chadd.org >
To: "Peter Jensen" <JensenP@childpsych.columbia.edu>
Date: 7/10/02 5:12PM
Subject: Child MH indicators

Dear Peter:

The CHADD board executive committee discussed the proposed child mental health indicators on last night's call. We appreciate learning of this needed initiative and being asked to review the draft indicators.

It is critically important for AD/HD indicators to be included in this document. Clearly, the original Surgeon General's report singled AD/HD out as a very important issue. Here are the suggestions for AD/HD indicators from our executive committee:

1. Extreme and persistent hyperactivity and/or impulsivity that impairs a child's functioning and/or puts him in physical danger.
2. Inability to sustain attention that significantly contributes to school failure measures, such as reading, written expression, or math.

We look forward to hearing if your project is able to include one or more common symptoms of AD/HD.

CHADD regrets that we can not endorse your indicator project until one or more of the most significant and common symptoms of AD/HD are included in the indicators.

Sincerely,

Chris Dendy and Clarke Ross on behalf of the CHADD board executive committee.

From: "Matthew D. Cohen" <mdcspedlaw@earthlink.net>
To: Clarke Ross <clarke_ross@chadd.org>

Date: 7/10/02 6:06PM
Subject: Re: Child MH Indicators: Initial CHADD Response

Folks-

I wonder if another important indicator would relate to a child's "academic behavior," such as whether the child demonstrates persistent and marked distractibility or inattentiveness, persistent inability to turn work in on time, persistent time management or tardiness problems, etc. I am concerned that the second indicators focuses excessively on measures of academic performance that are topic specific and may be assessed through standardized tests, without sufficient attention to the child's academic behavior. A child may be learning to do math, but be getting terrible math grades because of a failure to get math homework done and/or turned in. If we only assess the child's math skill, probably through an achievement test, and not the child's math performance in the classroom, we may also be missing an important area of need related to AD/HD.

Matt

From: "Chris Dendy" <chrisdendy@mindspring.com>
To: "Peter Jensen" <JensenP@childpsych.columbia.edu>
Date: 7/11/02 2:21PM
Subject: Child MH indicators

Hello Peter

Thanks to Matt Cohen's input we have further refined our second indicator. Here is some wording that he and I have developed.

2. Inability to sustain attention that significantly contributes to school failure: problems may be manifest in academic areas such as reading, written expression, math or study and organizational skills.

This wording may not be perfect but raises the major issues of concern.

Thanks for offering us this opportunity to provide input.

Regards,
Chris Dendy

Feedback from NAMI (National Alliance for the Mentally Ill)

From: "Darcy E. Gruttadaro" <darcyg@bellatlantic.net>
To: "Peter Jensen" <JensenP@child.cpmc.columbia.edu>
Date: 7/12/02 9:13PM
Subject: Re: indicators project

Peter,

Attached please find a document that contains the NAMI state and affiliate leader input and feed back on your indicators' project. I hope that 9:00 p.m. is still considered COB on Friday.

I hope that you find the information included in the enclosed document helpful. I think that there are some excellent comments. This is a terrific project and I am delighted that you included NAMI as one of the groups that you are involving in this project. As I indicate in the enclosed document, if you would like an official NAMI endorsement, then I will need to present this information to the NAMI BOD for its consideration at it's meeting in mid-September. Please let me know ASAP if that is something that you are interested in.

Thanks again.

Best,
Darcy

From: "Rick Birkel" <rick@nami.org>
To: Ron Honberg <ronh@nami.org>, Peter Jensen, <darcy@nami.org>
Date: 7/14/02 3:42PM
Subject: Re: Indicators Project

Darcy, Peter: I just finished reading the comments on the "indicators" project and was quite impressed with the excellent suggestions and insights here. I thought the parents did a great job.

Going forward, it would be helpful to have some guidance about the relation between formal screening programs (such as "Teen Screen") and a project such as this. Are these approaches compatible and interrelated, or alternative to one another? How do we advise our constituents in this regard?

