



*Planting the Seeds for Future Research*

# The Tuberculosis Behavioral and Social Science Research Forum Proceedings



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**Tuberculosis Behavioral and Social Science Research Forum:**

*Planting the Seeds for Future Research*

Atlanta, GA

December 10-11, 2003

**PROCEEDINGS**

Forum Proceedings prepared by the  
Communications, Education, and Behavioral Studies Branch  
Clinical and Health Systems Research Branch  
Division of Tuberculosis Elimination  
Centers for Disease Control and Prevention

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For more information about the CDC DTBE Forum,  
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March 1, 2005

Dear Colleague:

In December 2003, the Division of Tuberculosis Elimination (DTBE), National Center for HIV, STD and TB Prevention (NCHSTP), Centers for Disease Control and Prevention (CDC) convened The Tuberculosis Behavioral and Social Science Research Forum in Atlanta, Georgia. The theme was *Planting the Seeds for Future Research*. The goals of the Forum were to identify and prioritize TB behavioral and social science research gaps; to use that information to develop a feasible, goal-oriented research agenda that will guide TB behavioral and social science activities over a 5-year period; and to foster productive partnerships and ongoing communications between national, state, and local governmental and nongovernmental behavioral and social science researchers focusing on tuberculosis (TB).

The Forum brought together over 60 academicians, researchers, TB controllers and program staff, and CDC representatives. The expectation was that their varied perspectives would contribute to the development of a research agenda addressing high priority behavioral and social aspects of TB prevention and control.

The Forum was convened to address the need for further TB behavioral and social science research, as called for in the Institute of Medicine's 2000 report *Ending Neglect: The Elimination of Tuberculosis in the United States*. The Forum builds on the precedent of a 1994 workshop sponsored by CDC, the National Institutes of Health, and the Health Resources and Services Administration, *Tuberculosis and Behavior: National Workshop on Research for the 21<sup>st</sup> Century*.

Behavioral and social science research has the potential to make a tremendous impact on efforts to prevent and control the spread of TB. This research is needed to understand the behaviors of both patients and providers, and the impact of their actions on TB-related care seeking, diagnosis, treatment success, and prevention. In addition, health care service delivery and systems research are needed to address the structure and organization of health systems as well as the environmental, economic, and sociopolitical issues and laws that impact the delivery of TB services.

Progress has been made at CDC in incorporating behavioral and social science perspectives into TB prevention and control; however, there is still much work to be done in this area. At CDC and elsewhere, behavioral and social scientists are currently engaged in research addressing a broad range of relevant sociocultural, behavioral, and structural issues. Further research should be conducted in a systematic manner, based on sound theories and using rigorous methodologies.

DTBE is pleased to share with you the proceedings from the Forum. We hope that you will find the information of interest as you plan future behavioral and social science research and programmatic activities in your work addressing TB prevention and control.

If you have any specific questions or comments regarding the Forum or the Forum Proceedings, please join the TB Behavioral Science listserv at the following address:  
[http://cdcnpin.org/scripts/tb\\_behavioral\\_science.asp](http://cdcnpin.org/scripts/tb_behavioral_science.asp).

Sincerely,

Kenneth G. Castro, M.D.  
Assistant Surgeon General, USPHS  
Director  
Division of Tuberculosis Elimination  
National Center for HIV, STD, and TB Prevention  
Centers for Disease Control and Prevention

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## Executive Summary

In December 2003, the U.S. Centers for Disease Control and Prevention (CDC), Division of Tuberculosis Elimination (DTBE) convened the TB Behavioral and Social Science Research Forum: *Planting the Seeds for Future Research*. The Forum's overarching goal was to identify and prioritize TB behavioral and social science research needs, which will be used to develop a research agenda for TB prevention, control, and treatment. These Forum Proceedings include summaries of presentations and discussions, as well as a synthesis of research needs and priorities identified by attendees.

Forum presentations addressed behavioral and social science research in TB, including CDC's current research activities in these disciplines. Dr. Jessica Ogden and Dr. Masae Kawamura delivered keynote addresses on the role of behavioral and social sciences in TB control, and how research can improve TB treatment and control programs. Other speakers presented specific research findings addressing cultural, social, and environmental influences on TB education and patient adherence to treatment. A panel of patients and providers described their firsthand experiences with local TB programs. In addition, a panel of scientists described strategies to disseminate and translate research findings into practice.

The Forum included breakout sessions for participants to identify needs and priorities for TB behavioral and social science research. Section III of the Forum Proceedings is a compilation of the results of the breakout sessions. The identified topics, subtopics, methodologies, and research questions have been organized using five broad levels of influence based on a socio-ecological framework. The five broad levels, along with a few examples, are listed below:

- ***Intrapersonal:*** patients' knowledge, attitudes, and perceptions (KAP); health-seeking behaviors; acceptance of and adherence to treatment; patient satisfaction; social stigma; and providers' KAP, training, and practices
- ***Interpersonal:*** communication between patients and providers; family and peer influences
- ***Health systems and organizations:*** organizational structure (including collaboration between provider communities and systems; impact of sharing patient information); service delivery; contact investigations; health communications; and special challenges of high risk settings and populations
- ***Community:*** impact of TB services on communities and patients
- ***Public policy:*** government commitment and funding; health insurance and immigration policies

Forum participants' presentations and discussions reaffirmed the ongoing need for behavioral and social science research to improve TB prevention and control. It is CDC's hope that the Forum Proceedings will be widely used to plan future behavioral and social science research and programmatic activities to enhance TB prevention and control.

The Forum Proceedings document is divided into four main sections:

**Section I: Introduction and Background**

- Introduction
- Background information on TB behavioral and social science research

**Section II: Presentations and Panel Discussions**

- Summaries of Forum presentations and panel discussions

**Section III: Results of Breakout Group Sessions**

- Identification of TB behavioral and social science research gaps and needs
- Outline and descriptions of major TB behavioral and social science research topics and subtopics identified at the Forum

**Section IV: Appendices**

- Forum agenda
- Presentation slides
- List of major TB behavioral and social science research topics, subtopics, and questions
- Participant list
- References

# Section I. Introduction and Background

## Introduction

These proceedings summarize the presentations and discussions that took place during The Tuberculosis Behavioral and Social Sciences Research Forum: *Planting the Seeds for Future Research*, which was held in Atlanta, Georgia, on December 10-11, 2003. This meeting was built on the foundation of a previous workshop, *Tuberculosis and Behavior: National Workshop on Research for the 21<sup>st</sup> Century*, held in Bethesda, Maryland in 1994. Plans for holding a second workshop emerged largely in response to renewed calls for further TB behavioral science research. Specifically, the Institute of Medicine's (IOM) 2000 report *Ending Neglect: The Elimination of Tuberculosis in the United States* identified the need for further behavioral and social science research in TB control and treatment. The IOM report included the following: "Recommendation 5.3. To promote better understanding of patient and provider nonadherence with tuberculosis recommendations and guidelines, a plan for a behavioral and social science research agenda should be developed and implemented" (IOM 2000 report, page 123). The Forum provided an excellent and timely opportunity to revisit the behavioral science issues raised during the 1994 workshop.

The goals of the Forum were to provide participants an opportunity to

- Identify and prioritize TB behavioral and social science research gaps;
- Develop a feasible, goal-oriented research agenda that will guide TB behavioral and social science activities;
- Establish an ongoing partnership among national, state, and local governmental and non-governmental behavioral and social science researchers focusing on TB; and
- Create a mechanism for ongoing communication among TB behavioral and social science researchers.

The Forum was designed to be an interactive "working meeting" and included presentations, panel discussions, and breakout sessions. The Forum brought together an interdisciplinary group of over 60 individuals involved or interested in TB behavioral and social science research, including academicians, researchers, contractors, TB program staff and patients, and staff from the National Center for HIV, STD, and TB Prevention, including many from the Division of Tuberculosis Elimination.

We hope that this document will be useful in several ways. It may be cited as a statement of the need for interdisciplinary research that includes the perspectives of the behavioral and social sciences. It may also inspire researchers to conduct studies to address the identified research gaps and needs, leading to improvements in TB treatment and control. It is also hoped that it will serve as a foundation for the development of a TB research agenda for the behavioral and social sciences. Finally, it will also serve as an important document confirming the important role that behavioral and social sciences play in TB prevention and control and reminding researchers and program staff alike that, although we are making progress toward the elimination of tuberculosis, we still have much to learn and improve upon before we arrive at that goal.

# **Background**

## **Behavioral and Social Sciences in Disease Prevention**

Behavioral, psychosocial, and socio-cultural factors related to lifestyle contribute to many of the major causes of morbidity and mortality in the United States (Schneiderman, et. al, 2001). The past 50 years have shown that to adequately address many health problems, social science theories and methodologies must be incorporated into the design of effective interventions and prevention activities. In fact, many of today's public health challenges require the utilization of behavioral and social science to address a wide range of health problems ranging from cardiovascular health, smoking, obesity, and unintentional injuries, to infectious diseases such as HIV/AIDS and TB.

The U.S. National Institutes of Health (NIH) defines behavioral and social sciences research as a large, multifaceted field, encompassing a wide array of disciplines. The field employs a variety of methodological approaches including surveys and questionnaires, interviews, randomized clinical trials, direct observation, descriptive methods, laboratory and field experiments, standardized tests, ethnography, and evaluation. Yet, behavioral and social sciences research is not restricted to a set of disciplines or methodological approaches. Instead, the field is defined by substantive areas of research that transcend disciplinary and methodological boundaries. In addition, several key cross-cutting themes characterize social and behavioral sciences research. These include an emphasis on theory-driven research; the search for general principles of behavioral and social functioning; the importance ascribed to a developmental, lifespan perspective; an emphasis on individual variation, and variation across socio-demographic categories such as gender, age, and socio-cultural status; and a focus on both the social and biological context of behavior (<http://obssr.od.nih.gov/funding/definition.html>).

Our understanding of public health problems, as well as our identification of ways to address them, is informed by the application of behavioral and social sciences. Behavioral and social science research plays a critical role in developing, implementing, and evaluating disease control and prevention programs. In particular, it is clear that health programs are more likely to be effective if they are based on a clear understanding of the targeted health behaviors and the environmental context in which they take place (Glanz et. al, 1990, Snider and Satcher, 1997). Further, social science research can contribute to a better understanding of how operational and infrastructural factors may impact the control or prevention of a health problem.

## **Behavioral and Social Science Research at CDC**

As a result of lessons learned over the past two decades, the CDC has expanded its focus from a traditional epidemiological and biomedical approach to one that increasingly incorporates the behavioral and social sciences. This shift is a recognition that the solutions to many of today's public health problems require the application of multi-disciplinary research focusing on behavioral, societal, and cultural factors of individuals, groups, organizations, as well as health systems. The application of behavioral and social sciences in the development, implementation, and assessment of prevention programs helps the public gain a better understanding of risk group characteristics in addition to the frequency, context, and determinants of risk behaviors (Snider and Satcher, 1997).

CDC has taken steps to integrate behavioral and social sciences into prevention activities throughout the agency resulting in programs that vary by organizational setting and substantive focus. The incorporation of a behavioral and social science perspective into CDC's work can be seen in areas such as the development of surveillance systems, risk factor identification and determinants research, and intervention testing (Galavotti et. al, 1997). CDC has also realized the importance of establishing partnerships with other organizations, such as with professional societies including the American Psychological Association, the American Anthropological Association, and the American Sociological Association, to expand the role of behavioral and social sciences in co-sponsored educational activities (Snider and Satcher, 1997).

In addition, the expansion of CDC behavioral and social science activities can be further evidenced by the establishment in 1995 of a CDC Behavioral and Social Science Working Group (BSSWG), whose mission is to further the understanding and use of behavioral and social science at CDC, as well as to promote and ensure excellence in behavioral and social science research throughout the agency (Snider and Satcher, 1997).

### **Behavioral and Social Science Research in the National Center for HIV, STD, and TB Prevention (NCHSTP)**

Within CDC's National Center for HIV, STD and TB Prevention (NCHSTP), behavioral and social science research has become increasingly recognized as critical to the improvement of efforts to prevent and control these three public health areas. This is particularly true for HIV prevention, where behavioral interventions that seek to reduce risky behaviors offer the most commonly recommended methods to stem the epidemic. Transmission of HIV and other sexually transmitted diseases (STDs) have been reduced by applying effective behavioral interventions that address sexual and drug-using behaviors. Although tuberculosis' airborne mode of transmission places it in a different category from HIV and STD control in terms of behaviors that put people at risk and can thus be targeted for interventions, behavioral and social science research plays a crucial role in TB prevention and control. Due to the lengthy treatment regimen, the control of TB continues to be plagued by the persistent challenges associated with adherence to LTBI and TB medications. Acceptance of and adherence to lengthy treatment for the asymptomatic condition of LTBI further increase these challenges.

The 2000 Institute of Medicine report *Ending Neglect: The Elimination of Tuberculosis in the United States* called for additional research to understand the determinants of the behaviors of providers, patients, and systems and to improve methods for predicting and monitoring adherence to therapy (IOM, 2000). In addition, other issues relevant to effective TB control can be further addressed from a behavioral and social science perspective. These issues include, but are not limited to, identifying and treating LTBI and TB disease among persons in the United States, especially among African Americans in the Southeast and foreign-born persons; persons with TB/HIV co-infection; and persons with multidrug resistant TB (MDR-TB). Other issues include addressing stigma experienced by persons affected by TB; preventing the development of TB among persons at high risk; and addressing providers' non-adherence to guidelines and recommendations.

Furthermore, TB control efforts are challenged by the disparities in communities affected by TB. Social and economic factors such as poverty, homelessness, substance use, availability of and accessibility to appropriate care and services, and TB knowledge, attitudes and beliefs, have a significant impact on the personal TB experience. Behavioral and social science research in TB has helped us better understand the behavior of TB patients and contacts, as well as that of providers. It can further help us address questions such as: What point in the course of illness do people seek health care? What issues influence the decision to seek care? What issues influence acceptance of recommended medications? What factors affect the decision and ability to continue and complete treatment? Changes in the epidemic, such as the emergence of multidrug-resistant strains and the increasing impact on foreign-born persons, highlight the need for a broader, multi-disciplinary approach to create innovative strategies to enhance future TB prevention and control efforts.

The persistent challenges of preventing and controlling TB present a clear example of a public health problem that requires a multidisciplinary approach – one that looks beyond the biomedical model of TB control. Incorporating multiple perspectives that include not only the traditional social sciences but also includes such disciplines as economics, epidemiology, and health policy analysis that strengthen the research design and outcomes. These disciplines use a wide range of research methods and theoretical models to understand, predict, and influence attitudinal, behavioral, and social processes that impact health outcomes. Multi-disciplinary research is critical for the development and implementation of effective TB prevention and control programs.

### **Behavioral and Social Science Activities for TB Prevention and Control in CDC’s Division of Tuberculosis Elimination (DTBE)**

DTBE’s behavioral and social science research focuses largely on the major behavioral components influencing effective TB prevention and control -- issues including but not limited to treatment adherence, care-seeking behavior, patient-provider communication, perceptions of and ways to enhance the effectiveness of contact investigations, factors influencing acceptance of and adherence to LTBI treatment, and provider behaviors. Much of the research includes or targets pertinent high-risk populations, such as minorities, foreign-born, and disenfranchised populations.

In August 1994, CDC and the National Institutes of Health (NIH) co-sponsored a national workshop on tuberculosis behavioral research. The workshop was a response to the recommendation for behavioral and social science research on tuberculosis as stated in the “National Action Plan to Combat Multidrug-Resistant Tuberculosis” (MMWR 1992; 41 (No. RR-11): 1-48. This workshop brought together TB researchers, TB program staff, and interested stakeholders to establish an agenda for research on the primary behavioral, social, and health services aspects of tuberculosis treatment, prevention, and control. A total of 66 participants, including experts in tuberculosis, health education, and the social and behavioral sciences, as well as representatives of local and national governmental and international organizations, met in Bethesda, Maryland. The workshop was organized around five general and overlapping aspects of tuberculosis, including public knowledge of TB prevention and treatment; provider knowledge and practice; populations at high risk for TB; quality of TB control services; and patient adherence to treatment regimens.

Several years later, in 2000, the Institute of Medicine published *Ending Neglect: The Elimination of Tuberculosis in the United States*, a report that called for a behavioral science research agenda to help bring about the elimination of TB. Beginning in 2001, DTBE initiated a process to revitalize the tuberculosis research agenda, focusing on the behavioral and social sciences. The momentum generated by these events led to the December 2003 Tuberculosis Behavioral and Social Science Research Forum: *Planting the Seeds for Future Research*.

Extensive planning by an external steering committee, TB program staff, contractors, a CDC Planning Committee and other CDC colleagues culminated in the 2003 Behavioral and Social Science Research Forum, held in Atlanta, Georgia. The purpose of the Forum was to provide participants an opportunity to

- Identify and prioritize TB behavioral and social science research gaps;
- Develop a feasible, goal-oriented research agenda that will guide TB behavioral and social science activities;
- Establish an ongoing partnership among national, state, and local governmental and non-governmental behavioral and social science researchers focusing on TB;
- Create a mechanism for ongoing communication among TB behavioral and social science researchers.

Toward these goals, the Forum was designed to be a working and interactive meeting and was organized into various activities, including:

- Presentations on CDC's behavioral and social science research in TB control and elimination;
- Considerations and perspectives on TB control and behavioral and social science applications from panels of research, programmatic, and community representatives; and
- Facilitated breakout groups to identify behavioral and social science research gaps and needs and research questions

Recognizing that there is much work that still needs to be done before TB is eliminated, we hope this summary document of the Forum Proceedings will serve as a useful resource and provide the impetus for advancing efforts to control and eventually eliminate TB.

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## Section II. Presentations and Panel Discussions

The following section, which summarizes the Forum presentations and panel discussions, is organized according to the order of events at the Forum. For the reader's reference, a copy of the Forum agenda and presentation slides are included in Appendices A and B, respectively. The Forum began with opening remarks and presentations highlighting the role of behavioral and social science research in TB control and elimination. Following these presentations, a diverse group of researchers, scientists, community providers, staff of TB control programs, and patients shared their unique perspectives on TB control and behavioral and social science research in TB.

### DAY ONE

#### **WELCOME ADDRESS: OPENING REMARKS**

**Harold Jaffe, M.D.**

**Director, National Center for HIV, STD, and Tuberculosis Prevention, Centers for Disease Control and Prevention**

#### *Day 1, Morning Session*

Dr. Jaffe's opening remarks highlighted behavioral and social science research contributions to understanding the behavior of patients and providers in several health fields and their relevance to TB control and prevention. Early social science research has contributed to our understanding that cultural differences, race, gender, and ethnicity are as important as individual-level differences in predicting the success of health and disease prevention efforts. Behavioral sciences have been critical to U.S. and international activities addressing HIV/AIDS, STDs, and TB. For HIV/AIDS, behavioral sciences have enhanced our understanding of attitudes, health-seeking behaviors, treatment adherence, and prevention strategies. This research makes clear that "one size does not fit all" when developing prevention programs, a point that is also applicable to TB treatment and control strategies.

More recently, the Institute of Medicine report *Ending Neglect: Eliminating Tuberculosis in the United States* called for studies to understand how interventions can be tailored to particular high-risk populations. Clearly, there is an expanding role for behavioral and social science research in informing the fight against tuberculosis. This Forum marks the continuation and refinement of efforts to set an agenda for TB control and prevention research in these disciplines.

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**WELCOME ADDRESS: BEHAVIORAL AND SOCIAL SCIENCE RESEARCH IN TUBERCULOSIS CONTROL**

**Kenneth Castro, M.D.**

**Director, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

***Day 1, Morning Session***

Dr. Castro’s presentation on the role of behavioral and social scientists in TB control set the framework for the discussions that would guide the Forum. Drawing from research efforts in TB control that preceded the Forum, he specifically cited recommendations from the 1994 CDC/NIH national workshop to set a research agenda on *Improving Tuberculosis Treatment and Control*, and also cited the call for behavioral science research from the 2000 Institute of Medicine (IOM) report *Ending Neglect: Eliminating Tuberculosis in the United States*.

These efforts have helped shape the role of, and need for, behavioral and social science research in TB control. Dr. Castro outlined the TB research needed in these disciplines:

- Individual and interpersonal health behavior research is needed to address patient behaviors related to care seeking and adherence, provider behavior, and health care service delivery.
- Systems research is needed to address the structure and organization of health systems; environmental, economic, and sociopolitical dynamics; and policies and laws.

Behavioral and social scientists are conducting research to identify, understand, and address a broad range of relevant sociocultural, behavioral, and structural issues. They are also conducting systematic, theory-based multidisciplinary research based on scientifically rigorous experimental and quasi-experimental designs.

Although the ultimate purpose of the forthcoming TB behavioral and social science research agenda is to guide CDC research in these areas, Dr. Castro said he hoped that the research agenda would also be used to inform ongoing development and refinement of TB control strategies and policies for sister agencies, task forces, and academic institutions.

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**WELCOME ADDRESS: BEHAVIORAL AND SOCIAL SCIENCES IN TUBERCULOSIS ELIMINATION**

**Wanda Walton, Ph.D.**

**Chief, Communications, Education, and Behavioral Studies Branch, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

*Day 1, Morning Session*

Dr. Walton described the expanding role for behavioral scientists within the CDC’s Division of Tuberculosis Elimination (DTBE) and highlighted current behavioral and social science projects involving providers and patients. Current provider-focused studies include research to identify barriers to the acceptance and implementation of the 2000 guidelines for targeted testing and treatment for latent TB infection (LTBI) among private providers, and development of strategies to overcome such barriers. A second study aims to identify factors that facilitate or hinder health care workers’ adherence to local protocols for administration of annual worksite tuberculosis skin tests (TST) and treatment of LTBI.