After reading the comments from parents, I also want to make a few comments about the use of the term mental illness with children. Recognizing the long tradition among child advocates of emphasizing resiliency and protective factors, I understand how uncomfortable an illness model for this area can be. It does seem that NAMI families' experience leads them to emphasize biological over the environmental processes involved in kids' mental health. I suggest that we emphasize a strong "interactive" approach from the outset. Why not talk about "developmental, emotional, and psychological factors/indicators that may precede the development of serious mental illness". I think

it is important to recognize the concept of risk and to avoid any approach that may be perceived as biological determinism. On the other hand, NAMI families want to emphasize that for some children, "biological processes" are dramatic and overwhelm protective environmental processes. This is often the experience that brings people to NAMI.

In relation to ADHD. I would like to suggest that we help parents understand that learning and concentration problems in school are often associated with emotional problems and may indicate underlying illness processes as well. Unrecognized and untreated ADHD should be seen as a "co-traveler" with and predisposing factor for emotional and behavioral problems and potentially for mental illnesses. The important issue is to take it seriously and get supports, services and accommodations.

I hope these thoughts are helpful. This is an exciting project and I am thrilled that we are having this important discussion. Thanks.

Rick

Feedback from FFCMH
(The Federation of Families for Children's Mental Health)

October 10, 2002

Dear Peter:

I was pleased to see the Draft of Developing Mental Health Indicators for U.S. Children and Adolescents. We have been working on this project for some time and it is truly nice to see a product so well put together as this draft. It is a highly technical document that thoroughly described the process used and the deliberations of the project team and steering committee to date.

Families almost universally tell how they saw signs of their child's emotional disorder way before professionals were willing to take notice. Further, families frequently report that it took a long time – years in some cases – before an accurate diagnosis was made and effective treatments and supports provided. Clearly there is a great need for accurate and clear information to develop guidelines to correct these problems.

The goal of the indicators project is to make it possible to develop scientifically supported criteria to apply in the practice of identifying early warning signs of potentially serious emotional disturbances in children and adolescents. This information, when put into the hands of families, will contribute significantly their credibility when describing their child's emotional or behavioral problems to mental health and other professionals and seeking help for their child. The results of the indicators project will facilitate more accurate and earlier diagnosis and effective treatment for many, many children. In addition, its scientific accuracy can help reduce the stigma associated with mental health disorders and the shame and blame often experienced by families and children alike.

I am looking forward to further work with you on this important project. I am especially eager to see products that are readily understood by the general public and families can use to get appropriate help for their children at the earliest possible time.

Sincerely,

Barbara Huff, Executive Director

Feedback from AACAP
(American Academy of Child and Adolescent Psychiatry)

MEMORANDUM

TO: Virginia Q. Anthony, Executive Director, AACAP

FROM: James C. MacIntyre, M.D., Chairperson
Work Group on Consumer Issues

DATE: October 11, 2002

SUBJECT: **Child Mental Health “Warning Signs”/Indicators**

As requested, the Work Group on Consumer Issues has reviewed the draft indicators in the document, *“Developing Mental Health Indicators for U.S. Children and Adolescents”*. This draft was developed by the Center for the Advancement of Childrens Mental Health (CACMH) at Columbia University.

As you know, Peter Jensen, M.D., CACMH, asked for AACAP to review and give comments on the draft. He was also interested in feedback and comments on several specific issues/questions. The Work Group’s comments/feedback are in **bold**.

1. The appropriateness of the 12 selected draft indicators.

WGCI – 12 selected indicators are appropriate. General comment – These indicators represent a tremendous effort which has been done in a high quality manner.

2. Comments/edits on the actual wording of the 12 selected indicators (i.e. Is the language clear and parent/child friendly?).

WGCI – No suggested changes to wording.