Current patient-focused studies include:

- An ethnographic study seeking to understand the culturally-mediated perceptions, attitudes, and experiences regarding TB among five foreign-born populations in the United States;
- Research to develop culturally and linguistically appropriate patient education materials on TB;
- An assessment of the usefulness of social network techniques to increase the identification of female contacts during contact investigations; and
- Research to assess the knowledge, attitudes, and culture-specific beliefs about LTBI among several high-risk groups.

Three studies recently initiated through the TB Epidemiological Studies Consortium include:

- Task Order 11: Addressing TB Disease among African Americans in the Southeast;
- Task Order 12: Assessing TB Knowledge, Attitudes, Beliefs, and Practices Among Private Providers Serving Foreign-born Populations; and
- Task Order 14: Developing Culturally Appropriate Educational Materials for Hispanic Service Organizations.

Dr. Walton added that the research Forum is part of this expanding behavioral and social science capacity within the Division, and marks the beginning of the next 5-year cycle of DTBE’s activities in these disciplines.

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**KEYNOTE SESSION: WHEN SACRED COWS BECOME THE TIGER’S BREAKFAST: DEFINING A ROLE FOR THE SOCIAL SCIENCES IN TUBERCULOSIS CONTROL**

**Jessica Ogden, Ph.D.**

**Technical Specialist, International Center for Research on Women**

*Day 1, Morning Session*

Dr. Ogden presented a critical perspective on public health and TB control paradigms. Her presentation described a multidisciplinary approach to TB control that combines the strengths of the medical sciences with those of the behavioral and social sciences. Her proposed approach was informed by lessons learned from directly observed therapy short-course (DOTS) programs for TB treatment in India.

Dr. Ogden proposed a shift away from some of the “sacred cows” of classical public health thinking that emphasize disease control and elimination toward a social science paradigm focusing on the interactions among disease control personnel, individual patients, and the cultural and social contexts in which they live. At the level of the patient, such a paradigm emphasizes care, with particular attention to developing trust and fostering patient-provider partnerships. Outcomes in TB treatment and control are also strongly influenced by social and cultural contexts, including social structures within households, communities, and the policy-making environment. For example, social and cultural influences may determine who can adopt the sick role (and when), the range of treatment options available, and the extent to which a person can access and adhere to treatment.

A multidisciplinary, multilevel approach that takes into account the respective influences and roles of patients, communities, and households, as well as programs, providers, and policies can help to answer the following questions related to TB:

- Why don’t patients come for treatment?
- Why do they only come when it’s too late?
- Why don’t they complete their therapy?
- How can we make our programs accessible and acceptable?
- How can we meet the health needs of the community?
- How can we involve communities as participants in their own health?

Answering such questions in ways that address the multiple levels of influence is a critical step in improving TB control programs and the outcomes that they are able to achieve.

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**KEYNOTE SESSION: BEHAVIOR, SOCIETY AND TUBERCULOSIS CONTROL**

**Masae Kawamura, M.D.**

**Chairperson, Advisory Council for the Elimination of Tuberculosis; Director, Tuberculosis Control Section San Francisco Department of Public Health Tuberculosis Clinic, Ward 94 San Francisco General Hospital**

*Day 1, Morning Session*

Dr. Kawamura noted the accomplishments of TB control efforts and offered pathways to further improving TB control programs. In particular, she identified several ways in which behavioral and social sciences can be applied to TB control, including:

- Validating what we are doing right and wrong;
- Introducing new behavioral strategies that have been proven in other fields;
- Refining currently successful behavioral strategies, such as DOT, to improve implementation and outcomes;
- Determining when strategies are appropriate or harmful; and
- Framing TB data in their full context with demographics, social determinants, health disparities, and incidence of other diseases so the data are useful for advocacy and policy making.

She also offered the following considerations to guide TB research and programs.

- Research interventions must be practical and well planned.
- If new resources will be needed to implement interventions, then the costs, savings, and benefits of such interventions should be documented.
- When choosing staff, remember that civil service front-line staff may prove to be different from dedicated research staff.

Dr. Kawamura identified specific populations and LTBI issues that still need to be addressed. Strategies are needed to engage minority and foreign-born communities, especially undocumented persons and new immigrants living on both sides of the U.S.-Mexico border. More work is needed to engage these patients and improve contact investigation methods and LTBI adherence strategies among them. Additionally, health promotion and prevention for LTBI could be improved by integrating targeted testing and LTBI treatment into primary care. Nontraditional approaches that go beyond education and incentives and enablers are needed to increase LTBI treatment adherence. Finally, the root causes of TB must be addressed. Communities and countries must mobilize to take action, and TB-related information must be provided in useful formats.

Dr. Kawamura recommended a “macro” approach to enhance TB control efforts while acknowledging the individual-level strategies that have contributed to previous TB control successes. During the discussion with Forum participants, she emphasized that the time has come to insist on ways to improve TB interventions. She concluded by reminding participants that patients’ perspectives are greatly needed to inform programs.

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## **PRELIMINARY RESULTS FROM THE TUBERCULOSIS BEHAVIORAL AND SOCIAL SCIENCE LITERATURE REVIEW**

**Cathy Rawls, M.P.H., C.H.E.S.**

**Association of Schools of Public Health Fellow, Communications, Education, and Behavioral Studies Branch, Division of TB Elimination, Centers for Disease Control and Prevention**

**Cristina Booker, M.P.H.**

**Analyst, Public Health Applications and Research Area, Abt Associates, Inc.**

### *Day 1, Morning Session*

One element of DTBE's development of a research agenda includes a comprehensive review of TB behavioral and social science literature. Ms. Rawls and Ms. Booker presented preliminary results from the literature review, which was still in progress at the time of the Forum.

DTBE staff conducted a search in OVID across five databases (CINAHL, Embase, Medline, PsycInfo and Sociofile). This search identified literature that addresses behavioral, sociological, and cultural factors affecting TB prevention and treatment among affected populations and health care providers. General inclusion criteria used in this process were as follows:

- TB research that used social science methods or applied social science theory or concepts;
- Published works (including scientific, peer-reviewed literature, review articles, book chapters, and meta-analyses);
- Literature published after 1980; and
- Literature published in the English language that presents data or information for the United States or other countries.

A team of DTBE staff and contractors from Abt Associates reviewed and abstracted 175 articles that were identified for inclusion. To ensure consistency, the team created data abstraction tools for obtaining relevant information from the literature. Multiple reviewers conducted joint article reviews to ensure inter-rater reliability. Key items abstracted from the literature included study descriptions such as study design, objectives, theoretical basis, sampling design, data collection methods, target population, geographic location, structural setting, and quantitative and qualitative analysis; key findings; limitations; conclusions; and recommendations.

Ms. Rawls and Ms. Booker presented preliminary analysis on article types (e.g., research, evaluation, or non-research); broad issues addressed in the literature (e.g., patient adherence; provider adherence; cultural and social domains, including knowledge, attitudes, and beliefs; health-seeking behaviors; structural influences; and other domains); and geographic areas and populations covered. They also identified overarching themes that emerged from authors' conclusions and recommendations, including the following areas to be addressed by future TB research or practice:

- Underlying social or cultural factors associated with TB, such as poverty and patients' health beliefs;
- Health care-seeking behavior, such as health care-seeking delays related to stigma and length of treatment;
- Patient-related adherence issues, such as patient-identified barriers and facilitators to adherence;
- Provider-related adherence issues, such as diagnosis and treatment delays;
- Health education strategies, such as culturally appropriate interventions to increase accurate TB knowledge and reduce TB-related prejudices;
- TB control and eradication strategies, including novel and coordinated approaches that involve other health services and diverse types of providers; and
- Resource and funding allocations, including increased resources for interdisciplinary research and continued support for public health TB programs.

Continued activities for the TB behavioral and social science literature review will include a review of 100 additional articles and a database consisting of all the article reviews.

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**NEIGHBORHOOD HEALTH MESSENGERS: USING LOCAL KNOWLEDGE, TRUST, AND RELATIONSHIPS TO CREATE CULTURALLY EFFECTIVE TUBERCULOSIS EDUCATION AND CARE FOR IMMIGRANT AND REFUGEE FAMILIES**

**Stefan Goldberg, M.D.**  
**(on behalf of Patrick Chaulk, M.D., M.P.H.), Medical Officer, Clinical and Health Systems Research Branch, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

***Day 1, Morning Session***

Dr. Goldberg described a research project that utilized neighborhood health messengers, or “cultural case managers,” within a bilingual, bicultural TB control and prevention program, using local knowledge to create trust and relationships among immigrants and refugees. He provided details on two different cultural case management LTBI treatment programs: one in Seattle, WA, for new refugees and immigrants, and one in Boston, MA, for the Haitian community.

Based on experience in the Seattle project, the following factors emerged as attributes of effective cultural case managers:

- Having sufficient knowledge of the languages of target populations to formulate understandable and credible messages;
- Having experience with establishing effective and mutually trusting relationships with the target community;
- Being highly regarded in the target community, and therefore able to be trusted messengers in the community; and
- Being able to educate target communities about public health strategies and the complex health care system.

The Seattle program achieved a therapy acceptance rate of 88% and a therapy completion rate of 82%. Interviews suggested that the success of this program was largely due to the outreach workers' ability to build trusting relationships with their clients.

The Haitian Collaborative Project in Boston conducted community mapping activities as part of its cultural case management project. Dr. Goldberg offered the following selected cultural findings for this project:

- TB can be more stigmatizing than AIDS.
- There is no framework for understanding "latent TB infection." Offering treatment in the absence of patient symptoms may be seen as experimentation.
- Pharmaceuticals are often considered dangerous.
- There is widespread mistrust of American physicians.
- Health beliefs are often complex and may involve secular or spiritual components.
- Some words and phrases such as "negative" and "positive" test results may be difficult to translate or have unintended or unclear meanings.
- Perception that a positive reaction to the tuberculin skin test is common. In some populations, this is perceived as "normal" or a result of childhood vaccination with BCG.

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## **PSYCHOSOCIAL, SOCIAL STRUCTURAL, AND ENVIRONMENTAL DETERMINANTS OF TUBERCULOSIS CONTROL**

**Donald E. Morisky, Sc.D., M.S.P.H., Sc.M.**

**Professor, School of Public Health Department of Community Health Sciences, University of California, Los Angeles**

### *Day 1, Morning Session*

Dr. Morisky presented research results from two randomized studies of adherence to anti-TB regimens. The first study used cognitive and behavioral outcome markers, such as knowledge, beliefs, values, and attitudes, to assess the effectiveness of an educational intervention.

Participants were randomized to one of three intervention groups: 1) educational counseling, 2) incentives/rewards, 3) a combination of educational counseling and incentives/rewards, or to the control group. Those who participated in the educational counseling intervention showed a significantly higher level of medication compliance from baseline to exit interview. Dr. Morisky identified factors that may affect drop-out rates, such as ethnic background, gender, unemployment, homelessness, drug use, HIV status, primary language, and marital status.

The second study focused on foreign-born adolescents' adherence to LTBI treatment. Determinants of these adolescents' compliance with and completion of treatment were categorized as individual, environment, or other.

Individual determinants of compliance included:

- An understanding of the medical regimen;
- Belief in the benefits of treatment;
- Positive attitudes regarding treatment; and
- High levels of self-esteem and self-efficacy.

Environmental determinants of compliance included:

- Family member reinforcement in the home;
- Good patient/provider communication;
- Systematic approaches for patient monitoring, follow-up, and reinforcement;
- Convenience of picking up medication from the clinic; and
- Use of medication containers and cueing behaviors.

Other determinants of completion of care included:

- Regular appointment-keeping behavior;
- High levels of adherence;
- Use of community health workers;
- Reinforcement of positive behaviors by health care staff; and
- Use of peer counselors to clarify health concerns.

During the discussion with Forum participants, Dr. Morisky commented further on communication about non-adherence between patients and providers. Patients are often afraid of talking about non-adherence, and social desirability pressures further influence communication between patients and providers. To address this issue, families should be encouraged to provide positive reinforcement for patients who are adherent to their treatment regimens.

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**COMMUNITY PERSPECTIVES IN TUBERCULOSIS CONTROL AND ELIMINATION: THE PERSONAL EXPERIENCES OF PATIENTS AND PROVIDERS PANEL DISCUSSION**

**Robin Shrestha-Kuwahara, M.P.H.**  
**Behavioral Scientist, Clinical and Health Systems Research Branch, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

**Representatives from DeKalb County and Fulton County Public Health Departments**

*Day 1, Morning Session*

In this session, a panel of three TB patients and two TB outreach workers from local health departments in Georgia shared their personal experiences with and perspectives on TB treatment. The discussion was loosely structured to elicit the personal experiences that patients and outreach workers wished to highlight. Owing to this format, no slides or handouts were prepared. The following excerpts have been organized around the categories that emerged during the discussion.

**Patient experiences and perspectives**

**Reactions to tuberculosis diagnosis**

The patient panelists described their reactions and those of their family members to their being diagnosed with TB. Some patients talked of being initially shunned by their families and being asked to leave their homes. These patients understood that their families' responses were inappropriate and based on misinformation about TB transmission, but the rejection was nonetheless very painful to them. One patient brought up the denial that she initially felt upon being diagnosed with TB, but she emphasized how important her family's support was and how they urged her to seek care.

**Views of treatment and directly observed therapy**

All of the patients reported believing that directly observed therapy (DOT) worked for them, although all three had some problems with it. Two of the patients experienced stigma owing to their TB illness, but didn't use that specific term. At first, they felt that the outreach workers' visits were intrusive and embarrassing. The patients also mentioned that the medications themselves tasted unpleasant and had some bad side effects. Overall, however, the patients felt that DOT helped them get through the treatment.

### **Supports and enablers for tuberculosis treatment**

The patients mentioned several other factors besides DOT that assisted them during their course of treatment:

- Assistance with basic needs such as housing, food vouchers, and other financial help;
- Positive, trusting relationships with providers;
- Faith in oneself;
- Spiritual grounding; and
- Support of family and friends.

### **Provider experiences and perspectives**

Two outreach workers who provide DOT to TB patients also participated in the panel. Overall, they emphasized that patients have complex lives and problems; they need support and understanding to maintain adherence to TB medications and otherwise lead healthy lives. Key qualities for successful TB workers include patience, love of people, and a devotion to public health.

### **Challenges to tuberculosis care**

The outreach workers listed the following challenges in working with TB patients:

- Lengthy regimens that patients may desert once they are feeling better;
- Failure of some patients to make appointments or otherwise comply with treatment;
- Some patients' suspicion that their whereabouts will be divulged by TB workers to immigration or law enforcement authorities; and
- Common co-morbid conditions such as mental illness and substance use.

### **Key elements of effective tuberculosis care**

The outreach workers discussed the following key elements for addressing the above challenges and generally meeting the needs of TB patients:

- Nonjudgmental support and empathy for patients;
- Incentives for adherence, such as food vouchers and transportation;
- Clearly stated expectations regarding the treatment;
- Motivation for adherence, such as the threat of multi drug-resistant TB; and
- DOT, without which many patients would fail to complete their TB treatment.

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## **GROUP DISCUSSION OF THEMES AND ISSUES FROM DAY ONE**

**Mark Nichter, Ph.D., M.P.H.**

**Professor, Department of Anthropology, University of Arizona**

### ***Day 1, Afternoon Session***

Dr. Nichter led Forum participants in a group discussion of themes that emerged during the first day of the Forum. The following is a summary of the main themes and issues discussed.

#### **Patients' needs**

The group recognized the importance both of addressing the needs of TB patients, as well as overcoming the barriers to meeting those needs. More research is needed to gather patients' perspectives on the following topics:

- The value patients place on their health;
- The continuum of patient needs, including social needs and access to medications;
- Patients' negative opinions about TB treatment;
- Patients' mistrust of government agencies as a barrier to TB treatment; and
- The tradeoff between long-term benefits of taking TB medications and possible short-term drawbacks, such as unpleasant side effects.

Some underlying patient needs such as family support, housing, and financial assistance are well documented, but policy makers and funders must be convinced that addressing these needs may be critical to patient adherence to TB regimens. Families of TB patients can play either positive or negative roles in TB treatment. Supportive families may be especially important for adolescents and some ethnic groups.

Standardized and tailored approaches to working with TB patients must be balanced. Adherence to standardized TB treatment protocols is extremely important, but tailored interventions that meet patients' individual needs may be required to facilitate such adherence.

#### **Providers' needs**

More research should focus on identifying and understanding the needs of TB providers in areas such as adherence to guidelines and reimbursement for insured services. Providers also need more education and training on dealing with patients' emotional issues.

#### **Patient-provider relationship**

Building trust between patients and providers requires early and ongoing attention. If treated with respect and sensitivity, clients who may initially be considered challenging often develop good relationships with clinicians. If a provider has undue suspicions of a patient or has assumptions about patient non-adherence, these may present additional barriers to working with TB patients.

### **Directly observed therapy programs**

Participants discussed the strengths and limitations of DOT programs. Suggestions for improving these models included the following:

- Comparison of home-based and clinic-based DOT models based on patients' needs;
- DOT programs designed to address issues of TB-related stigma in work and home environments;
- Cost-effectiveness research comparing home- and clinic-based DOT models;
- Research to identify the characteristics of subpopulations and patients for whom DOT is particularly effective; and
- Research on the sustainability and educational and cultural appropriateness of different DOT approaches with diverse populations.

### **Health care systems**

Standard TB treatment protocols are needed in health care settings. Additionally, TB control programs need capacity building to prepare for new developments and trends, such as the increasing diversity of populations affected by TB and the programs needed to reach varying patient groups.

Additional challenges for health systems involve the image and reputation of health departments and many patients' mistrust of systems and the medications they provide. In particular, there is a need for better understanding of gender differences in seeking health services. Other health care systems issues that were discussed include the interactions between public health and private providers, and also those between different health care programs and services, e.g., the interaction between TB programs and HIV programs.

### **Policy makers**

Policy makers have extremely important roles to play in the development and support of TB programs. As they make decisions about programs, policy makers should be encouraged to address the following issues:

- TB education needs among patients, providers, and communities at large;
- Underlying socioeconomic and cultural factors contributing to TB and influencing responses to TB programs;
- Health insurance needs and problems associated with various insurance plans;
- Funding and other resources needed to support and sustain effective TB programs; and
- Disparities in TB rates among different populations.

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## **BREAKOUT GROUP SESSIONS I: IDENTIFYING RESEARCH GAPS AND NEEDS**

### ***Day 1, Afternoon Session***

Breakout sessions were held to identify TB research gaps and needs. A summary of the results can be found in *Section III: Results of Breakout Group Sessions: Identification of Tuberculosis Behavioral and Social Science Research Gaps and Needs*

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## **DAY TWO**

### **BREAKOUT GROUP SESSIONS II: DETERMINING AND PRIORITIZING RESEARCH QUESTIONS AND METHODS**

#### ***Day 2, Morning Session***

Breakout sessions were continued to prioritize research questions and methods identified on Day One. A summary of the results can be found in *Section III: Results of Breakout Group Sessions: Identification of Tuberculosis Behavioral and Social Science Research Gaps and Needs*.

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### **TURNING RESEARCH INTO PRACTICE PANEL DISCUSSION**

#### **Jane Mezzoff, DrPH**

**Behavioral Scientist, Communications, Education, and Behavioral Studies Branch,  
Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

#### ***Day 2, Afternoon Session***

CDC researchers from across the agency participated in a panel on the translation of research findings into practice. Recognizing the importance of disseminating and making practical use of research results “on the ground” as key components of an expanded research agenda, these presenters addressed the theoretical concerns and practical challenges associated with such an expansion. They offered several models from the HIV and asthma fields for using research findings to improve interventions and better serve communities. They also offered suggestions for tackling the “nuts and bolts” of disseminating and translating research findings to the field.

### **SHARPENING THE FOCUS ON TURNING RESEARCH INTO PRACTICE: THE PROMISE OF PARTICIPATORY RESEARCH APPROACHES**

#### **Shawna Mercer, M.Sc., Ph.D.**

**Health Scientist, Public Health Practice Program Office, Office of the Director, Centers for Disease Control and Prevention**

#### ***Day 2, Afternoon Session***

Dr. Mercer outlined challenges in translating research into practice and offered participatory research as an approach to addressing these challenges. The challenges include the following:

- There may be insufficient recognition of the complexities inherent in putting public health research into practice in diverse settings;
- Research findings may not be internally or externally valid; and
- Best practices may not be locally appropriate or affordable.

Participatory research is a flexible approach, rather than a set of specific methods, that may address these challenges by actively involving all stakeholders—practitioners, policy makers, and members of affected communities—in the research process from the beginning. Accordingly, it is more likely to keep communities involved and to produce locally relevant findings and implementation guidance.

The Office of Science and Extramural Research’s Extramural Prevention Research Grant Program (EPRP) solicited proposals for participatory research to develop community-based prevention strategies. EPRP funding currently supports 26 three-year grants for a total of about \$11.4 million. The funded projects address a wide range of health issues including preventing obesity, tobacco use, and injuries; supporting school health; reducing health disparities; and increasing access to health care. Among these, a project on diabetes among Appalachian Hispanics seeks to develop a model approach to addressing rural health problems.

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## **TWO CDC MODELS FROM HIV PREVENTION: REPLICATING EFFECTIVE PROGRAMS AND DIFFUSION OF EFFECTIVE BEHAVIORAL INTERVENTIONS**

**Agatha Eke, Ph.D.**

**Behavioral Scientist, Behavioral Intervention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention**

### *Day 2, Afternoon Session*

Dr. Eke described two sequential CDC initiatives to translate research into practice: Replicating Effective Programs (REP) and Diffusion of Effective Behavioral Interventions (DEBI). REP is involved with translation and packaging of science-based HIV interventions, while DEBI supports the diffusion of the translated interventions into practice. Both models are generally applicable to interventions on other public health topics such as TB.