3. Comments on the proposed approaches to presenting the indicators to various target audiences.

WGCI – In addition to proposed approaches, we suggest developing a website with the indicators as well as some public service announcements (videos) and “advertising” in printed media.

4. Identify any other “critical” indicators that should be added to the list.

WGCI – No suggested additional indicators.

I hope this is helpful to the Academy in formulating a response to Dr. Jensen. The Work Group appreciates the opportunity to participate in the review and development of this important initiative.

Feedback from NMHA
(National Mental Health Association)

From: Luanne Southern <lsouthern@nmha.org>
To: Peter Jensen <pj131@columbia.edu>
Date: 10/24/02 2:22PM
Subject: CMH Indicators Project

Dr. Jensen,

On behalf of Mike Faenza and myself here at the National Mental Health Association, I would like to commend you for the Children's Mental Health Indicators Project draft you sent to us several weeks ago. I noticed that you needed our information by October 15 so I am sorry this communication comes to you post due date.

I have read through the document and think it is wonderful! The only indicator that appeared to be missing is one that would include a loss of interest in social activities or friendships. As you know, the social aspects of development are essential as milestones for youth as they form social networks and establish interpersonal skills.

We are anticipating the release of this information and will utilize it as an effective means of informing the public about children's mental health as a prevention and public education strategy.

Thank you for contacting us. I am the new [as of June] Children's Mental Health, Prevention and Juvenile Justice Director. I moved here from Austin, TX after working 18 years in the public mental health system there in various capacities within the child, adolescent and family field.

Luanne Southern
(703) 837-4797

APPENDIX IX:
INDICATORS GUIDE: AN OVERVIEW

CHILD MENTAL HEALTH INDICATORS GUIDE: AN OVERVIEW

Background and Purpose: Despite well-documented levels of emotional and behavioral problems in the nation's youth, studies have repeatedly shown that youth with these problems are usually not identified and usually do not receive needed care. Stigma and lack of awareness likely contribute substantially to this problem.

To address these and other related problems, the Surgeon General issued a "call to action" in January 2001, and urged the development of a crisp set of warning signs or indicators that when present, warrant additional professional assistance. This document provides a brief summary of the initial phase (Phase I) of the indicators development process, and outlines future activities needed in subsequent project Phases II and III.

These indicators have been developed using rigorous research methods, as well as through the input of parents, doctors, teachers, and youth, so that they are worded in common-sense non-stigmatizing terms, yet still indicate significant emotional problems that should lead one to getting further professional input and possible help. Based on the extensive review and input of parents, educators, scientists, and providers, all of these indicator candidates have been rated using the following framework. Only candidates meeting at least level 2 are summarized below. Please note, 9 indicators meet the highest level of review (3), and an additional 3 indicators meet level 2.

| <u>Level</u> | <u>Description</u> |
|--------------|--|
| 1 = | Acknowledged psychological symptom or profile in standard texts, such as DSM listed symptom or behavior. Unclear whether language is interpretable or applicable across various stakeholders, settings, ethnic groups, gender, age. |
| 2 = | Level 1, plus: Language and understandability of specific terms have been vetted through multiple focus groups and stakeholders, including parents, teachers, providers, different ethnic groups, etc. Widespread agreement that each indicator conveys a severe, face-valid, widely recognized behavior that should warrant further evaluation and possible intervention. |
| 3 = | Levels 1 and 2, plus: indicator examined in multiple epidemiologic (community based, non-referred sample) data sets, and frequency determined to approximate 1%, and be present across ethnic, gender, and age groups. In addition, most youth who have the indicator are not receiving services. Also, on average most youth who have one or more of the indicators meet criteria for a formal mental health diagnosis using established (DSM) diagnostic criteria. As a final scientific criterion, we specified that indicators should achieve a positive predictive value of >50%. Of note, we have been able to meet this objective, as <u>more than half of all children with any indicator, meet criteria for one or more DSM-IV diagnoses.</u> |

These indicators are not by any means exhaustive of all types of emotional and behavioral problems, but each by itself may represent a medically serious situation in need of further evaluation. Other types of emotional and behavioral problems are manifested by different symptom patterns, but are often not as easily recognized as these. It is hoped that this indicators guide will provide a framework for increased awareness of youths' mental health problem, decreased stigma, and increased access to appropriate services.