The REP project is in line with the recommendations made in the Institute of Medicine HIV prevention report of September 2000 and CDC’s HIV Prevention Strategic Plan; both spoke to the need for development and use of effective, evidence-based HIV prevention interventions at all levels. REP sought to move HIV prevention beyond the endpoint of researchers publishing their results to a new paradigm in which researchers, practitioners, and communities are in active collaboration to translate research into improved prevention practice. Initiated in 1996, REP has thus far produced packages for seven HIV prevention interventions whose effectiveness has been documented through rigorous research methods. Four more intervention packages are currently in development. These intervention packages are then selected and implemented by local agencies.

Some important lessons emerged from the implementation phase of the initial REP packages:

- Importance of keeping the interventions as simple as possible, focusing on “core elements”;
- Flexibility to allow adaptation to local contexts;
- Need for maintaining detailed records and documentation of implementation;
- Value of clear “how to” materials;
- Importance of collaboration among researchers, practitioners, and communities; and
- Value of technical assistance during implementation.

DEBI represents the next step along the continuum of CDC's technology transfer and dissemination efforts in HIV prevention. It develops and coordinates a national strategy for diffusing science-based HIV interventions to state- and community-level programs. DEBI objectives for each intervention are accomplished in three phases that involve planning and development of curricula and related materials; implementation of an institute for master trainers; and larger scale roll-out in which up to 700 facilitators at state and local levels are trained and provided technical assistance and individualized coaching. Additional mechanisms for diffusing science-based interventions include satellite broadcasts, newsletters, Web-based discussion forums, and conference calls.

The DEBI model represents a further important effort to bridge the gap that commonly exists between public health researchers and practitioners. In the funding process for this initiative, there were specific requirements and incentives for the collaborations among researchers who have developed and evaluated the interventions, the front-line practitioners who will be trained to replicate or adapt these interventions, and the communities in which they will be implemented. Lessons learned from DEBI include:

- Active partnership and clear communication among all stakeholders are very important to a successful translation of research into practice;
- Multiple disciplines and skills are needed for the process to succeed;
- Implementing interventions with fidelity is important, but local adaptation may also be necessary to maximize effectiveness;
- Differences between researchers' and communities' definitions of "effective" interventions must be harmonized; and
- Successful diffusion may help to overcome myths about lack of capacity and inability to collaborate across sectors.

A member of the audience noted that the TB field is far behind the HIV field in such translation of research into practice, and that this represents very important work in which there is much to learn from the HIV experience.

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**EFFECTIVE INTERVENTION FOR ASTHMA**

**Leslie Boss, M.P.H., Ph.D.**  
**Epidemiologist, Environmental Health Division, National Center for Environmental Health, Centers for Disease Control and Prevention**

*Day 2, Afternoon Session*

Dr. Boss presented a model for continuously generating and refining interventions through ongoing translation of research findings. She gave some examples of translated interventions in the field of asthma control and treatment. For effective interventions to be widely adopted, they need to be widely known, evidence-based, appropriate to the target population and setting, well documented in accessible materials, and suitable for implementation by available staff, assuming access to proper training. Through implementation experience, gaps in interventions may be discovered that can then be addressed by further intervention research and translation of these research findings into additional interventions that fill these gaps.

Dr. Boss then provided some examples of asthma interventions based on translation of research findings. These interventions target various age groups (e.g., pre-school age, elementary school age, teens, and adults) in different settings (e.g., health care, school, and home). Information about this ongoing research and translation of research findings into implementation practice may be disseminated by means of the Internet, searchable literature databases, conferences, and various types of publications. More information can be found at the following website:

<http://www.cdc.gov/nceh/airpollution/asthma/interventions/interventions.htm>

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**POTENTIAL FUNDING OPPORTUNITIES**

**Kathryn O’Toole, M.B.A.**  
**Associate Director of Management and Operations, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

*Day 2, Afternoon Session*

Ms. O’Toole summarized CDC’s TB-related funding. In fiscal year (FY) 2003, DTBE allocated almost \$140 million for domestic and international activities. The majority of this funding goes to support TB programs in state and big city health departments. About \$2 million goes to support international activities. A certain portion of DTBE’s budget is set aside to fund research projects submitted by staff of CDC, TB Epidemiologic Studies Consortium (TBESC) researchers, and investigators from the TB Trials Consortium. Applicants first submit research concepts that are initially screened by the TBESC Research Chair and DTBE Associate Director for Science, then reviewed and scored by a special committee and DTBE senior staff. Investigators whose concepts receive high scores are asked to develop and submit full proposals for review by DTBE.

Because of anticipated budgetary shortages in FY2004, no new projects will be funded through this process this year. Depending on the budget situation in FY2005, some new projects may be funded in that fiscal year.

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**CLOSING REMARKS: MAINTAINING THE MOMENTUM ON DEVELOPMENT OF A TUBERCULOSIS RESEARCH AGENDA**

**Nick DeLuca, M.A.**

**Team Leader, Education, Training, and Behavioral Studies Team, Communications, Education, and Behavioral Studies Branch, Division of Tuberculosis Elimination, Centers for Disease Control and Prevention**

*Day 2, Afternoon Session*

Nick DeLuca, CDC DTBE’s Forum Team Co-Leader, delivered closing remarks. He acknowledged the Forum Steering Committee, local TB program staff, and CDC staff and contractors who helped plan and implement the Forum. Mr. DeLuca described the following next steps that CDC may take to maintain the momentum for developing the TB behavioral and social science research agenda:

- Behavioral science listserv and e-mail communications to generate more input on TB research needs from Forum participants and interested persons who could not attend;
- Database to store the literature reviews; and
- Report of the TB behavioral and social science literature review, guided by the themes identified in breakout group discussions.

Information gathered from Forum presentations, panel discussions, and breakout sessions reaffirmed the ongoing need for behavioral and social science research to inform improvements in the practice of TB prevention, control, and treatment. Solid research is needed to address important TB outcomes, such as patient adherence and provider practices, and social and cultural issues that influence all facets of the ongoing TB epidemic and responses to it. Several key points came out of this Forum:

- TB patients, providers, and researchers offer diverse and important perspectives on the challenges and potential solutions to be addressed by future TB behavioral and social science research and TB treatment and control programs;
- Multidisciplinary and multilevel approaches to improving TB control and treatment efforts should involve key stakeholders such as patients, providers, families, communities, health systems, and policy makers; and
- Innovative research and tailored interventions are needed to improve existing TB treatment and control efforts and to overcome the social, cultural, environmental and structural challenges faced by patients, providers, communities, and TB programs.

The perspectives compiled from Forum attendees and ongoing Forum-related activities will be essential components of the CDC DTBE’s forthcoming TB research agenda. The Forum Proceedings will be shared with stakeholders and interested parties. It is CDC’s hope that this document will be widely used by those working in TB prevention, control, and treatment.

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## Section III. Results of Breakout Groups Sessions

### Identification of Tuberculosis Behavioral and Social Science Research Gaps and Needs

#### Summary of Breakout Sessions at the Forum

There were four small breakout groups consisting of approximately 12 participants that met once each day during the Forum. The objectives for the breakout sessions of the Forum were to 1) identify areas that have been sufficiently researched, 2) to identify and prioritize research needs and gaps, 3) to articulate research questions for each gap area, and 4) to delineate research methods/approaches to fill the identified research needs. The breakout sessions included brainstorming and small group discussions. At the end of the small breakout sessions, all four groups reconvened to the larger group to report out and share the highlights from their discussions.

Forum participants used the National Institutes of Health (NIH) definition of behavioral and social science research as the basis for group discussion. (Refer to the *Background Section* on p. 2 for a complete definition).

To guide the discussions, the four groups were formed around two major themes or domains: “external” vs. “internal” influences. Though the framework is artificial, the purpose of these groupings was to initiate thinking from the perspective of factors influencing behaviors, such as health-seeking, initiating and adhering to treatment, and providing diagnostic, care, and treatment services with respect to provider behaviors, rather than focus on the behaviors themselves. This framework was intended to facilitate discussion about and development of research concepts that focus on interventions that directly address the influential factors, and narrow the already broad focus to either “external” or “internal” influences to the extent possible. Overlap was expected and inevitable, due to the multiple dimensions of influences on behaviors and the complex way that these influences interact with one another. Examples of these types of influences were provided during the breakout sessions and are noted below.

- 1) “External” influences on health and health behaviors may include factors in the physical or ‘external’ environment, organizational structures, policies, regulations, guidelines, poverty, racism, economic inequality, disparities in care, availability and access issues, legislation (e.g., immigration, public health laws).
- 2) “Internal” influences on health behaviors may include individual and cultural beliefs, etiologies or explanations of causality, knowledge, attitudes, and perceptions.

Influences such as stigma, social norms and customs could and did fall under both domains, depending on whether the discussion was on how these influences are *internalized* OR how they are *expressed* in society.

The breakout sessions, each headed by a trained facilitator, were very interactive, consisting of independent brainstorming activities in which participants wrote down their ideas on notecards and flip charts and subsequently shared information with the breakout group for discussion. Each breakout session was followed by a sharing of that group’s ideas with the larger group of Forum participants for questions and discussion.

For the purpose of organizing the Forum Proceedings, the notes and flip charts were reviewed and synthesized using the five broad levels based on the Socio-Ecological Framework. The five broad levels identified are listed below:

- Intrapersonal
- Interpersonal
- Health Systems and Organizations
- Community
- Public Policy

### **Organization of the Breakout Sessions Findings**

The **Socio-Ecological Framework** was used to organize the information generated by the participants during the Forum breakout sessions because of its multi-layered structural components. According to Sallis and Owen (1997), the Socio-Ecological Framework focuses on multiple levels of influence and proposes that health and behavior are caused by multiple factors. It assumes that organisms cannot exist or act in isolation; instead they work as an interdependent network of relationships influenced by internal and external forces. More specifically, behaviors are influenced by intrapersonal (i.e., individual), social and cultural, and physical environment factors. These multiple factors and interaction among them are relevant for understanding and changing health behaviors of individuals, communities, and organizations as a whole.

Using this framework, the most relevant levels of the model were identified and modified for the purposes of the Forum breakout sessions (*Refer to Figure 1: The Socio-Ecological Framework*). The levels that were used to systematically organize the information derived from the Forum breakout sessions are listed below.

**Intrapersonal:** This level focuses on influences (e.g., knowledge, attitudes, and perceptions; patient satisfaction; and social stigma) that affect the individual behavior of patients, such as health seeking behaviors and adherence to treatment. This level also addresses individual-level issues that may affect providers' behaviors, such as adherence to guidelines and recommendations.

**Interpersonal:** This dyadic level focuses on the relationship between two individuals or units regarded as a pair. Examples of this level include the patient-provider relationship and its impact on both the patient and provider as well as influences of a family member, significant other, or peer on a patient.

**Health Systems and Organizations:** This larger social system focuses on how individuals, small groups, and communities can be affected by structural, economic, and other organizational forces. Examples include the provision, accessibility, and use of health care services, and collaboration between provider communities and other systems.

**Community:** This level focuses on influences that affect behavior on a small-group level (e.g., family and social networks) in addition to larger groups, such as those in community settings. Examples include the influences of family and social networks on individuals; the relationship between local health services and individuals and communities; social norms; and social stigma.

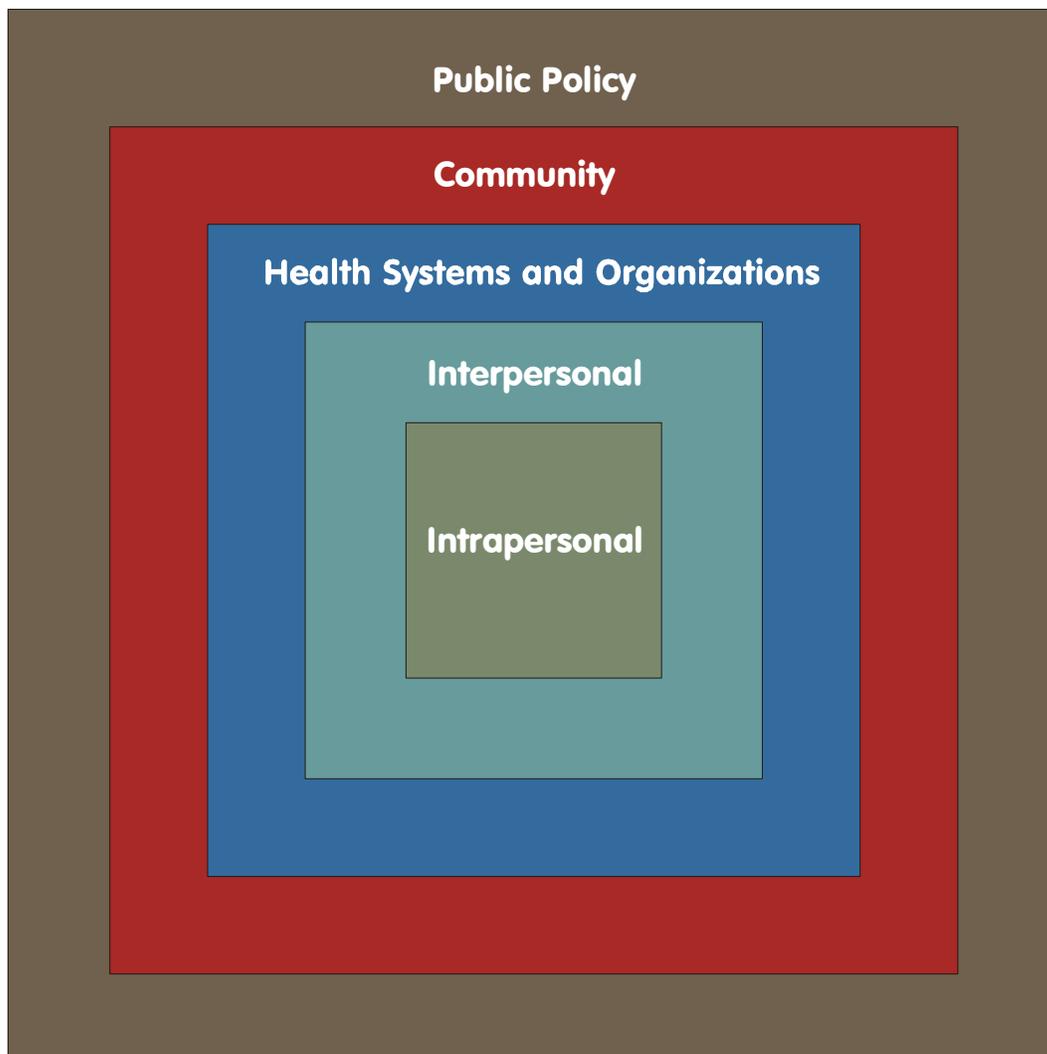
**Public Policy:** This level focuses on the implications of public policy on the behaviors of individuals, groups, communities, and organizations, with special emphasis on issues relating to

government commitment, funding, health insurance, and immigration policies.

Major research topics and subtopics were grouped to the extent possible under the five broad levels delineated in the Socio-Ecological Framework. More detailed information on specific topics identified by Forum participants are presented in the sections titled *Outline of Major TB Behavioral and Social Science Research Topics and Subtopics Identified at the Forum* on pgs. 28-30, and *Descriptions of TB Behavioral and Social Science Research Topics and Subtopics Identified at the Forum* on pgs. 31-43.

Specific research questions generated by Forum participants can be found in *Appendix C: Tuberculosis Behavioral and Social Science Research Gaps and Needs: Major Topics, Subtopics, and Research Questions*.

**Figure 1: The Socio-Ecological Framework**



# **Outline of Major TB Behavioral and Social Science Research Topics and Subtopics Identified at the Forum**

## **I. Background**

### **A. Health disparities**

## **II. Intrapersonal**

### **A. Patients' knowledge, attitudes, and perceptions**

### **B. Patients' behaviors**

1. Health care-seeking behaviors
2. Adherence to treatment

### **C. Patient satisfaction**

### **D. Social stigma**

### **E. Providers' knowledge, attitudes, and perceptions**

### **F. Provider training and practices**

1. Diverse training
2. Cultural competency
3. Clinical practices

## **III. Interpersonal**

### **A. Communication between patients and providers**

### **B. Family and peer influences**

## **IV. Health Systems and Organizations**

### **A. Organizational structure**

1. Collaborations between provider communities and systems
2. Impact of sharing patient information

### **B. Service delivery**

1. Patient-centered approaches
2. Case management
3. Advantages and disadvantages of directly observed therapy
4. Role of incentives and enablers
5. Contact investigations
6. Health communications
7. Special challenges of high risk settings and populations
  - a. HIV/TB
  - b. Homelessness, unstable housing, and mental health issues
  - c. High mobility jobs and migrant labor
  - d. Incarceration
  - e. Substance use
  - f. Foreign born
  - g. Pediatrics

## **V. Community**

### **A. Impact of TB services on communities and patients**

1. Influences of family and social networks
2. Social stigma

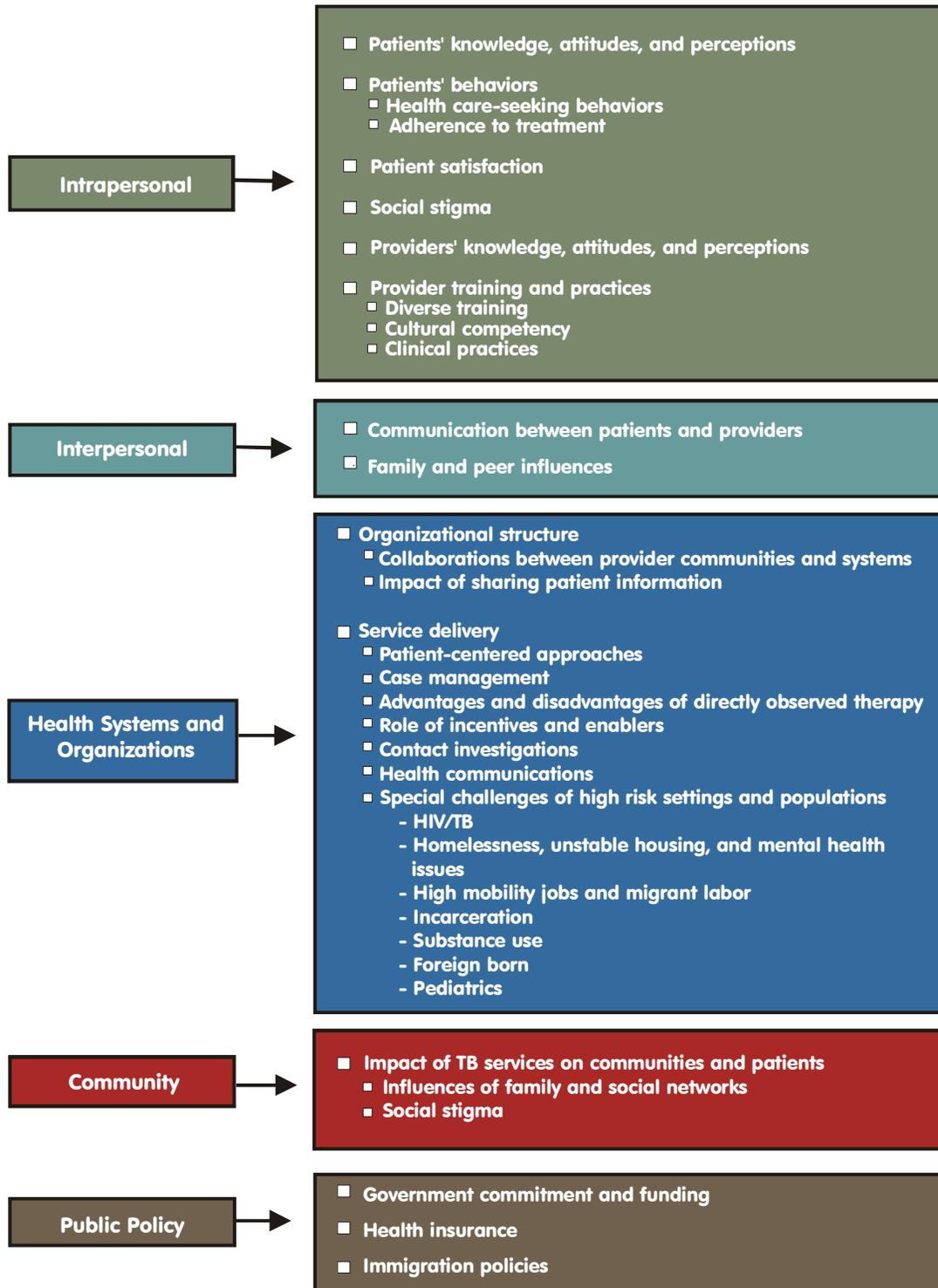
## **VI. Public Policy**

### **A. Government commitment and funding**

### **B. Health insurance**

### **C. Immigration policies**

**Figure 2: Outline of Major TB Behavioral and Social Science Research Topics and Subtopics**



## **Descriptions of Major TB Behavioral and Social Science Research Topics and Subtopics Identified at the Forum**

The following section provides a range and scope of topics that were generated at the Forum. For each topic, a brief description is given, followed by an italicized paragraph(s) summarizing the general research concepts that were elicited by Forum participants. For the entire list of topics, associated research concepts, as well as specific research questions, refer to *Appendix C*.

### **I. Background**

#### **A. Health disparities**

Vast disparities exist in TB case rates, treatment outcomes, and TB mortality among many different population strata. Historically, these disparities have often been based on socioeconomic status and within racial and ethnic minorities, the incarcerated, substance abusers, and homeless populations--populations especially vulnerable to poorer TB outcomes. In 2002, TB case rates among non-Hispanic blacks continued to be eight times greater than non-Hispanic whites.<sup>1</sup> In addition, the past decade has seen disparities emerge between U.S-born and foreign-born populations in the United States. Identifying and eliminating disparities in TB case rates, as well as determining effective measures to reduce existing disparities, are important steps toward controlling and eventually eliminating TB.

*During the breakout sessions, Forum participants identified the need to better understand and address disparities in TB case rates and treatment outcomes.*

### **II. Intrapersonal**

**Intrapersonal influences on behavior such as knowledge, attitudes, and perceptions, patient satisfaction, and social stigma affect the individual behavior of patients including health seeking behaviors and adherence to treatment. This level also addresses individual-level issues that may affect providers' behaviors, such as adherence to guidelines and recommendations.**

#### **A. Patients' knowledge, attitudes, and perceptions (KAP)**

An individual's knowledge, attitudes, and perceptions with respect to health in general and with a specific illness, such as TB, influence his/her behavior. Specifically, these factors can influence health seeking, understanding of the diagnosis, understanding of treatment, treatment initiation, treatment adherence, and general interactions with health care providers.

*Forum participants identified the importance of further understanding patients' knowledge, attitudes, and perceptions with respect to TB, with a particular focus on latent tuberculosis infection (LTBI). The need to identify any differences in these factors among different ethnic and cultural groups, specifically Latinos and other foreign-born populations, was emphasized. Finally, participants called for the further use of health behavior models and theories to be used as frameworks to better understand the factors that influence knowledge, attitudes, beliefs and practices of TB patients.*

## **B. Patients' behaviors**

### **1. Health care-seeking behaviors**

Health care-seeking behavior for TB includes the recognition of TB-related symptoms, presentation to health facilities and/or alternative medical resources (e.g., family and community healers), and adherence to effective treatment regimens and treatment monitoring. Individual factors, such as knowledge, attitudes, gender, sex, ethnicity, income, and education, in addition to health service barriers, including accessibility and acceptability of care, cost of services, and quality of care, can often delay or prevent a person from seeking TB care and treatment.

*Forum participants identified the need to further understand and influence the barriers and facilitating factors to seeking health care for LTBI and TB diagnosis, treatment monitoring, and completion of treatment for different populations. Specific questions were raised regarding the availability, accessibility, acceptability, and affordability of care. In addition, the group discussed the role of further understanding how an individual's perceptions of the health care system and health care providers influence their health seeking behavior.*

### **2. Adherence to treatment**

Treatment regimens for LTBI and TB include providing the safest, most effective therapy in the shortest amount of time and ensuring adherence to prescribed regimens. The major determinant of a successful treatment outcome is patient adherence to the prescribed drug regimen. Nonadherence can lead to inadequate treatment which can result in relapse, continued transmission, and the development of drug resistance.

Directly observed therapy (DOT) and self-administered therapy are two strategies commonly used in TB control. DOT, a major component of case management, is currently recommended for all patients with TB disease. In addition to DOT, research has shown the use of incentives and enablers can also enhance patient adherence.

Directly observed treatment for LTBI is less common due to limited resources. Ensuring treatment completion of LTBI poses unique challenges as it is often self-administered.

*Forum participants identified the importance of further understanding the barriers and facilitators that affect the initiation, duration, and completion of treatment of LTBI and TB disease, specifically for different populations, such as foreign-born persons and incarcerated/newly-released prisoners. Discussion focused on ways to better understand and enhance DOT. In addition, a focus of the discussion centered on how to improve patient acceptance of LTBI treatment. The discussion also posed questions on how behavior change theories and models could be utilized to better understand and overcome barriers to treatment for LTBI and TB disease.*

### **C. Patient satisfaction**

Patient satisfaction is how individuals regard the health care services or the manner in which they are delivered by health care providers as useful, effective, or beneficial. It is often based on patient expectations of care and the self-assessment of their experiences. Patient satisfaction may play a major role in a patient's behaviors. If a patient is dissatisfied with the relationship with their provider or with the clinical setting, he or she is much less likely to be adherent to medications, keeping appointments, identifying contacts, and so forth. Research has shown that patient satisfaction can be increased with effective patient-provider communication and development of a trusting relationship.

*Forum participants identified the importance of the relationship between a patient and the provider or health care system that serves them and the need to better understand this relationship and the role it plays, especially from the perspective of different ethnic and cultural groups. Forum participants also expressed the importance of determining how patient satisfaction may be influenced by TB care and services. They also highlighted the need to explore the influence of patient satisfaction on behavior such as adherence.*

### **D. Social stigma**

Evidenced both in research and in practice, stigma associated with TB appears to be universal. The consequences of stigma can be seen affecting care-seeking behaviors, as persons have been known to hesitate or choose not to disclose their TB status to family, friends, and co-workers out of fear of being socially ostracized, in addition to losing their employment and/or temporary housing. Research has demonstrated that in some cases, personal rejection occurs as a result of the stigma surrounding TB. Stigma has also been shown to hinder adherence to treatment. By identifying the consequences of stigma, social science research has illustrated the need for effective intervention strategies to mitigate it.

*During breakout discussions, the research questions surrounding stigma highlighted the continuing need to identify the effects or consequences of stigma on care seeking, adherence to treatment, and cooperation with health care providers, especially during contact investigations, to determine whether certain populations or sub-populations (e.g., foreign-born communities) are adversely affected by stigma and in which settings (e.g., residential or workplace). Forum participants also raised the issue of better understanding different perspectives and sources of stigma. Additionally, discussions revolved around the need for identifying and testing effective ways to mitigate the influences that stigma has on individuals and communities.*

### **E. Providers' knowledge, attitudes, and perceptions**

A health care provider's knowledge, attitudes, and perceptions (KAP) about LTBI/TB play an important role in their ability to diagnose and treat individuals with TB. A variety of factors, such as medical and health-related training (e.g., U.S.-training vs. foreign training, generalist, or specialist), cultural and ethnic background, practice settings, preferred sources of information and learning styles can influence providers' knowledge, attitudes and beliefs about LTBI and TB.

*Forum participants identified the need to better understand the TB-related knowledge, attitudes, and perceptions of different providers in a variety of practice settings, including: private physicians, primary care physicians, civil surgeons, international medical graduates (IMG), and providers who serve foreign-born populations. Forum participants called for the further use of health behavior models and theories to be used as frameworks to better understand the factors that influence knowledge, attitudes, beliefs and practices of TB providers and how these factors influence their ability to diagnose and treat TB patients.*

## **F. Provider training and practices**

Providers serving individuals at risk for TB in the United States come from a wide range of backgrounds and perspectives. They may have differing knowledge, attitudes, and practices related to TB prevention and control based on factors such as, where they completed their medical training, residency, board certification requirements, and continuing education experiences. Personal and cultural factors may also affect their practices. All of these factors may influence the providers' level of professional competence, cultural competency, and clinical behaviors, including their adherence to professional practice guidelines.

### **1. Diverse training**

Providers have different levels of knowledge, attitudes and practices related to TB prevention and control, based on factors such as where they completed their medical training, residency, board certification requirements, and continuing education experiences. Moreover, many foreign-trained providers and international medical graduates (IMG) have an increasingly important role in TB prevention and control efforts, as they may be the first point of contact for foreign-born individuals with TB.

*Forum participants identified the need to assess the impact of working with providers of different cultural and professional backgrounds, who have undergone different types of training in the area of TB control. Participants also identified the need to improve collaborations between health department and non-health department providers.*

### **2. Cultural competency**

The role of cultural competency in U.S. TB programs has become increasingly important, especially over the past two decades as the proportion of persons with TB who are foreign born has rapidly increased and now surpasses U.S.-born cases. In addition, widening disparities have emerged among other U.S.-born groups, such as African Americans in the Southeast. Efforts to promote health and prevent and treat disease within culturally diverse groups will involve building the capacity of programs to become culturally competent. This is extremely important in health care, as it has generally been shown that minority groups use fewer services and are less satisfied in general with their care. Furthermore, patients may avoid care out of fear of being misunderstood or discriminated against. Providers need to be aware of and understand the impact that culture can have on a patient's TB knowledge, attitudes, beliefs, and practices. By increasing the cultural competency of providers, they will be better equipped to provide the most appropriate TB care and treatment.

*Forum participants identified the need to further understand the role of cultural competency on the delivery of services to TB patients and ways to increase cultural competency among health care providers, including public health nurses and outreach workers. In particular, participants focused on how culturally competent health care workers can influence patient's adherence to treatment for LTBI and TB.*

### **3. Clinical Practices**

Clinical practices of providers can include TB screening and treatment, patient management, collaborating with the health department for contact investigations, and adherence to guidelines and recommendations. Just as patients are faced with individual or structural barriers to adhering to LTBI and TB treatment, health care providers also face numerous challenges and barriers to adherence to TB screening and treatment guidelines and recommendations. Providers must be aware of CDC and American Thoracic Society (ATS) guidelines in order to implement them. In addition, other barriers such as provider background and practice setting may influence their adherence to guidelines. Identification of barriers to the awareness of and adherence to guidelines and ways to address these barriers can improve provider practice and lead to the provision of more effective health care.

*Forum participants identified the need to determine ways to increase providers' awareness and adherence to TB treatment guidelines for providers in different health care settings. In these discussions, "providers" include private providers, community health workers, case workers, non-health department physicians, and foreign-trained providers.*

## **III. Interpersonal**

**Interpersonal influences on behavior focus on the relationship between two individuals or units regarded as a pair. Examples include the patient-provider relationship and its impact on both the patient and provider as well as influences of a family member, significant other, or peer on a patient.**

### **A. Communication between patients and providers**

Communication between patients and providers is critical for effective health care. It is a fundamental element that helps to shape the patient-provider relationship and foster trust. Communication includes appropriate linguistic concordance, optimal use of interpreters when necessary, verbal and nonverbal expressions and cues, and good listening skills by providers. Communication also ultimately reflects the dynamics of the relationship between a provider and the patient. Provider-patient communication can impact trust, patient satisfaction, and treatment adherence.

*Forum participants identified the need for additional research to understand the role of provider-patient communication in effective TB case management. Participants discussed the need to foster positive interactions and to build trusting and caring relationships between patients and providers.*

### **B. Family and peer influences**

A TB patient's family, peers, and social networks can be very influential on the patient's behavior. Family and peer influences can affect an individual's decision to seek treatment and to adhere to provider treatment recommendations. In addition, peer and social influences can impact a TB patient's willingness to identify contacts during a contact investigation.

*Forum participants identified the need for research to further understand the family and peer in terms of whether and when a patient enters (and remains in) care.*

## **IV. Health Systems and Organizations**

**Influences of health systems and organizations on behavior focuses on how structural, economic, and other organizational forces can affect the views of individuals, small groups, and communities. Examples include the availability, accessibility, and use of health care services by individuals, and collaboration between and among provider communities and other systems.**

### **A. Organizational structure**

The way in which the health care system is organized may play a role in affecting both patient and provider behaviors. Whether the system has a vertical or horizontal structure, whether services are integrated with other health and social services or are part of a collaborative network, and how the health care system is impacted by other systems within a society may impact the availability, delivery, and acceptability of services.

#### **1. Collaborations between provider communities and systems**

There are many different social and behavioral determinants involved in TB transmission, identification, and treatment success. Certain factors that place individuals at high risk for TB, such as poverty, substance abuse, and homelessness, can be greatly impacted by the availability and quality of social services. Both private and public collaborations between and among existing social service agencies and TB control efforts, as well as timely and appropriate social service referrals for individuals with TB, may play an important role in the efforts to successfully eliminate TB.

There are also a number of relevant collaborations between TB services and other health-related entities that may need to be better understood and cultivated. Given the high rate of TB/HIV co-infection among certain populations, collaboration between or integration of TB and HIV services may lead to better treatment outcomes and improved satisfaction among persons receiving these services. Collaborations with mental health and substance abuse services, homeless shelters, and correctional facilities hold equal promise.

*Forum participants identified the need to determine ways to increase collaboration between TB programs and other health and social service agencies for related conditions (such as HIV/AIDS, mental health, and substance abuse) to improve TB diagnosis, case management, and integration of services. Specific areas for increased research include focusing on patients with multiple and varied needs, U.S.-Mexico border issues, and collaboration with correctional systems, Immigration and Customs Enforcement, and other agencies.*

#### **2. Impact of sharing patient information**

Patients who have other health and/or social issues such as TB/HIV co-infection, diabetes, substance abuse, and mental health issues, in addition to TB or LTBI, may have multiple providers. The sharing of patient information becomes a crucial component in the provision of proper and effective health care, especially as it relates to a patient's TB treatment regimen and follow-up care. Providers who take a holistic approach to their patient's health and who thus have a complete picture of their patient's health and well-being are better equipped to make well-informed decisions that ensure the most appropriate TB care and treatment.

*Forum participants identified the need to focus upon the impact of sharing (or not sharing) patient information on case management, service coordination, and health outcomes among managing providers in varying settings, such as health departments and correctional, mental health, and substance abuse facilities.*

## **B. Service delivery**

The delivery of health services plays a major role in how patients receive TB care and treatment. From an organizational perspective, accessibility and acceptability of services, cost of services, and quality of care can often delay or prevent a person from seeking TB care and treatment. Through the use of patient-centered approaches and effective case management, these systematic barriers can be reduced or alleviated, resulting in improved provision of care and better treatment outcomes.

### **1. Patient-centered approaches**

Patient-centered approaches focus on bringing together compassion, empathy, responsiveness, and resources to the needs, values, and expressed preferences of individual patients. Effective patient centered care is essentially a partnership between the provider and the patient. It involves determining individual patient needs and expectations while ensuring that efforts are made to address those needs and expectations by the health care provider(s).

*Forum participants recognized the potential benefits of delivering TB control services which embody a patient centered-approach, and suggested that additional research is needed to identify, compare, and standardize different methods and models for patient-centered care.*

### **2. Case management**

Quality case management is an important component of effective TB care. It holds the potential to increase treatment adherence and treatment outcomes by tailoring case management to the patient, by making appropriate referrals to needed health and social services, and helping to remove barriers to treatment success. However, little empirical evidence exists that systematically confirms the effect of the various types of case management practices. Part of the reason for this may be that many case management practices are not standardized and vary based on case management models and institutions.

*Forum participants identified the need to determine the influences of case management on multiple outcomes (e.g., treatment outcomes, reduced homelessness, care for substance abuse, receipt of other appropriate social and other health resources) as well as approaches to strengthen case management practices.*

### **3. Advantages and disadvantages of directly observed therapy**

Directly observed therapy (DOT), in which a health care worker or other qualified individual watches the patient swallow every dose of the prescribed drugs, is an extremely effective strategy for making sure patients take their medicines. DOT is strongly recommended as part of a patient-centered case management plan because it is difficult to reliably predict which patients will be adherent. Successful treatment programs are dependent upon public health programs and providers accepting responsibility for a patient's care by ensuring that DOT is appropriately administered.

As TB incidence declines and programs are turning their attention to the treatment of LTBI, more TB programs are trying to use DOT for LTBI patients. Data indicating low completion rates among patients on treatment suggests the importance of determining the appropriate use for DOT with LTBI patients.

*Forum participants identified the need to conduct further research on the effectiveness of varying DOT modalities for LTBI and TB, such as clinic, home, or field-based DOT. Forum participants also raised the need to identify patient-centered DOT strategies that are most appropriate to the particular needs of patients, questioning the one-size fits all mentality. Participants also focused on the need to further delineate the usefulness of DOT in treating TB and other co-morbid conditions, such as HIV.*

#### **4. Role of incentives and enablers**

Research has shown that the use of incentives and enablers can enhance patient acceptance as well as adherence to treatment for both TB disease and LTBI.

Incentives and enablers help patients continue and complete treatment and are widely used in facilities providing TB services. Incentives and enablers are most beneficial when they are tailored to the patient's special needs and interests. Learning as much as possible about individual patients through the use of patient-centered approaches will help to identify their needs and better assist them in completing treatment.

*Forum participants identified the importance of further understanding the barriers and facilitators that affect the initiation, duration, and completion of treatment of LTBI and TB disease, and the role that incentives and enablers can have in achieving TB treatment goals, specifically for diverse populations, such as foreign-born persons and incarcerated or newly released prisoners.*

#### **5. Contact investigations**

The contact investigation (CI) is an important component of TB prevention and control efforts, as it is a process for identifying persons exposed to someone with infectious TB, evaluating them for LTBI and TB disease, and providing appropriate treatment for LTBI or TB disease. In TB programs in the U.S., there is wide variability in the way in which contact investigations are conducted. Furthermore, the contact investigation can be sensitive for TB patients as they are required to elicit personal information, such as who they interact with, how often, and where. Little is known about the social and emotional impact of these investigations on the individuals involved and on the identification and follow-up of contacts.

*Forum participants identified the need to determine ways to improve contact investigations by, for example, gaining a better understanding of patient and contact perceptions and being more sensitive to involved parties to enhance contact investigation outcomes. Finally, more research is needed with providers to examine their perspectives on contact investigations.*

#### **6. Health communications**

Health communications can be used to share information on TB with the general public, local communities, patients and contacts, as well as providers. Research has demonstrated that misconceptions about TB and the stigma associated with the disease still abound, suggesting the continuing need to increase knowledge and awareness of TB through

effective channels of communication. Further research to better understand informational needs, identify appropriate and effective media for channeling information, and testing health messages related to many aspects of TB for a variety of audiences will enhance the effectiveness of TB control efforts and hopefully mitigate the stigma associated with TB.

*Forum participants identified the need to identify specific and tailored messages and messengers for improving communication about LTBI and TB diagnosis and treatment among patients and providers, as well as among family members and within the community.*

## **7. Special challenges of high risk settings/populations**

### **a. HIV/TB**

Co-infection of TB and HIV presents challenges for both patients and the providers serving them. One challenge is related to the potential lack of collaboration among TB and HIV programs. It is important that TB providers offer HIV voluntary testing and counseling to both TB patients and high risk contacts, and that HIV providers offer TB screening and follow-up. Patients who have both TB and HIV may also face challenges associated with the burden of taking medicine for both diseases, as well as with the stigma associated with both illnesses.

*Forum participants identified the need to conduct research on patient, provider, and agency barriers to the integration of voluntary HIV testing and counseling in TB programs as well as the incorporation of TB services in HIV/AIDS programs.*

### **b. Homelessness, unstable housing, and mental health issues**

TB control also faces significant challenges when dealing with homeless populations or with individuals who may also be experiencing mental health or substance abuse issues. These issues, combined with a lack of stable housing, make TB screening and follow-up, diagnosis, contact investigations, treatment initiation, adherence, and completion of treatment extremely challenging.

*Forum participants identified as important the need to assess the TB knowledge, attitudes, and perceptions (KAP) as well as other influences on behavior of homeless populations. Participants also identified the need to consider using patient-centered case management strategies to identify and address competing health and social issues for this population.*

### **c. High mobility jobs and migrant labor**

Given their mobility, migrant farm workers and other migrant populations present unique challenges to TB prevention and control programs with respect to diagnosis, treatment, continuity of care, and contact investigations. U.S.-Mexico border issues, such as immigration and frequency of border crossings, create additional challenges.

*Forum participants suggested conducting descriptive and ethnographic research using case studies as a possible method, among this special population. This type of research might help to determine ways to access migrant networks, mechanisms for tracking patients in a non-stigmatizing way, and ways to increase completion of care.*

#### **d. Incarceration**

Jails and prisons pose a unique challenge for TB prevention and control. Efforts have been made to improve the relationships between health department TB programs with jails and prisons to enhance TB screening and follow-up among inmates and correctional personnel. In addition, continuity of care can be a particular challenge for TB patients who are incarcerated during treatment and who are later released from prison or jail while on treatment.

*Forum participants discussed the need to conduct further research to identify ways to improve TB screening activities, as well as adherence to and completion of treatment for incarcerated persons and newly released prisoners. In addition, participants called for further research to examine how screening and treatment for TB can be incorporated into the diagnosis and treatment for other diseases such as HIV.*

#### **e. Substance use**

Substance abusers are at increased risk for TB. Substance abusers may have competing priorities that may prevent them from being diagnosed with TB, accepting and adhering to treatment regimens, and identifying contacts.

*Forum participants identified the need to better understand the TB knowledge, attitudes, and perceptions (KAP) of substance abusers as well as determine the best ways to address these issues, so that this population will receive the most effective TB care and services.*

#### **f. Foreign born**

Although TB case rates have steadily declined since 1992, TB in foreign-born persons represents a significant challenge for TB control efforts in the United States. In 2002, TB case rates among the foreign born comprised 51% of reported TB cases in the U.S.<sup>2</sup> Foreign-born populations may have unique cultural characteristics, practices, and circumstances related to their re-settlement and adjustment to the U.S., that may influence their TB treatment and care.

*Forum participants identified the need to acknowledge, understand, and incorporate different health-related cultural beliefs and practices of foreign-born patients. Other issues that warrant exploration included foreign-born persons' perceptions of the U.S. health care system and/or the providers who deliver care, determining the role of gender and ethnic differences between patients and providers, and identifying and addressing the wide range of barriers foreign-born persons encounter when accessing services related to LTBI/TB diagnosis, treatment initiation, adherence, completion, and follow-up.*

#### **g. Pediatrics**

Children with LTBI and TB represent another population with unique characteristics and needs, as the prevention, diagnosis, and treatment of children is often dependent upon the role of the parent, primary care giver, and other adults.

*Forum participants felt it was important to conduct research to test alternative models to increase LTBI and TB screening and treatment among children.*

## V. Community

**Influences that are community-related affect behavior on both small and large-group levels, such as those in community settings. Examples include influences of family and social networks on individuals, the relationship between local health services and individuals/communities, and the impact of social stigma of TB on groups.**

### A. Impact of TB services on communities and patients

Whether defined by a geographic region, a common interest, or shared ethnic or cultural background, communities play an important role in people's lives. Because a community typically shares a set of common interests and values and gains strength from this collective entity, it is important for health care providers to understand the communities they serve to effectively meet the community's needs. Developing a respectful, collaborative relationship with communities may strengthen the delivery of health services and improve the general health and well-being of communities as a whole.