Additional candidate indicators will be reviewed in Phase II of the Indicators Project.

Indicators (Level 3).

- Extreme sadness and/or emotional withdrawal lasting 2 weeks or more
- Trying to seriously harm or kill oneself, or making plans to do so.
- Sudden overwhelming fear for no apparent reason, sometimes accompanied by racing heart and shortness of breath
- Starting frequent fights, using a weapon, and/or wanting to seriously hurt others
- Using laxatives or vomiting to make oneself lose weight
- Extreme preoccupation with body image, exercise and losing weight that endangers one's health
- Extreme worries or fears that interfere with friendships, school work, or play activities
- Persistent, severe inattention or hyperactivity that puts the child at risk for physical injury ("or school failure", pending additional analyses)
- Repeated use of illegal drugs

Additional Potential Indicators (Level 2) (pending future [Phase II analyses] to support their use)

- Frequent and severe explosive or out-of-control behavior that has harmed or threatens to harm others
- Severe mood swings affecting relationships with others
- Drastic changes in behavior or personality

Potential Use With Teachers. Teachers generally like the idea of a poster that could be placed in a classroom. This may be more workable for elementary school and middle school settings than in high school settings, where youth may have become somewhat openly skeptical and more likely to hold stigmatizing attitudes.

In addition, for teachers longer descriptions of each of the indicators should be provided, so that they are aware of other signs and symptoms of emotional and behavioral disturbances. In-service training meetings with teachers, possibly presenting a video of real youth with significant mental disorders, would be a useful means of presenting teachers additional information.

Teachers indicate that they want materials that they can present to youth. This could be in the form of lesson materials for a health class, or for younger children, story materials that present stories with characters that children can identify with, and where significant mental/emotional difficulties are presented.

Potential Use with Health Care Providers. Straightforward lists of the indicators can be provided on pocket-size cards that health care providers can carry with them. In addition, suggestions should be made how best to ask the questions of both a youth and a parent that are likely to facilitate open communication. Also, lists of resources, such as the names of screening tools proven to assist in identifying youth with significant emotional/behavioral disorders, should be provided. In addition, copies of actual screening tools may prove useful. With physicians, additional information on indicators can be provided, describing the various disorders each indicator is linked to, and a brief synopsis of available proven treatments.

Potential Use with Parents. For parents, as well as for children and youth, messages on mental health should avoid the word “mental” and use instead “emotional health” and “behavioral.” Messages about emotional health should be prefaced with positive messages about physical health, followed by positive messages about emotional health, and then by presenting warning signs.

Indicators should only be used if there exist resources where a parent can turn for additional help and advice, if they feel their child has one of the indicator signs. In addition, the SC is greatly concerned that indicators should be prospectively tested with various groups to ensure that the message and meanings intended with a given indicator are appropriately conveyed to the parent, and that the parent clearly understands what s/he should do if the child has one or more indicator signs.

Parents in particular may find short brochures with an indicator checklist useful, perhaps in pediatricians’ offices, accompanied by a suggestion that they talk with the doctor if they have questions or concerns.

Because parents will often not know what a teenager is feeling or thinking, special emphasis should be placed on indicators that the parent can observe. Parents should receive mental health messages in the context of “not blaming themselves,” as feelings of guilt can significantly deter a parent from seeking help.

For parents of younger children, public messages to parents to draw their awareness to potential emotional and/or behavioral problems should focus on positive messages about “school readiness”, perhaps listing the positive characteristics of a child who is “ready” for school, followed by what one should do if their child is experiencing behavioral and/or emotional difficulties.