*Forum participants identified the need to determine the perceptions of TB within communities and to understand the origins of those perceptions and the influence of forces that affect people's perceptions, such as the media. Participants also expressed the need to develop tailored, culturally-specific interventions to increase understanding of TB and reduce the stigma associated with TB.*

*Participants across all groups discussed the need to determine the optimal relationship between health departments and the local communities they serve, as well as the role of community groups like community-based physicians in increasing TB awareness and delivering TB services. Suggestions were made to conduct more participatory action research and to define and determine how local communities can become involved in locally driven research.*

#### 1. Influences of family and social networks

Family groups and social networks have been shown to be extremely influential on many different health outcomes. In terms of TB outcomes, this influence can manifest itself positively by facilitating or supporting, for example, care-seeking, treatment adherence, and other patient behaviors. Conversely in other cases, misconceptions held by those close to individuals with TB can have negative effects such as increasing the level of stigma attached to the disease resulting in social ostracism or isolation. Furthermore, family units and social networks are often adversely affected by the introduction of TB and the consequent stressors into their networks. Successful TB control efforts based on a strong understanding of these issues may maximize the positive influences of social networks and minimize disruptions to family and social networks.

*Forum participants identified the need to better understand the role of social networks on health behaviors and determine strategies for strengthening the positive influences of social networks. Specific focus was given to identifying ways in which TB programs can work with families to better understand and mitigate the impact of TB services on social networks.*

## 2. Social stigma

Evidenced both in research and in practice, stigma associated with TB appears to be universal. The consequences of stigma can be seen affecting care-seeking behaviors, as persons have been known to hesitate or choose not to disclose their TB status to family or friends out of fear of being socially ostracized. Research has demonstrated that in some cases, personal rejection occurs as a result of the strong stigma surrounding TB. Stigma has also been shown to hinder adherence to treatment. By identifying both the sources and consequences of stigma, social science research has illustrated the need for effective intervention strategies.

*Social stigma was an issue raised in all of the breakout groups, highlighting the shared perception of the need to better understand its sources and identify effective ways to address it. During breakout discussions, forum participants specifically noted the need to define stigma from various perspectives, identify existing research to understand the impact of stigma, and propose specific measures to address and reduce stigma. Among these measures, it was suggested to identify ways in which the public health community can alter its presentation of epidemiologic data to avoid the perpetuation of existing stigmatizations and to reinforce that TB is a curable disease.*

*Proposed research questions focused on identifying the effects or consequences of stigma on care seeking and adherence to treatment, and determining whether certain populations or sub-populations are adversely affected by stigma.*

## VI. Public Policy

**Public policy influences focus on the implications that public policies have on the behaviors of individuals, groups, communities, and organizations with special emphasis on issues relating to government commitment, funding, health insurance, and immigration policies.**

### A. Government commitment and funding

Governmental entities, from federal to local, play a critical role in TB-related services. From federal-level research funding to service delivery at local health departments, TB control is influenced greatly by policy decisions. Given these arrangements, the development of a better understanding of the policy process and greater engagement of decision-makers by those working in TB control may lead to improvement in TB services.

*Forum participants identified as important the need to focus on identifying appropriate decision makers, potential advocates, and strategies to influence TB-related policies. They also specifically addressed funding issues such as the identification of effective ways to advocate for TB funding as well as possible models for allocation of funds within the TB framework.*

## **B. Health insurance**

As of 2002, data from the U.S. Census Bureau indicated that 43.6 million people were uninsured in the United States.<sup>3</sup> The lack of health insurance among people in the U.S. creates a serious impediment for those who seek or wish to seek health care for LTBI or TB disease, especially as it relates to TB testing and treatment. It is unknown to what extent a lack of appropriate insurance coverage or fear of treatment costs hinder care-seeking, but it is suspected that this economic deterrent has clear negative implications.

*Forum participants identified the need to determine the effect of health insurance or lack of appropriate coverage for TB services on health behaviors and health outcomes, including access to TB diagnosis and treatment. Further research is needed to determine the impact this has on TB patients and their families, in addition to finding alternative funding solutions to increasing health care costs and expenses.*

## **C. Immigration policies**

With over half of TB cases in the United States occurring among individuals born outside of the country, the link between immigration and TB services has become increasingly important in recent years. Efforts to coordinate public health efforts with immigration activities pose an evolving challenge as changes occur to immigration policy and enforcement agencies. Understanding the impact of these specific changes, as well as developing a broader body of knowledge of immigrant issues in general, will likely lead to improved TB services and better health outcomes.

*Forum participants identified as important the need to focus on the effect of immigration policies, specifically regarding recent changes to policies, on TB services. Additional discussion focused on the need to develop strategies for collaboration with immigration authorities to increase access to immigrant communities.*

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3. The United States Census Bureau. The Health Insurance Coverage: 2002 page. Available at <http://www.census.gov/>

## Section IV. Appendices

### Appendix A: Forum Agenda

#### Tuberculosis Behavioral and Social Science Research Forum Agenda *Planting the Seeds for Future Research*

December 10–11, 2003 • Sheraton Colony Square • Atlanta, Georgia

#### DAY 1: Wednesday, December 10, 2003

Time	Session	Presenter(s)
7:00 am - 8:30 am	Registration and Breakfast	
8:30 am – 8:40 am	Welcome	Nick DeLuca, M.A. Lead Health Education Specialist, DTBE, NCHSTP
8:40 am – 9:00 am	Opening Remarks	Harold Jaffe, M.D. Director, NCHSTP  Ken Castro, M.D. Director, DTBE, NCHSTP  Wanda Walton, Ph.D. Chief, Communications, Education, and Behavioral Studies Branch, DTBE, NCHSTP
9:00 am – 9:30 am	When Sacred Cows Become the Tiger’s Breakfast: Defining a Role for the Social Sciences in TB Control	Jessica Ogden, Ph.D. Technical Specialist, International Center for Research on Women
	Perspectives from TB Programs	Masae Kawamura, M.D. Director, San Francisco TB Control
9:30 am - 9:45 am	Preliminary Results from the Behavioral and Social Science Literature Review	Cathy Rawls, M.P.H., C.H.E.S. ASPH Research Fellow, DTBE, NCHSTP  Cristina Booker, M.P.H. Research Analyst, Abt Associates, Inc.

**DAY 1: Wednesday, December 10, 2003 (cont.)**

9:45 am – 10:45 am	<p>Neighborhood Health Messages: Using local knowledge, trust, and relationships to create culturally effective TB education and care for immigrant and refugee families</p> <p>Psychosocial, Social, Structural, and Environmental Determinants of TB Control</p>	<p>Stefan Goldberg, M.D. Medical Officer, DTBE , NCHSTP</p> <p>Donald E. Morisky, Sc.D., M.S.P.H., Sc.M. Professor, UCLA School of Public Health</p>
10:45 am – 11:00 am	Break	
11:00 am – 12:15 pm	Community Perspectives in TB Control and Elimination	<p>Facilitator: Robin Shrestha-Kuwahara, M.P.H., Behavioral Scientist, DTBE, NCHSTP</p> <p>Panelists: Representatives from DeKalb County and Fulton County Public Health Departments</p>
12:15 pm – 1:15 pm	Lunch	
1:15 pm – 1:45 pm	Interactive Group Discussion of Morning Sessions	Mark Nichter, M.A., Ph.D., M.P.H Professor, University of Arizona
1:45 pm – 2:00 pm	Charge to Breakout Session Groups	Robin Shrestha-Kuwahara, M.P.H. Behavioral Scientist, DTBE, NCHSTP
2:00 pm – 3:45 pm	Breakout Group Sessions I: Identifying Research Gaps/Needs Groups A & B: Internal Influences Groups C & D: External Influences	<p>Facilitators: Kelly McCarrier, M.P.H. Rachel Albalak, Ph.D. Gaby Benenson, M.P.H. Betsy Carter, M.P.H., C.H.E.S. DTBE, NCHSTP</p>
3:45 pm – 4:00 pm	Break (Reconvene in large group)	
4:00 pm – 5:00 pm	Report and Discussion of Breakout Group Sessions I (10 minutes for each group)	Paul Colson, Ph.D. Program Director, Charles P. Felton National TB Center
5:00 pm	Adjourn	

**DAY 2: Thursday, December 11, 2003**

7:30 am – 8:30 am	Breakfast	
8:30 am – 8:40 am	Overview of the Day's Activities	Nick DeLuca, M.A. Lead Health Education Specialist, DTBE, NCHSTP
8:40 am – 10:40 am	Breakout Group Sessions II: Determining and Prioritizing Research Questions/Methods Groups A & B: Internal Influences Groups C & D: External Influences	Facilitators: Kelly McCarrier, M.P.H. Rachel Albalak, Ph.D. Gaby Benenson, M.P.H. Betsy Carter, M.P.H., C.H.E.S. DTBE, NCHSTP
10:40 am – 11:00 am	Break	
11:00 am – 12:30 pm	Report and Discussion of Breakout Group Sessions II (10 minutes for each group)	Paul Colson, Ph.D. Program Director, Charles P. Felton National TB Center
12:30 pm – 1:30 pm	Lunch	
1:30 pm – 2:30 pm	Turning Research into Practice Panel Discussion	Facilitator: Jane Mezoff, Dr.PH., Behavioral Scientist, DTBE, NCHSTP  Presenters: Shawna Mercer, M.Sc., Ph.D. Health Scientist, Public Health Program Practice Office, CDC  Agatha Eke, Behavioral Scientist, Division of HIV/AIDS Prevention, NCHSTP  Leslie Boss, M.P.H., Ph.D. Air Pollution and Respiratory Health Branch, CDC
2:30 pm – 2:45 pm	Break	
2:45 pm – 4:00 pm	Potential Funding Opportunities Maintaining the Momentum: Recap and  Next Steps Closing Remarks	Kate O'Toole, M.B.A. Associate Director of Management and Operations, DTBE, NCHSTP  Nick DeLuca, M.A. Lead Health Education Specialist, DTBE, NCHSTP
4:00 pm	Adjourn	

## Appendix B: Presentation Slides

### BEHAVIORAL AND SOCIAL SCIENCE RESEARCH IN TUBERCULOSIS CONTROL

**Kenneth G. Castro, MD**

Director, Division of Tuberculosis Elimination  
Centers for Disease Control and Prevention

*Tuberculosis Behavioral and Social Sciences  
Research Forum, December 10-11, 2003*

### Behavioral and Social Science Research in TB Control

Kenneth G. Castro, M.D.  
Assistant Surgeon General, USPHS  
Director, Division of Tuberculosis Elimination  
National Center for HIV, STD, and TB Prevention  
Centers for Disease Control and Prevention



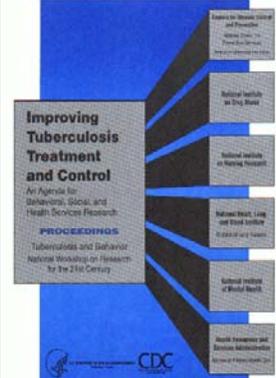
### Behavioral and Social Science Research in TB Control

- 1950s: “Health Belief Model” examined motivators of free TB screening programs
- Recently behavioral research studies emphasized treatment adherence



### Behavioral and Social Science Research Efforts in TB Control

- 1994: *TB and Behavior: National Workshop on Research for the 21<sup>st</sup> Century* (CDC co-sponsor)
- 2000: IOM Report, *Ending Neglect: The Elimination of Tuberculosis in the United States*
- 2003: TB Behavioral and Social Science Research Forum



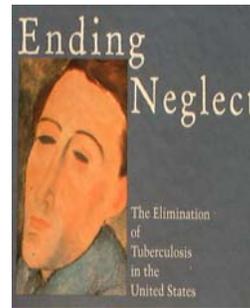
**Improving  
Tuberculosis  
Treatment  
and Control**  
An Agenda for  
Behavioral, Social, and  
Health Services Research

**PROCEEDINGS**  
Tuberculosis and Behavior  
National Workshop on Research  
for the 21<sup>st</sup> Century



### Themes from 1994 Conference

- How to inform the public about TB and overcome stigma?
- How to identify and reach persons at highest risk for TB?
- How to increase patient adherence?
- How to improve provider practices?
- How to identify and implement the best mix of TB control services?



“Studies are needed to determine how basic behavioral theories can enhance understanding for the creation of tailored interventions for high risk populations”

—Institute of Medicine Report, *Ending Neglect: The Elimination of Tuberculosis in the United States*, 2000



### IOM Call for Behavioral Science Research

- Explore impact of behavior change models on health seeking and adherence
- Identify cultural barriers to Rx, P&C, and role of incentives and enablers
- Tailor adherence interventions to needs, lifestyles, social support system, and beliefs
- Ensure translation of research into TB programs

### Role of Behavioral and Social Science Research in TB Control (1)

- Individual and interpersonal health behavior research
  - Patient care seeking behavior
  - Patient adherence behavior
  - Provider behavior
  - Health care service delivery



### Role of Behavioral and Social Science Research in TB Control (2)

- Systems research
  - Health systems structure and organization
  - Environmental, economic, and sociopolitical dynamics
  - Policies and laws



### Role of Behavioral and Social Science Research in TB Control (3)

- Identify, understand, and address broad range of relevant socio-cultural, behavioral, and structural issues
- Engage systematic, theory-based, multidisciplinary research with scientifically rigorous experimental and quasi-experimental designs



## BEHAVIORAL AND SOCIAL SCIENCES IN TUBERCULOSIS ELIMINATION

**Wanda Walton, Ph.D.**

**Chief, Communications, Education, and Behavioral Studies Branch  
Division of Tuberculosis Elimination,  
Centers for Disease Control and Prevention**

### **Behavioral and Social Science in Tuberculosis Elimination**

Wanda Walton, PhD  
Communications, Education, and Behavioral  
Studies Branch  
Division of Tuberculosis Elimination



### **Building TB Behavioral and Social Science Capacity within DTBE**

Communications, Education, and Behavioral  
Studies Branch

- Conduct research on individual and social factors affecting health seeking and treatment outcomes related to TB
- Provide consultation
- Provide technical assistance
- Coordinate behavioral science activities of DTBE, CDC, and others



### **Building TB Behavioral and Social Science Capacity within DTBE (cont.)**

- Division staff with behavioral and social science backgrounds
  - Communications, Education, and Behavioral Studies Branch
  - Clinical and Health Systems Research Branch, Health Systems Research Team
- Association of Schools of Public Health fellows



### **Selected Current Behavioral and Social Science Projects in DTBE**



### Patient Studies

#### Perceptions of TB Among Foreign-born Persons: An Ethnographic Study

- To understand the culturally-mediated perceptions, attitudes, and experiences regarding TB among five foreign-born populations in the U.S.

#### Culturally Appropriate Patient TB Education Materials

- To develop culturally and linguistically appropriate patient TB education materials



### Patient Studies (Continued)

#### Social Network Techniques in Expanding Women's Access to LTBI Treatment

- To assess the usefulness of social network techniques as tools to increase the identification of women during contact investigations

#### Study of Factors Associated with Acceptance of and Adherence to Treatment for LTBI

- To assess the knowledge, attitudes, and culture-specific beliefs about LTBI among several high risk groups



### Provider Studies

#### Identifying Barriers to the Implementation of the 2000 Targeted Testing and Treatment for LTBI Recommendations among Private Providers

- To identify barriers to the acceptance, implementation, and adherence to the guidelines and development of strategies to overcome barriers

#### Factors Influencing Health Care Worker Adherence to Worksite TB Screening and Treatment Policies

- To identify factors that facilitate or hinder health care workers' abilities or decisions to adhere to local protocols for annual TST and LTBI treatment



### Research Activities in the TB Epidemiologic Research Consortium

- Task Order 11: Addressing TB Disease Among African Americans in the Southeast
- Task Order 12: Assessing TB Knowledge, Attitudes, Beliefs, and Practices Among Private Providers Serving Foreign-born Populations
- Task Order 14: Developing Culturally Appropriate Educational Materials for Hispanic Service Organizations



### TB Behavioral and Social Science Research Forum



*Planting the Seeds for Future Research*



### TB Behavioral and Social Science Research Forum - 2003

#### Goals

- Identify and prioritize TB behavioral and social science research gaps
- Develop a feasible, goal-oriented research agenda that will guide TB behavioral and social science activities over a 5-year period



**Planned TB Activities Related to the Forum**

- Systematic inventory and review of published TB behavioral and social science literature
- A behavioral science list-serv for ongoing discussion and information exchange
- Ongoing workgroups on derived themes



**Tuberculosis is a social disease,  
and presents problems that  
transcend the conventional  
medical approach.**

Rene and Jean Dubos  
1952



**We've only just begun...**

Karen Carpenter



## KEYNOTE SESSION

### WHEN SACRED COWS BECOME THE TIGER'S BREAKFAST: DEFINING A ROLE FOR THE SOCIAL SCIENCES IN TUBERCULOSIS CONTROL

Jessica Ogden, Ph.D.

Technical Specialist

International Center for Research on Women



When sacred cows becomes the tiger's breakfast:

towards defining a role for the social and behavioral sciences in TB control

Jessica Ogden



#### Acknowledgements

- John Porter, London School of Hygiene & Tropical Medicine
- Mukund Uplekar, Communicable Diseases Cluster (Stop TB), WHO
- Sheela Rangan, Maharashtra Association of Anthropological Sciences
- Varinder Singh, Lala Ram Swarup Institute of TB and Allied Diseases
- Christian Lienhardt, Institute Research du Developpment, Senegal



#### Overview of presentation

- Situating a social science perspective
- Defining our roles:
  - Who are we not? orientations and contributions of the medical sciences in public health/TB control
  - Sacred cows whose time has come
  - Who are we instead? Strengths (and limitations) of social/behavioral science approaches (and another 'sacred cow')
- Proposed (draft) framework
- Key questions a multi-disciplinary approach can answer
- Some principles to guide our way forward



#### Classical Public Health Paradigms: 'elimination of disease' orientation

*Addressing the microbe in relation to an individual or population*

*Establishing foundations for diagnosis & treatment*

- Epidemiology: interactions between infectious agent, the host and the environment:
  - ? identify source of infection; interrupt transmission
- Microbiology & genetics
  - ? understanding the bacteria and developing new drugs
- Immunology & molecular biology
  - ? refining response to infection and developing new vaccines



Sacred Cow #1: the Broad Street pump handle

- Cholera epidemic in London, 1854
- John Snow identifies source of infection (water supply)
- John Snow removes pump handle (interrupts transmission)
- Cholera epidemic ends
- Theory of disease transmission proved
- Deaths prevented
- Community empowered?



Sacred Cow #2: TB and the limits of 'control'

- Control in the community
  - ? May lead to neglect of wider social realities: ordinary life, poverty, health care system constraints
- Power and Agency: who has them and who does not?
  - ? Who has the power to determine success? Who 'should' have it?
  - ? Are people able to take the actions we suggest?
  - ? Are people willing to take these actions?
- Questions of trust: does the control paradigm foster or challenge efforts to build trust?



Those of us involved in TB would do well to consider a shift in paradigm - a shift from a focus on **control** to a focus that privileges **care**.

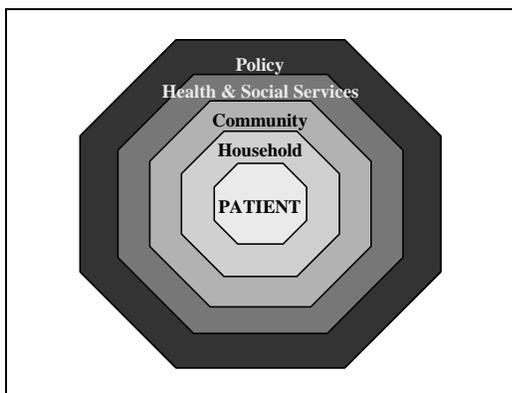
- Attentive to Trust
- Fostering Partnership



Social Science Paradigm: wellbeing orientation  
"the production of health"

*Understanding how the person and the disease interact in context of everyday life*

- Health outcomes understood in terms of context
- People's responses to ill health made intelligible
- Individual 'nested' within layers of social context
  - ? influencing whether individuals are able and willing to obtain, maintain and complete treatment
- Relating the individual to the local, national and the global





Sacred Cow #3: 'beliefs' and 'behaviors'

Study of 'beliefs' and 'behaviors' alone will not answer our questions

- what people think and what people do mediated by elements of culture but also by elements of social structure (e.g. poverty)
  - affects **availability**, **accessibility** and **acceptability** of health care options
  - impacts on **agency** - freedom/ability to make choices within a range of options, or the ability to take action according to belief

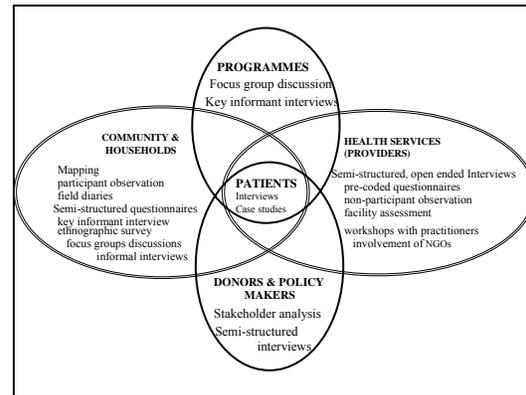
*Does not account for global and local power relations that **produce** and **shape** sickness and health*



Social structures within household, community, polity determine

- Who can adopt the sick role, and when
- Range of treatment **options** available
- Extent to which a given person has **access** to Rx
- Extent to which a given person will **obtain** diagnosis & Rx
- Extent to which a given person can **adhere** to Rx

These are all aspects to which research and policy can respond




Multi-disciplinary Approach

- Combines strengths of medical sciences and social/behavioral sciences
- Answering the 'why' questions
  - ? Why don't patients come for treatment?
  - ? Why do they only come when it's too late?
  - ? Why don't they complete their therapy?
- Answering the 'how' questions
  - ? How can we make our programs accessible and acceptable?
  - ? How can we meet health needs of community?
  - ? How can communities be involved as participants in their own health?

**KEYNOTE SESSION**

**BEHAVIOR, SOCIETY AND TUBERCULOSIS CONTROL**

**Masae Kawamura, M.D.**

**ACET Chairperson**

**Director, Tuberculosis Control Section**

**San Francisco Department of Public Health**

**Tuberculosis Clinic, Ward 94**

**San Francisco General Hospital**

**Behavior, Society and  
Tuberculosis Control**

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L. Masae Kawamura, M.D.  
Director, TB Control Section  
San Francisco Dept. of Public Health



**Program Perspective**

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- If TB control was exclusively related to its biologic cause and biologic cure, we would be close to eradication
  - But TB persists.....why?
    - Root causes are imbedded in society
    - Successful TB Control depends on the behavior of individuals at all levels: patient, provider, program and society
- 

**Where we are...**

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Good news: TB incidence is at an all time low  
Take a closer look:

- TB cases essentially unchanged (24% Mexican-born)
  - US born cases are dominated by African Americans and minorities
  - Case rates in inner cities and in poor communities in the SE US are as high as rates in developing countries
  - Outbreaks continue all over the US despite contact investigation
- 

**Where we are...**

---

TB has retreated in populations that are most difficult to reach

- Disenfranchised homeless
  - Addicts and substance users
  - Impoverished communities
  - Incarcerated
  - New and old immigrants
  - Individuals who move freely across the border
- 



### **TB Control success...**

We are premier experts on effective behavioral strategies to improve adherence and patient/provider relations

- Patient centered DOT
- Hiring culturally appropriate staff and providing cultural competence training and mentoring
- Use of housing, food, transportation vouchers, cash, methadone, education, etc as enablers and incentives



### **What we accomplished and continue to strive for..**

TB Control is about building and maintaining supportive/trusting relationships with patients and their communities

- Repairing societal connections with the disenfranchised
- Creating societal connections with those who are not yet integrated in society



### **We have done so much but it is not enough...**

Long way to go in engaging patients, providers, communities and society :

- undocumented persons and those living on both sides of the US-Mexico border
- Minority communities
- New immigrants

Contact investigation: methods and treatment adherence



### **Yet to be addressed...**

Health promotion and prevention

- Integration of targeted testing and LTBI treatment as a primary care issue
- Adherence to LTBI treatment beyond traditional approaches of education, incentives and enablers

Addressing the root causes

- Mobilizing communities and countries to take action
- Translating TB information into a meaningful format

### **What behavioral and social science research can do for TB control..**

- Validate what we are doing right and wrong
- Introduce new behavioral strategies that have been proven in other fields
- Refine current successful behavioral strategies to improve implementation
- Determine when integration strategies are appropriate and or harmful
- Frame TB data in its full context with demographics, social determinants, other health disparities and incidence of other diseases so it is meaningful to society

### **Word of caution about research and research application**

- Research interventions must be practical and well thought through
- If new resources will be needed for implementation, cost savings and health benefits should be well characterized

Remember: civil service front-line staff may prove to be very different than dedicated research staff



---

Although we may need to take a more  
“macro” approach to furthering our  
success in TB control, let us never  
forget the individual approaches and  
strategies that have made us incredibly  
successful.



# PRELIMINARY RESULTS FROM THE TUBERCULOSIS BEHAVIORAL AND SOCIAL SCIENCE LITERATURE REVIEW

**Cathy Rawls, M.P.H., C.H.E.S.**  
**ASPH Fellow**  
**Division of Tuberculosis Elimination,**  
**Centers for Disease Control and Prevention**

**Cristina Booker, M.P.H.**  
**Analyst**  
**Public Health Applications and**  
**Research Area**  
**Abt Associates Inc.**

**TB Behavioral and Social Science Research Literature Review**

Presented by:  
Cathy Rawls, M.P.H., CHES,  
ASPH Behavioral Research Fellow, DTBE, CDC

Cristina Booker, M.P.H.,  
Abt Associates, Inc.

Tuberculosis Behavioral and Social Science Research Forum  
December 10-11, 2003



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**Literature review and database development**

Activities:

- Created abstraction form and guide
- Reviewed and analyzed articles
- Developed access database
- Synthesized preliminary results

1

**Literature review methods**

Search strategy:

- Conducted in OVID across 5 databases
  - CINAHL, Embase, Medline, PsycInfo, and Sociofile
- Focused on behavioral, sociological, and cultural factors for TB prevention and treatment
- Used refined subject headings and keywords

3

**Inclusion criteria**

- TB research that used social science methods or applied social science theory or concepts
- Published after 1980
- US-based and/or international literature in English
- Published works (including scientific, peer-reviewed literature, review articles, books (including book chapters), and meta-analyses)

4

### Key items abstracted

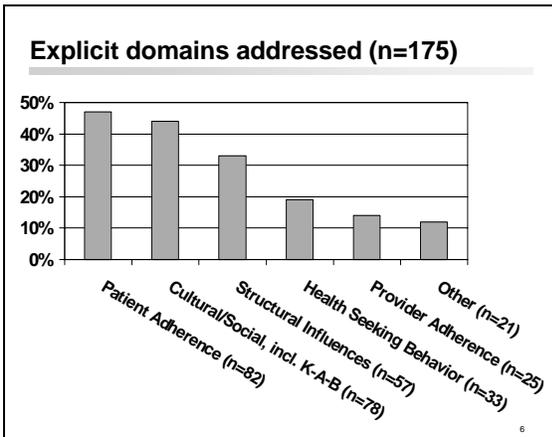
- **Study descriptions and methods**
  - Topic areas, study design, theory, sampling design, data collection methods, target populations, geographical and structural settings
- **Key results/findings**
- **Limitations**
- **Conclusions**
- **Recommendations**

### Article types

■ **175 documents reviewed/abstracted (mostly peer-reviewed journal articles)**

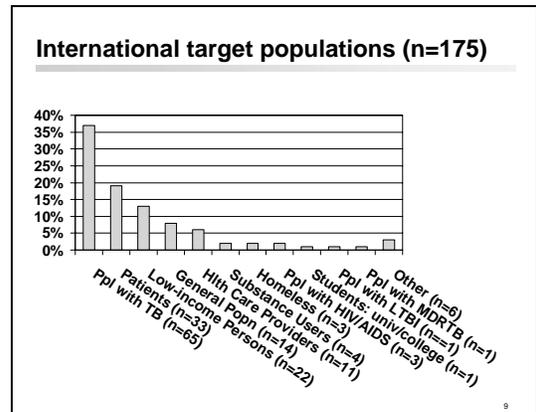
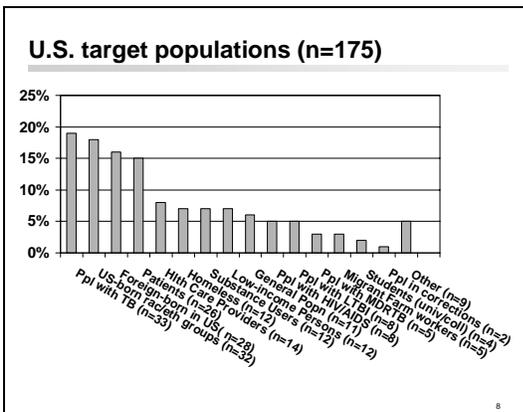
Article Type	Percentage
Research	59%
Evaluation	12%
Non-research	29%

■ ~33 involved interventions



### Geographic locations (n=175)

Literature	n	%
U.S.-based	82	47
International-based	63	36
Non-location specific (e.g., concept/position papers)	30	17



### Themes from the literature review

- Underlying social/cultural factors:
  - Poverty, gender differentials
  - Health beliefs
- Health seeking behavior:
  - Barriers and facilitators to care
- Patient-related adherence:
  - Social support, economic aid, & education
- Provider-related adherence:
  - Medical education about TB diagnosis & treatment

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### Themes from the literature review (cont.)

- Health education strategies:
  - Essential for TB control/eradication
- TB control/eradication strategies:
  - Integration with other health services
- Resource/funding allocations:
  - Interdisciplinary research and interventions that integrate biological, psychological, behavioral, and social variables

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### Next steps: literature review report

- Based on the data abstraction forms & Access database
- Features:
  - Descriptive data
  - Key outcomes/results
  - Needs, gaps, and recommendations for future research or practice
- Expected to be finalized for CDC in early 2004

12

### Next steps: database

- Created in Access to store the data abstraction forms
- Database features:
  - Keyword searches
  - Preset queries and reports
- Expected to be finalized for CDC in early 2004

13

### Acknowledgements

#### Literature review team:

#### CDC Team

Nick DeLuca  
Kelly McCarrier  
Jane Mezoff  
Cathy Rawls  
Robin Shrestha-Kuwahara

#### Abt Assoc. Team

Cristina Booker  
Ted Hammett  
Brandon Long  
Jotham Stavely

14

# NEIGHBORHOOD HEALTH MESSENGERS: USING LOCAL KNOWLEDGE, TRUST AND RELATIONSHIPS TO CREATE CULTURALLY EFFECTIVE TUBERCULOSIS EDUCATION AND CARE FOR IMMIGRANT AND REFUGEE FAMILIES

**Stefan Goldberg, M.D.**  
**Medical Officer**  
**Division of TB Elimination,**  
**Centers for Disease Control and Prevention**

## Neighborhood Health Messengers

Using local knowledge, trust, and relationships to create culturally effective TB education and care for immigrant and refugee families

Patrick Chaulk, MD, MPH  
Annie E. Casey Foundation  
Baltimore City Chest Clinic  
Johns Hopkins Schools of Medicine and Public Health  
Baltimore, MD

Stefan Goldberg, MD  
CDC

## Impact of Immigrants and refugees on U.S. Culture

- **Large influx of immigrants and refugees during the 1990s:**
  - Increasingly a multi-cultural nation
    - Over 300 languages spoken in the U.S.
  - Nearly 20% of the U.S. population speaks a language other than English:
  - Spanish speakers increased by 43% between 1990 and 2000
  - Over 21 million individuals self-report that they speak English less than "very well".
- **Virtually all these refugees and immigrants come from countries endemic with TB**
  - TB account >50% of all active US cases
  - TB is the leading marker for racial health disparities

Source: US Census, CDC, National Center for Health Statistics

## Program Performance Measures

Therapy acceptance rates  
Treatment completion rates  
Referrals for other social services

### Seattle's Cultural Case Management Program: 2,194 immigrants tested 1999 - 2000

442 offered treatment  
389 (88%) started on treatment  
319 (82%) completed 6-9 month regimen  
(vs. 60% nationally, 37% Seattle)  
93% of client encounters also involved discussions about housing, ESL, mental and physical health, employment and employment training, child care, transportation .

## 1998 Seattle-King County IPT assessment & epidemiology

- **Epidemiology**
  - 67% of cases foreign-born
  - Greatest immigration from Former Soviet Union, Former Yugoslavia, and Somalia
- **Findings**
  - Continued growth in demand for TB clinic services
  - TB clinic move to Harborview Medical Center, site of *Community Housecalls* and *Ethnomed* programs
- **Recommendations**
  - Stop "routine" TB clinic preventive therapy except for highest risk (ie. "regardless of age" categories and children)
  - Develop **Cultural Case Management program** in partnership with *Community Housecalls*

### Cultural Case Management for Treatment of Latent TB Infection

- Federal and grant-funded partnership with Harborview Medical Center for “bilingual, bicultural case management.”
- Three major groups of new refugees and immigrants: Somali, Bosnian, and Russian-Ukrainian.
- All refugees evaluated by the TB Clinic were evaluated in a custom-designed database January 1999 through June 2001.

### Cultural Case Management Principles

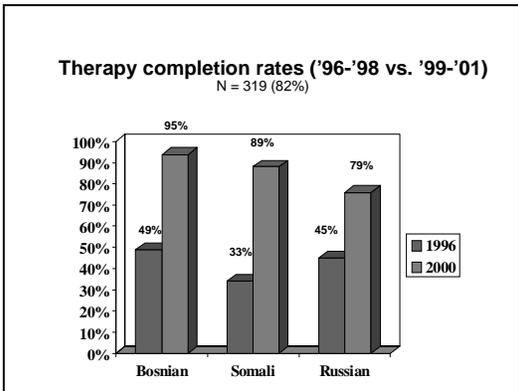
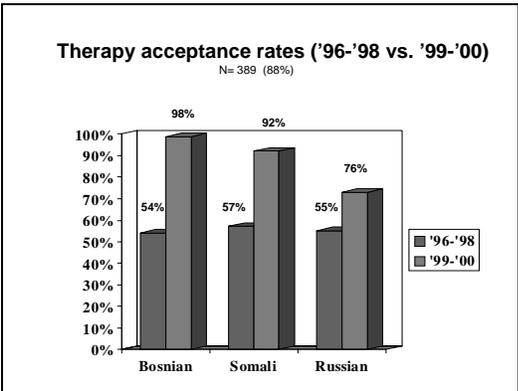
- Based on experience of Harborview Medical Center’s Community Housecalls Program
  - 2-way communication and support between providers and affected individuals and communities
  - Case Managers - Cultural Mediators (CCM)

### Neighborhood Health Messengers: “Cultural Case Managers (CCM)”

- **Bilingual, bicultural program using local knowledge to create trust and relationships** among immigrants and refugees.
  - **Extensive community mapping/participatory research approach**
    - Identify local assets, understand local culture and practice.
  - **Recruit and train community residents to:**
    - Help create effective messages and education strategies
    - Serve as TB field workers and case managers
    - Conduct extensive neighborhood outreach to:
      - » Recruit residents for TB testing and therapy
      - » Assist with clinic visits, home delivery of medications
      - » Conduct at least monthly house calls; twice-a-week phone calls;
      - » Establish social networks; assist with other needs.

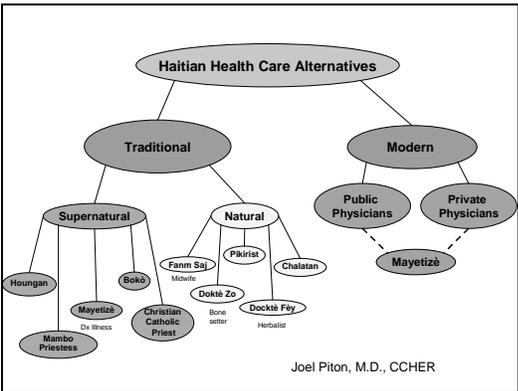
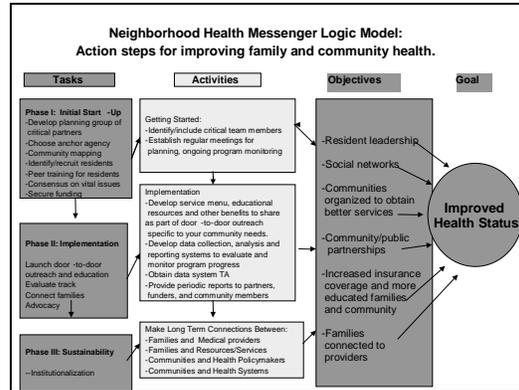
### Characteristics of Effective CCMs

- **Knowledge:**
  - Of refugee language beyond mere translation: refugee cultures, customs, beliefs, gender roles, family structure. **Creates credible messages.**
- **Experience:**
  - With history of effectively serving the target refugee community. **Creates relationships.**
- **Social standing:**
  - Highly regarded in the target refugee community; just “being from the community” is necessary but not sufficient. **Creates trusted messengers.**
- **Capacity:**
  - Belief in and ability to explain U.S. medical strategies and its complex health care system. **Creates effective education.**



### Elements of Success

- Interviews suggest the success of this program is largely due to the outreach workers building trusting relationships with their clients.
  - Bilingual, bicultural
  - Patient-centered, community-centered approach
  - Supporting needs identified by the patient and the community



### Haitian Collaborative Project

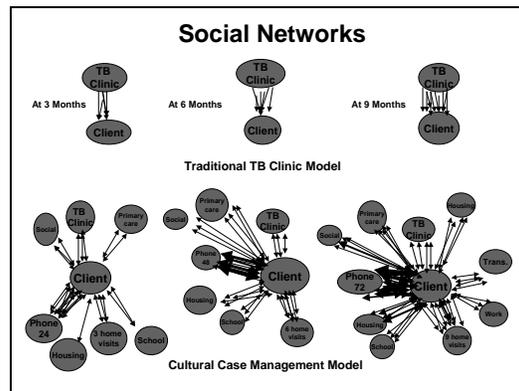
**Radio outreach**

**Community focus group**

## Rete An Sante, Pran Swen Kó-w

stay healthy, take care of your body

Your doctors care about you and want you to stay healthy



### Selected Cultural Findings From Community Mapping

- **TB more stigmatizing than AIDS**
  - Often viewed as a curse or test from God.
- **No framework for “latent infection”**
  - Treatment without symptoms = experimentation.
- **Pharmaceuticals are dangerous**
  - Not natural products
  - Pollutants
  - Liquid “safer” than pills
  - US medicines appropriate for Americans not them.
- **Mistrust of American physicians**
  - Mistrust/insecurity of American systems especially since 9/11
- **Health belief system often complex**
  - Secular, religious, and mystical or supernatural components

### Selected Cultural Findings From Community Mapping

- **Translated words carry different semantics**
  - “Negative” versus “Positive” test results.
- **PPD reactions are common**
  - So, in some populations, they are perceived as “normal”.
  - Or, are a result of childhood immunization with **BCG**.
- **Bosnian Story**
  - Interpreter: “don’t trust what they tell you about TB”
- **Russian Story**
  - Initial interpreter telling the wrong things.
  - Repeat BCG and PPD till Positive showing protection from TB

### Selected Cultural Findings From System Mapping

- “Treating your TB is very important”...but client can’t get a TB clinic appointment for at least another 2 -3 months.
- Clinic visit sometimes disrespectful.
- Recommendations on the treatment of LTBI inconsistent:
  - 12 v. 6. v. 9 months; eligibility age raised from 29 to 50.
- **Fear of becoming a focus of research and publicity**
  - E.g. reporting unfamiliar symptoms (has become a reason for concealing personal health information.)
- Doctors seem more concerned with saving time than serving clients; Too busy to spend the time to understand their health concerns; Lack patience, compassion and care patients expect of them.
- Immigration process misleading: (-) CXR = no TB so:
  - “Why am I being screened again when I was screened in Somalia?”
  - How could I have TB if I was told I didn’t have it when I left Somali?
  - (+) PPD = prior BCG
- US health care system too confusing

### Other Lessons Learned

- **Cultures are not monolithic:**
  - E.g., nearly 40 tribes in the Sudan w/ war-like histories
  - Class and SES distinctions
- **Immigrants have many other more important concerns**
  - Many do not speak English and “interpreters” may speak on behalf of the health care system not client.
  - Illiteracy high: graphics needed for communication/education
  - Employment: limited marketable skills.
  - Misunderstanding/misinterpretation of some our health care practices.
    - Western male clinicians and immigrant female clients unacceptable.
  - Erosion of traditional male power and roles.

### Replication

- Matapan:
  - Community Center for Haitian Education & Research
- San Diego
  - Nile Sisters, Horn of Africa, Africa Call
- District of Columbia
  - Mary Center For Women & Children
- Denver
  - Sisters of Color For Education

### Next Steps

- **Complete replication, refine documentation & evaluation**
- **Influence the field through:**
  - Local CCM “experts”; replication tool kit**
  - Dissemination**
    - Presentations at professional meetings
    - National Jewish Medical Center TB Course
    - CDC, national, state, local TB control programs
  - Publications:**
    - Clinical results (IJTLD 8(1):1-7)
    - Cost effectiveness analysis
    - Cultural lessons document
  - Peer site exchange in May 2003
  - RESULTS.org**
  - Casey Public Health Fellowship @ CDC

## Final Thoughts

- **Costs:**
  - Goal is to **cross train CCMs and thereby cross fund**
  - Leverage Medicaid and **other funding streams**
- **Replication**
  - **Focusing on the process** not the knowledge
    - **Focus groups are an effective engagement strategy to develop** not just knowledge but **trust and relationships**
  - Go beyond a TB program to **broader community building agenda**
    - Promote the benefits of this strategy
  - **Refine asset mapping and replication tool kit**
  - **Develop customized technical assistance pool**

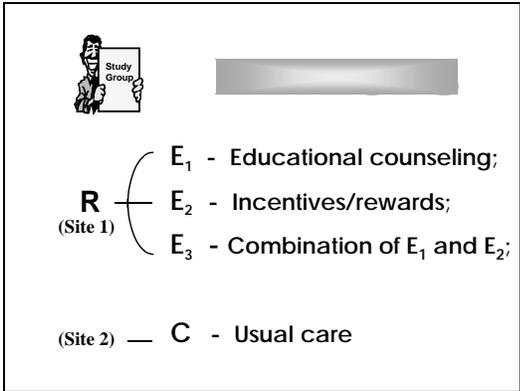
**PSYCHOSOCIAL, SOCIAL STRUCTURAL, AND ENVIRONMENTAL DETERMINANTS OF TUBERCULOSIS CONTROL**

**Donald E. Morisky, Sc.D., M.S.P.H., Sc.M.**  
**Professor, Department of Community Health Sciences**  
**UCLA School of Public Health**

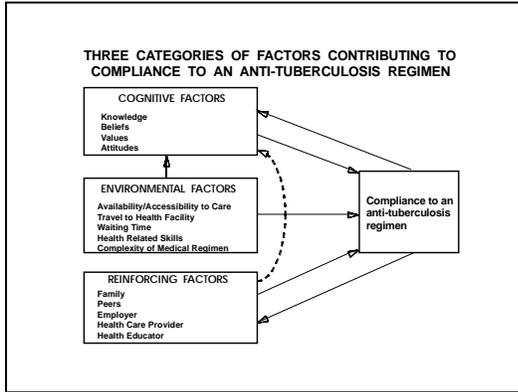
**Psychosocial, Social Structural, and Environmental Determinants of TB Control**

**Donald E. Morisky, Sc.D., M.S.P.H., Sc.M.**  
**Professor and Program Director for Social and Behavioral Determinants of AIDS and Tuberculosis Training**  
**Department of Community Health Sciences**  
**UCLA School of Public Health**

- 
- Typically associated with homelessness, drug or alcohol abuse and/or minimal educational achievement
  - Multiple drug resistant TB (MDR-TB)
  - Cited as the major cause of the increase in incidence rates of TB
  - Directly Observed Treatment -- Short Course (DOTS)
  - Reason for Dots.