Potential Use with Children and Youth. For children and youth, messages on mental health should avoid the word “mental” and use instead “emotional” and “behavioral.” Messages about emotional health should be prefaced with positive messages about

physical health, followed by positive messages about emotional health, and then by presenting warning signs.

As a vehicle to communicate content to youth, cartoon images, such as Calvin and Hobbs, youth-to-youth video messages, or messages from a well-known teen idol may be most appropriate. With youth in particular it should be stressed,

“Healthy body, healthy mind” or other such messages. For youth who may receive indicator messages and apply them to themselves, it may be useful to indicate:

“You are not alone.”

“You are not one in a million, you are one in five.”

“Get help, it works.”

Actual contact information should be provided. For younger children, a story format may be a useful way to communicate this information, and a simple list of indicators is less likely to prove useful.

Phases II and III.

The Steering Committee strongly recommends that the indicators should be prospectively tested during subsequent project phases with youth, parent, and other groups to ensure that the message and meanings intended with a given indicator are appropriately conveyed to the youth, that it does not increase stigma or is used pejoratively, etc. These additional activities are listed below in roughly the chronological order that they should be accomplished:

Phase II.

- *Additional Data Sets.* Examine the extent to which each of the indicators can be identified in additional data sets, and the extent to which these indicators characterize children most often not receiving needed mental health services.
- *Publications.* Scientific papers for publication in professional journals based on analyses conducted in Phase I.
- *Additional Focus Groups.* Additional focus groups should be conducted involving pediatricians, high-risk parents, and others.
- *Preliminary Practical Testing.* Begin testing by introducing selected indicator(s) in a pediatric setting, to determine how pediatricians use the indicator(s), how parents understand indicators, how well the indicators function in case-finding against clinical diagnosis, how clinicians, parents, and youth respond when an indicator is positive, etc.

Phase III.

- *Expanded Prospective Testing.* After initial testing (as described above) clarifies modalities for applying the indicators, each of the indicators should be tested with other major target audiences. to determine if they are understood

and applied appropriately, and how well they identify or characterize children or youth with significant mental health needs.

- *Develop Dissemination Tools and Materials.* After field-testing has established the most useful ways of utilizing these indicators, tools and materials will be developed that are specific to the major professional and advocacy organizations that are likely to apply the indicators. Such tools might include the following:
 - For Advocacy Organizations:
 - Briefing kits for presenting the indicators and related stories to local media, business, etc. (slides, videotape with youth and parent telling their own personal story how the illness affected the youth, handouts)
 - Carefully vetted text that can accompany the indicators if more information is desired
 - Recommendations/suggestions for further spread and use of the indicators
 - For Health Professional Organizations
 - Training materials for presentation at annual meetings
 - Speakers bureau of experts who can speak about the indicators to primary care providers
 - Materials to assist the health professional in his/her practice, such as screening checklists, office brochures, pocket cards with indicators and appropriate interview questions, etc.
 - For Educational Organizations
 - Training materials for presentation at teacher in-service and other meetings (videotape, handouts, etc.)
 - Speakers bureau of experts who can speak about the indicators to teachers students
 - Materials to assist the educator in the classroom, such as posters, lesson materials, tailored to different age groups.
- *Support Technical Assistance Capacity to Serve Organizations/Persons Using Indicators.* A clearing house and technical assistance capacity should be established to provide camera-ready copies of materials for use by selected groups, background text for reporters, videotape for “B-roll” for persons seeking to develop television programs, and possibly, a Video News Release at the time the indicators are formally launched. This clearing house should also provide a web site, where indicator materials are available for downloading off the web, where additional requests for information can be received, and where lists of contacts and additional resources for persons seeking professional assistance for their youth can be obtained.

In addition to providing the appropriate materials, this same technical assistance center should be able to provide end users advice and suggestions how they can best utilize finally agreed-upon indicators, as well as what actions end-users of indicators should take to address concerns that arise.