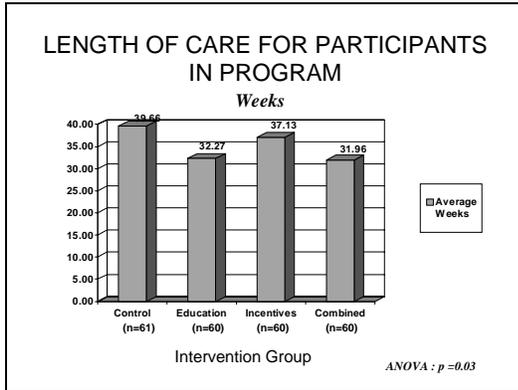


- 
- A total of 241 patients were randomly assigned to one of three intervention groups or the control.
  - The patients were followed throughout their treatment program. Cognitive and behavioral outcome markers were used to assess the effectiveness of the educational intervention.



**DEMOGRAPHIC**  
 For all eligible participants interviewed (N=241)

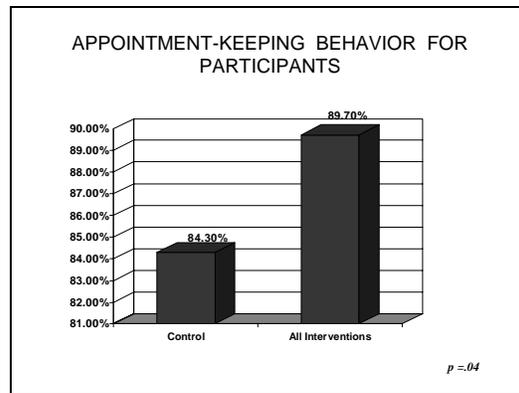
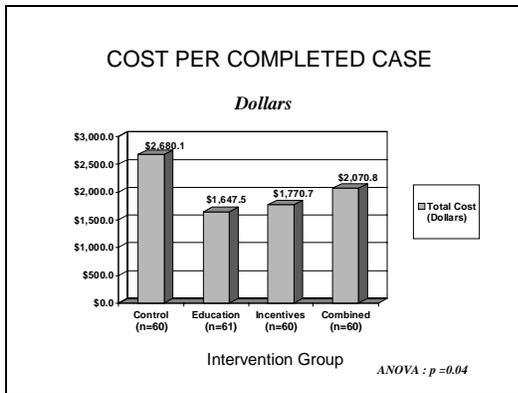
Survey Item	Distribution
<b>Male</b>	<b>63%</b>
<b>Ethnicity</b>	
- Hispanic	62%
- Black	25%
<b>Spanish-speaking</b>	<b>60%</b>
<b>Unemployed</b>	<b>63%</b>
<b>Education &lt; High School graduate</b>	<b>55%</b>
<b>Annual Family Income &lt; \$10,000</b>	<b>42%</b>

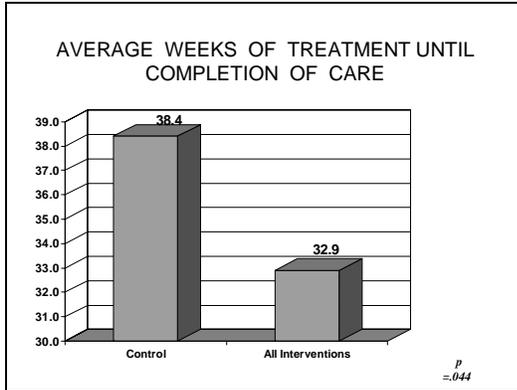


**INTERVENTION EFFECTS BETWEEN BASELINE INTERVIEW AND EXIT INTERVIEW**

Intervention Group	Percentage Difference (Post-test vs Pre-test)	p - value (Paired t-test)
<b>Knowledge Scale</b>		
C - Control	+ 1.5%	.860
E <sub>1</sub> - Education	+ 31.7%	.009**
E <sub>2</sub> - Incentives	+ 20.5%	.059
E <sub>3</sub> - Combined	+ 26.7%	.046*
<b>Medication Compliance</b>		
C - Control	+ 9.7%	.47
E <sub>1</sub> - Education	+ 26.5%	.006**
E <sub>2</sub> - Incentives	+ 14.1%	.067
E <sub>3</sub> - Combined	+ 16.7%	.061

\* :  $p < 0.05$ ; \*\*  $p < 0.01$





**Factors to consider for drop out rates**

- ☞ **Ethnic Background**
- ☞ **Sex**
- ☞ **Unemployment**
- ☞ **Homeless**
- ☞ **Drug Use**
- ☞ **HIV**
- ☞ **Primary Language**
- ☞ **Marital Status**



**Why Focus on Adolescents ?**

- Incidence of TB increases at adolescence<sup>1</sup>
- Adolescents more susceptible to active TB<sup>2</sup>
- Time interval between infection and development of active disease is shorter<sup>3</sup>
- Adherence among adolescents

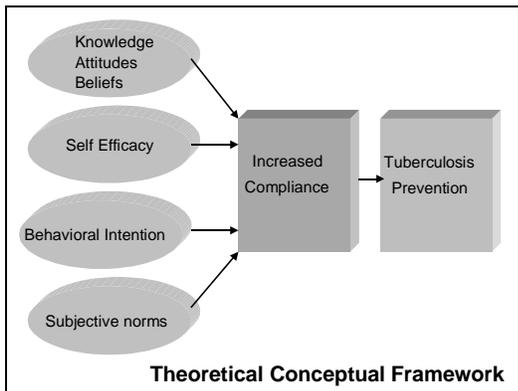
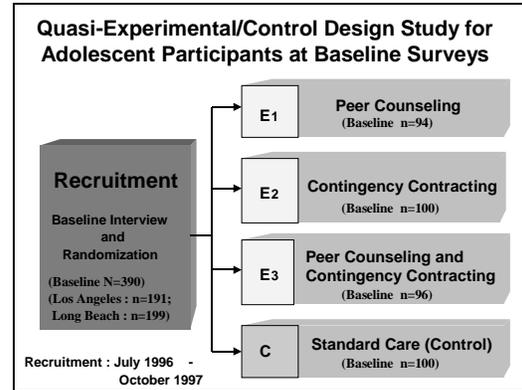
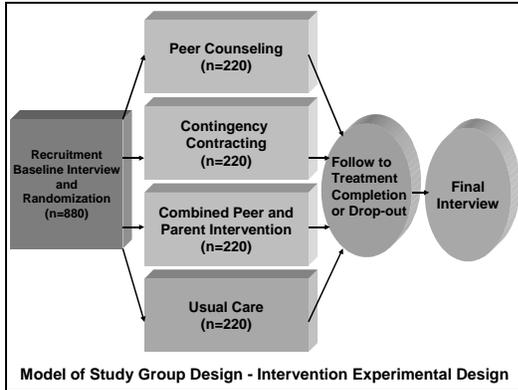
1. Starke, JR. Infectious diseases of health significance among children and adolescents in Texas. *Texas Med* 90:35-45, 1994.  
 2. Wilcox WD, Laufer S. Tuberculosis in Adolescents. A Case Commentary. *Clinical Pediatrics*, 1994; 33:258-262.  
 Smith MHD. Tuberculosis in adolescents. *Clinical Pediatrics*, 1967; 6:9-15.  
 3. McCue M, Aliff LA. Using peer helpers for tuberculosis prevention. *J Am College Health* 1996 Jan, 44(4):173-6.

**Background of TB Study**

- Rationale: Preventive TB treatment study
- Sites: Long Beach and Inglewood Public Health Clinics
- Participants: Ethnically diverse adolescents aged 11-19 years old (n=794)
- Randomized in 4 treatment groups (peer counseling only, incentive only, combination of peer counseling and incentive, usual care)
- Procedure-Face to face interviews, baseline and 6 month follow-up
- The present report only includes foreign-born adolescents (80% of study population)

**Independent Variables**

- Socio-demographic variables
- Clinic related variables (e.g. waiting time)
- High-risk behaviors (alcohol, drug use, gang membership, incarceration)
- Psycho-social variables (self-esteem, mastery, self-efficacy)



- ### Characteristics of Foreign-born Adolescents
- 20% failed to complete treatment
  - 45% live with both parents
  - 78% rate their health as good
  - 2% are gang members
  - 23% are sexually active
  - 8% report a history of incarceration

- ### Factors Associated with Completion of Care
- Age (OR=0.85; 95% CI: .76-.85)
  - Asian ethnicity (OR=3.37; 95% CI: .99-.11.44)
  - Living with both parents (OR=2.13; 95% CI: 1.37-3.31)
  - Speaking only English with parents (OR=0.34; 95% CI: .16-.74)
  - Sexually active (OR=0.43; 95% CI: .28-.68)
  - Gang member (OR=0.26; 95% CI: .07-.87)
  - Incarceration (OR=0.50; 95% CI: .26-.94)
  - Medication taking behavior (OR=1.25; 95% CI: 1.14-1.37)

- ### Independent Predictors of Completion of Care
- Medication taking behavior (OR=1.28; 95% CI:1.16-1.41)
  - Living with both parents (OR=1.87; 95% CI:1.08-3.25)
  - Sexual intercourse (OR=0.54; 95% CI-.31-.94)
  - Speaking mostly or only English with parents (OR=.34; 95% CI .12-.91)

### **Recommendations**

- Need to collect more specific information
- Encourage clinic procedures that increase compliance
- Recruit supportive family members /friends to facilitate treatment
- Future research should focus on foreign-born adolescent populations in various regions of the US

### **Individual Determinants of Compliance**

- Understanding the medical regimen
- Belief in the benefits of treatment
- Positive attitudes regarding treatment
- High levels of self esteem and self efficacy

### **Environmental Determinants of Compliance**

- Family member reinforcement in the home
- Good patient/provider communication
- Systematic approaches for patient monitoring, follow up and reinforcement
- Convenience of picking up medication from the clinic
- Use of pill containers and cueing behaviors

### **Individual/Environmental Determinants of Completion of Care**

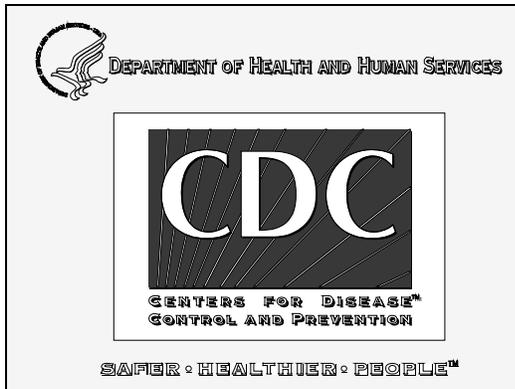
- Regular appointment-keeping behavior
- High levels of adherence
- Community health workers
- Reinforcement of positive behaviors by health care staff
- Peer counselors to clarify health concerns

# SHARPENING THE FOCUS ON TURNING RESEARCH INTO PRACTICE: THE PROMISE OF PARTICIPATORY RESEARCH APPROACHES

Shawna Mercer, M.Sc., Ph.D.

Health Scientist,

Public Health Practice Program Office, Office of the Director  
Centers for Disease Control and Prevention



**Sharpening the Focus on Turning Research into Practice: The Promise of Participatory Research Approaches**

Shawna L. Mercer, PhD, MSc  
Office of Science and Extramural Research  
Public Health Practice Program Office  
Centers for Disease Control & Prevention



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**Bottleneck in Translating Public Health Research into Practice**

- There is insufficient recognition of the complexities inherent in putting public health research findings into practice across diverse communities, settings, and situations
  - To be relevant for practice, research must meet diverse practice needs



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**Challenges for Taking Research Results to Practice**

1. Internal vs. external validity (generalizability):
  - Internal:
    - Are we measuring what we purport to measure?
  - External:
    - How applicable is this to real-world rural settings and situations?



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### Challenges for Taking Research Results to Practice

2. Best practices vs. locally appropriate and affordable practices

- ▶ For special populations
  - e.g., minority populations in rural areas
- ▶ In underserved areas
- ▶ For those of lower socioeconomic status, lower education
- ▶ Behavioral vs. medical interventions



### Best Practice Application Gaps

- Accessibility gap
  - ▶ Do I have the same resources as the experimenters?
- Credibility gap
  - ▶ How different is their situation of practice from mine?
- Expectations gap
  - ▶ Is it really necessary for me to strive for such lofty goals in my practice?
    - » Lancaster B. Closing the gap between research and practice. Health Educ Q 1992;19:408-411



### A Solution for Taking Research Results to Practice

☞ An *upstream* approach

- ▶ By actively engaging practitioners, policy makers, community members in the research process, it is more likely the results will be relevant to their needs



### Participatory Research is...

- “Systematic inquiry
- With the collaboration of those affected by the issue being studied
- For the purposes of education and taking action or effecting social change”

Green, et al., 1995  
Study of Participatory Research in Health Promotion.



### What is Participatory Research?

- It is not a method
- It is an approach
  - ▶ Involves engaging potential users and beneficiaries of the research in the research process
  - ▶ A wide range of study designs and research methods can be used
    - Selection depends on the research questions and feasibility issues



### Whose Participation Should be Sought?

- Who is to be affected by the research results?
  - ▶ Geographic communities
  - ▶ Other groups sharing common characteristics
    - Ethnic groups, practitioners, policy makers, health departments
    - Minority or special populations living in rural settings





### EPRP's Second Round of Grants: Response and Funding

- **Response:**
  - 570 letters of intent (LOI)
  - 311 full applications
- **Funding:**
  - 40+ projects approved for funding
  - ~\$11.4 million
  - ~25 projects funded
  - Each project: ~\$450,000 per year for 3 years



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### Range of Projects Funded

- **Cross-cutting research such as:**
  - Diabetes, asthma, obesity
  - physical activity, nutrition, tobacco prevention, drug prevention, violence/injury prevention
  - youth and school-based health
  - workforce development
  - reduction of health disparities
  - Increasing access to care



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### Diabetes in Hispanic Appalachians

- **Issue:**
  - Growing numbers of Hispanics moving into rural Appalachia (migrant and permanent)
  - High levels of diabetes; low access to care
- **Research team:**
  - East Tennessee State University Researchers
  - Hispanic community and provider partners
- **Site:**
  - Southern Appalachia
- **Intervention:**
  - Development of tailored interventions to enhance detection, management, and prevention of diabetes
  - Education to increase the capacity of Hispanic community to identify and solve its other health problems



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### References

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- Minkler M & Wallerstein N (Eds.). *Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass, 2003.

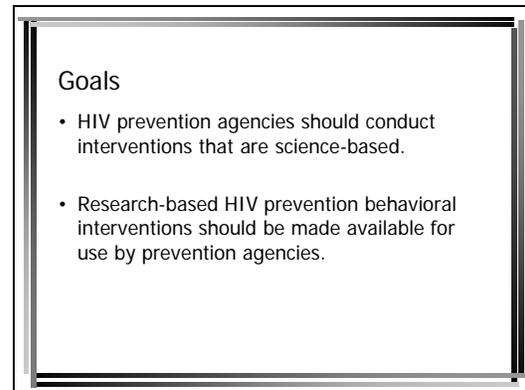
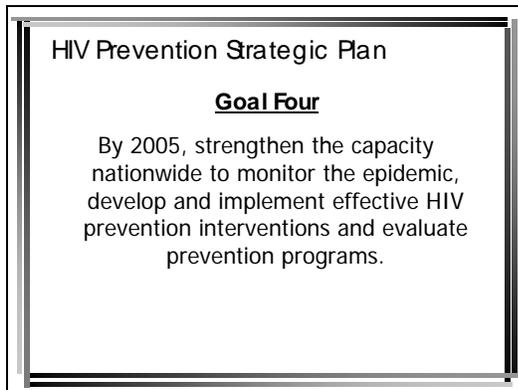
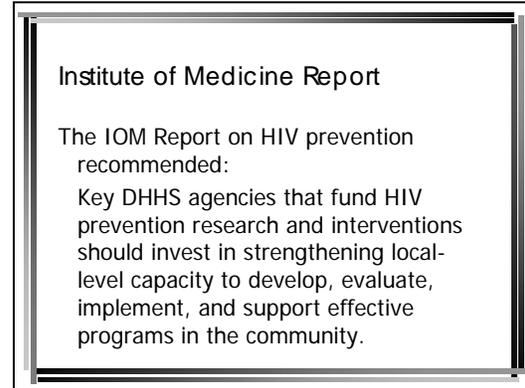
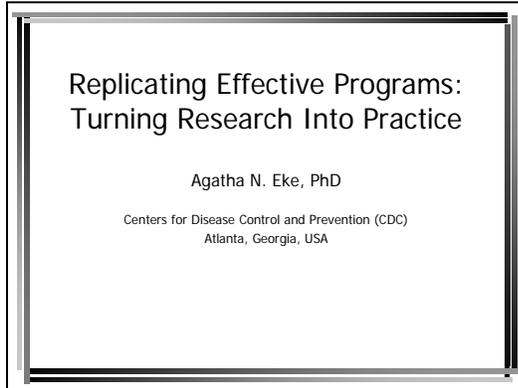


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## REPLICATING EFFECTIVE PROGRAMS: TURNING RESEARCH INTO PRACTICE

**Agatha Eke, Ph.D.**  
**Behavioral Scientist,**  
**Division of HIV/AIDS Prevention,**  
**Centers for Disease Control and Prevention**



### Experience

Our experience in the Centers for Disease Control and Prevention's (CDC) Replicating Effective Programs (REP) project has taught us valuable lessons on what researchers & prevention agencies need to do to achieve these goals.

### A New Model of Behavioral Research

- Old Model = Research project ends with publication of articles that present research findings
- The research community has a responsibility to translate and transfer the fruits of research in ways that are useful to society [**A shift in paradigm**].
- New Model = Active partnership among researchers, prevention agencies, & communities at all stages of research & transfer into practice

### The REP Project: Part of the New Model

- Started in 1996 as a 2-year project
- US\$400,000 for each effective, research-based intervention
- Converts interventions into packages (kits) for use by local HIV prevention agencies
- Funds researchers to collaborate with community advisors to prepare the intervention packages
- Other prevention agency collaborators conduct trials/case studies of implementing the intervention using the packages, training, & TA

### The REP Project: Continued

- So far, REP has:
  - converted 7 interventions into packages
  - 3 packages in formal preparation
  - 1 package in informal preparation (*CITY*)

### REP Criteria to Determine An Intervention's Effectiveness

- Completed research study
- Measured behavioral or biologic outcomes
- Collected pre- and post-test data
- Used treatment & control/comparison groups
- Retained  $\geq 70\%$  of participants
- Evaluated using quantitative statistics
- Found to have statistically significant positive effects

### Translation and Transfer Steps for Researchers

#### Year 1 of REP

- Form advisory committee of HIV prevention providers and community members
- Translate science into lay language
- Develop package contents & format with advisory committee
- Find other HIV prevention agencies to field test package

### Translation and Transfer Steps for Researchers (cont')

#### Year 2 of REP

- Orient agency to intervention and collaboratively tailor & adapt it
- Train agency staff in technical skills & intervention delivery
- Provide technical assistance on implementation and problem-solving
- Evaluate the process & debrief the agency staff
- Refine package based on agency input & produce final version

### Transfer and Implementation Phases for HIV Prevention Agencies

#### Pre-Implementation Phase

- Obtain administrative, agency staff, & community buy-in
- Line up resources & designate responsibilities
- Orient gatekeepers
- Get training for staff who will conduct the intervention

### Transfer and Implementation Phases for HIV Prevention Agencies (cont')

#### Implementation Phase

- Tailor delivery to agency & local circumstances
- Adapt intervention for population & setting
- Schedule start-up steps
- Assure quality of delivery & fidelity to Core Elements
- Obtain technical assistance

### Transfer and Implementation Phases for HIV Prevention Agencies (cont')

#### Maintenance Phase

- Dedicate sufficient resources
- Institutionalize as part of agency's mission
- Re-adapt to changing circumstances
- Obtain gatekeepers' acceptance of intervention modifications

### Lessons for Converting Research into Prevention Practice

- Keep detailed, accessible records of interventions
- Identify "core elements" of interventions to simplify implementation by prevention agencies
- Researchers should work with prevention agencies in converting research into practice
- Develop simple, clear packages of "How to" materials designed for prevention agencies
- Shorter & simpler interventions are easier to implement

### Records of intervention

- Intervention's design & protocol
- Copies of original posters, brochures, videos, & other materials
- Details of procedures & logistics
- Costs of intervention separate from costs of research

### Identify "core elements" of intervention

- Critical features of an intervention's intent & design
- Thought to be responsible for an intervention's effectiveness
- Identified by operationalization of the underlying theory & experience in using the intervention

### Researcher and prevention agency collaboration

- Have researchers, agencies, and communities design & test packages together
- Adapt interventions to agency resources, community needs, & local priorities
- Provide training & technical assistance along with packaged intervention protocols
- Collaborate until agency is comfortable with the intervention

### Packages of "How to" materials

#### Protocol manual

- » Sufficient detail but concise
- » Non-technical language
- » Clearly written
- » Practical
- » Appealing & easy to use

Sample posters, brochures, videos, and other materials

### Short and simple interventions

- Few components
- Brief
- Easy delivery skills
- Simple technology
- No monetary incentives

New Model = Active partnership among researchers, prevention agencies, and communities at all stages of research and transfer into practice

If this perspective is accepted as the model for putting science-based interventions into practice,

- Researchers should design interventions that can be conducted by prevention agencies
- Researchers need to plan ahead for the transfer process during their research studies
- Funders need to pay for all stages of the research, transfer, and implementation process

### Conclusions

- REP is a part of a new model for researchers & funders.
- Transfer is complex and expensive but possible.
- Transfer requires alliance between researchers & prevention agencies.
- Infrastructure & support for conversion, dissemination, & implementation are needed.
- Challenges will be compounded when transfer becomes nationwide.
- Challenges of wide-scale transfer of effective behavioral interventions must be met to impact the AIDS epidemic.

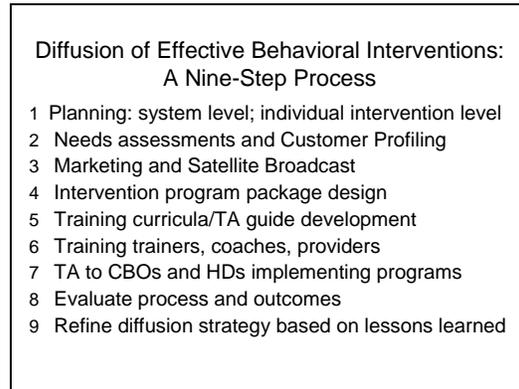
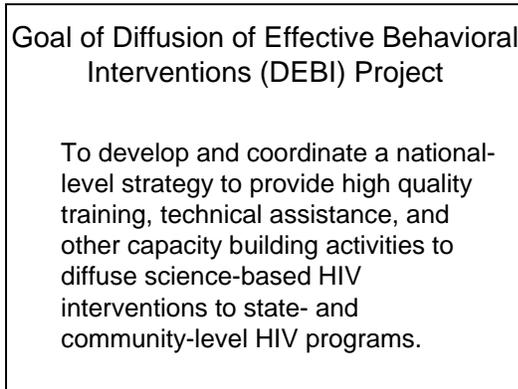
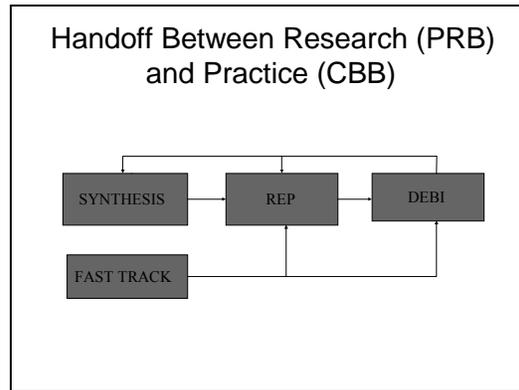
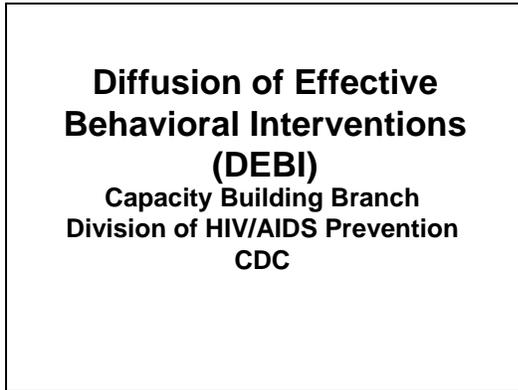
For more information

Visit the *Replicating Effective Programs* plus (REP+) website at:  
[www.cdc.gov/hiv/projects/rep/default.htm](http://www.cdc.gov/hiv/projects/rep/default.htm)

Consult CDC's special journal supplement on technology transfer:  
Turning HIV Prevention Research Into Practice,  
*AIDS Education and Prevention*, 12,  
Supplement A, 2000

## DIFFUSION OF EFFECTIVE BEHAVIORAL INTERVENTIONS

**Agatha Eke, Ph.D.**  
**Behavioral Scientist,**  
**Division of HIV/AIDS Prevention,**  
**Centers for Disease Control and Prevention**



### DEBI Three Phases

- **Planning Phase (12-months):** design/pilot/ conduct interest/needs assessment; produce pkg. copies; design/pilot evaluation tools; build partnerships; plan marketing & diffusion strategy; develop/pilot TOT/TOC, TOF guide, & TA Guide
- **Implementation Phase (3-months):** train master trainers & coaches ("Training Institute")
- **Roll-Out Phase (24-months):** train 700 agency facilitators, provide TA, evaluate process, monitor outcomes

### Training Components

- **Curricula design** to teach prevention providers the methods to implement the intervention.
- **Intervention institutes** to teach trainers how to train direct prevention service providers.
- **Regional, state-wide, and local intervention trainings** to widely diffuse the intervention technology to direct prevention service providers.

### Intervention Training Curricula

- Approved by original researchers
- Highly explicit, detailed guidance
- Based on Adult Learning Principles
- Appropriate for as a TOT or direct provider curriculum
- Piloted/ revised prior to major roll-out.

### Intervention Institutes Train the Trainer/Coach

- Researcher involvement
- Intensive skill-building around the intervention
- Develops trainer/coach partnerships
- Develops training/coaching implementation plans

### Regional, state-wide, and local intervention trainings

- Coordinated by AED
- Provided by training teams
- Intervention manuals and other intervention materials will be distributed

### Training Partners

- CBB Training Team
- Prevention Training Centers
- Education Training Network
- CBA Trainers

### Family of Coaches

- CBA Priority Area 2 Providers
- BSSV
- CBB Science Application Team
- Health Department capacity building providers

### Coaching

Coaching is on-site, phone, or e-mail technical consultation by a mentor or role-model technical assistance or capacity building provider

### Other supports for diffusing effective interventions

- Satellite Broadcasts
- Chat rooms or list serve
- Newsletters
- Follow-up conference calls
- Distribution of package updates
- Conference affinity session for current users of an intervention package

### 2002: Started Blending REP & DEBI

- In REP's Year 1, DEBI:
  - Helps REP PIs with their TOF curriculum
  - Provides TA Guide template
  - Develops a TOT/TOC curriculum
  - Starts planning diffusion strategy with REP PI
- In REP's Year 2, DEBI:
  - Observes facilitator training
  - Trains trainers & coaches
  - Has coaches observe REP implementation
  - Makes plans for package production

### Lessons Learned

- In order to move research to practice, an active partnership is needed at all stages among communities, researchers, prevention agencies and diffusion agents.
- Need to strengthen communication between communities, applied scientists, researchers, and all partners.

### Lessons Learned

- Diffusion is a multidisciplinary effort that includes people with shared vision: peers, frontline staff, community/agency change agents, curriculum writers, trainers, TA providers, researchers, and agency administrators.

### Lessons Learned

- Understanding more about the relationship between agency capacity and implementing with fidelity will improve diffusion efforts.
- What researchers identify as an “effective intervention” be not be perceived as “effective” by the community.

### Lessons Learned

- Everybody wants to “adapt” interventions to make them their own.
- Adaptation and tailoring are absolutely critical to maintaining the efficacy of the intervention.
- “Playing” with or implementing part of an intervention may build conceptual utility and lead to adoption.

### Lessons Learned

- Successful diffusion involves overcoming many myths such as:
  - CBOs don’t want or can not handle science based interventions.
  - Researchers and communities do not work well together
  - Interventions can not be changed or updated
  - Interventions are meant to replace the current work of communities

### For more information

Visit the Disseminating Effective Behavioral Interventions (DEBI) website at:  
<http://www.effectiveinterventions.org>

## EFFECTIVE INTERVENTION FOR ASTHMA

**Leslie Boss, M.P.H., Ph.D.**

**Epidemiologist,**

**National Center for Environmental Health,  
Centers for Disease Control and Prevention**

### Effective Interventions for Asthma

Leslie P. Boss, MPH, PhD  
Air Pollution and Respiratory Health Branch  
National Center for Environmental Health  
CDC  
lboss@cdc.gov



### Objective

- Share our approach to:
  - Increasing availability of effective community interventions for asthma
  - Know what interventions existed
  - Know the result of asthma intervention research activities from the past
  - Know what intervention research is currently ongoing
  - Identify intervention gaps



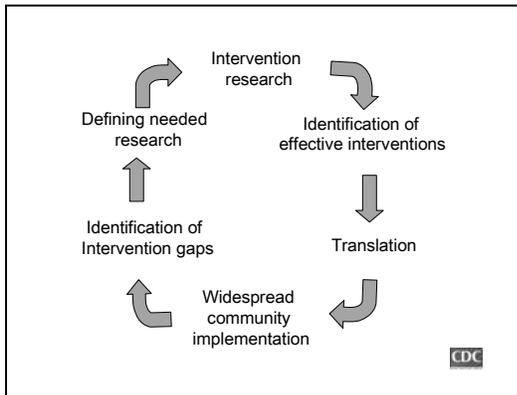
### Asthma

- Roughly one in 17 Americans have asthma
- Traditionally addressed clinically
- Complex disease, challenging to diagnosis and treat
- Under diagnosed and under treated
- Behavior change needed
  - People with asthma
  - Parents of children with asthma
  - Medical care providers
- Complex interventions

### Implementing Effective Interventions

- Such interventions have to exist
- Need to know about them
- Must be appropriate for the population in need of intervention
- Need to have access to the documented procedures and materials
- Need to have staff with necessary competencies for implementation or provide training needed to meet the competencies





### Widespread Implementation

- Rooted in the community
- Science-based
- Implemented as part of a comprehensive and integrated program

### Intervention gaps?

Are there populations in need of intervention for whom there appear to be no effective interventions?

If yes, is there already an effort underway to fill that gap?

### Is Additional Intervention Research Needed?

- What interventions already exist?
- What intervention research is currently underway?
- Does that research have the potential to provide interventions for populations in need?

### Intervention Research

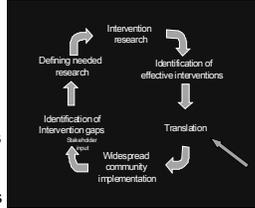
- Often funded by outside organization, usually NIH
- Positive health outcome
- Dissemination of results
- Research designed with translation in mind?

### Identification of Effective Interventions

- Identified criteria for labeling interventions as effective
- 193 publications reviewed
- Initially 16 interventions identified as effective; now 43.
- Initially 2 of 16 ready to implement; now 5.

## Translation

- Removes research elements;
- Modifies the protocol based on research findings;
- Updates materials;
- Develops components as needed;
- Assures that revised procedures and materials are widely available.



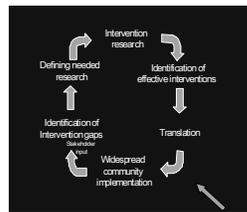
## Translated Interventions

Intervention site	Pre-school	Young school	Teens	Adults	Providers
Clinic/ED/hospital	Wee Wheezers	ACT for Kids (NCICAS)		ALA project	Medical Home
School		Open Airways (RAP)	Power Breathing		
Home	Wee Wheezers at Home				



## Sharing the Information

- Internet
  - Summary of publications of effective intervention research
  - Accessing intervention packages
  - Case studies
  - Bibliography
- Searchable database
  - Ongoing intervention research
- E-mail, conferences, publications, etc.



[www.cdc.gov/nceh/airpollution/asthma/interventions/interventions.htm](http://www.cdc.gov/nceh/airpollution/asthma/interventions/interventions.htm)

(or go to [www.cdc.gov/asthma](http://www.cdc.gov/asthma),  
 And follow the trail to 'Interventions')



**POTENTIAL FUNDING OPPORTUNITIES**

**Kathryn O’Toole, M.B.A.**  
**Associate Director of Management and Operations,**  
**Division of Tuberculosis Elimination,**  
**Centers for Disease Control and Prevention**

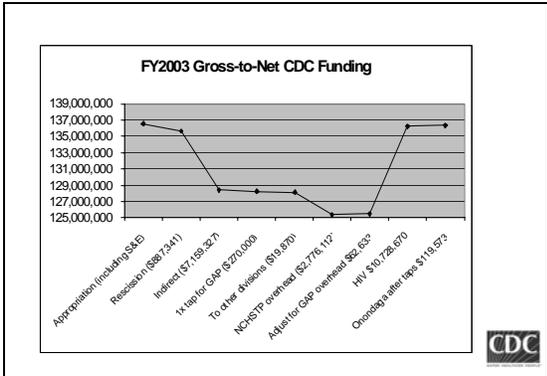
**DTBE Appropriation and Funding**

Kate O’Toole, MBA  
 Associate Director for Management  
 and Operations




FY2003 Congressional Appropriation  
 to CDC for Tuberculosis

- FY2003 Appropriation = \$136,514,000 (includes S&E)
- Earmark = \$125,000 in PHPPO’s budget

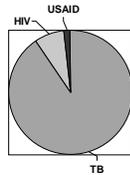



**USAID Funding to DTBE**

- USAID total funding = \$2,551,246
- Overhead tap (15%) = \$ 382,687
- Balance = \$2,168,559



### Discretionary Funding to DTBE



### Project Concept Solicitation: April 1, 2003

- DTBE solicited research concepts from CDC, TBESC, and TBTC investigators.
- A standardized "project concept form" was used.
- For CDC staff, all funding proposals (research and other) were submitted, but only research proposals were forwarded to the CDC/TBESC research concept reviewers.



### Determination of Appropriateness for TBESC: Early April 2003

- TBESC Research Chair and the DTBE Associate Director for Science (ADS) determined if a appropriate for TBESC.



### TBESC RC Review of Project Concepts: April 10, 2003

- Before and at the TBESC semi-annual meeting, the RC reviewed the research concepts that were considered appropriate for TBESC.
- Prioritized each project concept by giving it a score of high, medium, or low.
- TBESC and CDC investigators whose concepts were ranked high or medium were allowed to revise and resubmit their project concepts incorporating the RC's comments/recommendations.



### TB Leads review of project concepts: Early May

- The DTBE Senior Staff independently reviewed the project concepts using the same ranking system as the RC: low, medium and high with comments/recommendations.
- They ranked concepts based on the merit of the concept to the Division and its mission, and the comprehensiveness of collaboration.



### Joint TBESC RC/DTBE TB Leads meeting: May 12, 2003

- The joint TBESC RC/DTBE TB Leads group met in Atlanta to discuss the TBESC RC/TB Leads report.
- The final report to the TBESC and CDC investigators included the summary ranking of the TBESC RC and TB Leads group (including discrepant results) and recommendations to the PIs from each group.
- Investigators whose concepts were ranked high by both groups were encouraged to develop their concepts into full TB Leads proposals.
- A number of investigators whose proposals were ranked high and medium were also encouraged to develop their concepts into full proposals.



**Submission of TB Leads  
proposals: October 1, 2003**

- TBESC and CDC investigators and their collaborators developed and submitted proposals.
- Only investigators who submitted project concepts were allowed to submit TB Leads proposals.



**TB Leads Evaluation: October 14,  
2003**

- The proposals were reviewed by the DTBE TB Leads group and ranked. This included both research proposals and non-research related proposals that did not go through the TBESC review process. Final funding decisions will be made when the congressional budget for TB is available but **no** projects are expected to be funded in FY2004.



**FY2005**

- Similar process
- Later initial deadlines
- Earlier decisions



## MAINTAINING THE MOMENTUM: RECAP AND NEXT STEPS

**Nick DeLuca, M.A.**

**Lead Health Education Specialist,  
Division of TB Elimination,  
Centers for Disease Control and Prevention**

### Next Steps Proceedings

- Entertain additional input on further research needs (e.g. via list-serv, email, etc.)
- CDC Team will synthesize ideas
- Share and solicit input on initial draft
- Finalize



### Next Steps for Agenda

- Forum results
- Literature review
- Workgroups



### Acknowledgements

#### External Steering Committee

- Patrick Chaulk
- Paul Colson
- Ana Lopez-Defede
- Don Morisky
- Mark Nichter
- Jessica Ogden
- Charles Wallace

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- Francine Greiner (DeKalb County Health Department, GA)



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  - Cristina Booker
  - Brandon Long
- Institute of Cultural Affairs
  - Martha Talbot



### Acknowledgements

#### CDC/National Center for HIV, STD, and TB Prevention Colleagues

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>• Rachel Albalak</li><li>• Gaby Benenson</li><li>• Warren Benson</li><li>• Regina Bess</li><li>• Betsy Carter</li><li>• Ken Castro</li><li>• Hsin-Hsin Foo</li><li>• Maria Fraire</li><li>• Sherry Hussain</li></ul> | <ul style="list-style-type: none"><li>• Brenda Holmes</li><li>• Teresa Goss</li><li>• Harold Jaffe</li><li>• Heather Joseph</li><li>• Elizabeth Kalayil</li><li>• Amara Khan</li><li>• Scott McCoy</li><li>• Kate O'Toole</li><li>• Paul Poppe</li><li>• Wanda Walton</li></ul> |
|--|---|



## **Appendix C: TB Behavioral and Social Science Research Gaps and Needs: Major Research Topics, Subtopics, and Research Questions**

### **Overview**

The following section provides a listing of the major TB behavioral and social science research topics, subtopics, and specific research questions generated by the Forum participants. For each topic and subtopic, a brief description is given, followed by an italicized paragraph(s) summarizing the general research concepts that were elicited by Forum participants; (a condensed list describing only the major research topics and subtopics can be found on p. 31-43). Under each topic and subtopic, the specific questions generated by Forum participants have been roughly organized in order from simplest research design (such as questions that would lead to descriptive or exploratory research) to most complex and most detailed (such as those which might lead to experimental or intervention research). Because issues can be multi-dimensional focusing on different levels and behaviors, some research questions were placed under more than one major research topic and subtopic.

In addition to research questions, participants also suggested methodologies that could be used to address the research gaps and needs. Suggestions included greater utilization of behavior change models and theories as a basis for conducting behavioral and social science research; conducting needs assessments with a focus on patient-centered approaches; and moving from descriptive, exploratory research to developing and implementing interventions and utilizing evaluation methods to assess intervention effectiveness and efficiency. Research questions that pose methodological points of inquiry are generally grouped together towards the end of each section.

All questions were recorded verbatim from the flip chart notes and overhead slides collected at the Forum. Every attempt was made to preserve the original intended meaning and context of the research gaps identified by Forum participants during the discussions. Several questions that were either difficult to understand, did not fit under a specific category, or did not focus on behavioral or social science research were extracted from the list.

## Major Research Topics, Subtopics, and Research Questions

### I. Background

#### A. Health disparities

Vast disparities exist in TB case rates, treatment outcomes, and TB mortality among many different population strata. Historically, these disparities have often been based on socioeconomic status and within racial and ethnic minorities, the incarcerated, substance abusers, and homeless populations--populations especially vulnerable to poorer TB outcomes. In 2002, TB case rates among non-Hispanic blacks continued to be eight times greater than non-Hispanic whites.<sup>1</sup> In addition, the past decade has seen disparities emerge between U.S-born and foreign-born populations in the United States. Identifying and eliminating disparities in TB case rates, as well as determining effective measures to reduce existing disparities, are important steps toward controlling and eventually eliminating TB.

*During the breakout sessions, Forum participants identified the need to better understand and address disparities in TB case rates and treatment outcomes.*

- What types of research on disparities in TB should be conducted at the community level? Why do the disparities exist, and what can be done to reduce them?

### II. Intrapersonal

Intrapersonal influences on behavior such as knowledge, attitudes, and perceptions, patient satisfaction, and social stigma affect the individual behavior of patients including health seeking behaviors and adherence to treatment. This level also addresses individual-level issues that may affect providers' behaviors, such as adherence to guidelines and recommendations.

#### A. Patients' knowledge, attitudes, and perceptions (KAP)

An individual's knowledge, attitudes, and perceptions with respect to health in general and with a specific illness, such as TB, influence his/her behavior. Specifically, these factors can influence health seeking, understanding of the diagnosis, understanding of treatment, treatment initiation, treatment adherence, and general interactions with health care providers.

*Forum participants identified the importance of further understanding patients' knowledge, attitudes, and perceptions with respect to TB, with a particular focus on latent tuberculosis infection (LTBI). The need to identify any differences in these factors among different ethnic and cultural groups, specifically Latinos and other foreign-born populations, was emphasized. Finally, participants called for the further use of health behavior models and theories to be used as frameworks to better understand the factors that influence knowledge, attitudes, beliefs and practices of TB patients.*

- How well do patients understand LTBI and TB disease? Is knowledge associated with adherence?
- What are the KAP of TB in Latino immigrants?

- What is the explanatory model of TB in Latino immigrants? (Including beliefs about health and sources of illness from Kleinman)
- What are the health education needs of people with TB? What are patients' knowledge on TB facts, treatment, adherence, etc.?
- What are the health education needs (and KAP) of newly arrived immigrants and/or "transient" foreign-born persons with respect to TB transmission, treatment, and adherence?
- What emotions do patients feel when hearing their diagnosis? How can we best assess these emotions and help address them?
- What are the effects of knowledge and attitudes among different ethnicities and nationalities on LTBI treatment initiation, adherence, and completion?
- What is the relationship of patient fears about TB diagnosis and/or treatment and completion of treatment?
- How can behavior change theories and models be used to better understand and intervene (interventions) for LTBI?
- Can we adapt the Prochaska and DiClemente's Transtheoretical Model utilizing the stages of change constructs to TB patient education (particularly LTBI)?
- What intervention(s) and activities effectively remove or minimize patient engagement barriers? How do other barriers, including patient fear, affect TB treatment completion?
- What qualitative (ethnographic) research (e.g., case studies) can we conduct with patients in each group to provide descriptive content on 1) changes in experience over time, and 2) communication to family, peers, and others in a patient's household?
- What literature exists on the accuracy of self-reporting, including issues that relate to interviewer and respondent relationships (e.g., gender, class), patient sensitivity, social desirability bias, and demand characteristics?

## **B. Patients' behaviors**

### **1. Health care-seeking behaviors**

**Health care-seeking behavior for TB includes the recognition of TB-related symptoms, presentation to health facilities and/or alternative medical resources (e.g., family and community healers), and adherence to effective treatment regimens and treatment monitoring. Individual factors, such as knowledge, attitudes, gender, sex, ethnicity, income, and education, in addition to health service barriers, including accessibility and acceptability of care, cost of services, and quality of care, can often delay or prevent a person from seeking TB care and treatment.**

*Forum participants identified the need to further understand and influence the barriers and facilitating factors to seeking health care for LTBI and TB diagnosis, treatment monitoring, and completion of treatment for different populations. Specific questions were raised regarding the availability, accessibility, acceptability, and affordability of care. In addition, the group discussed the role of further understanding how an*

*individual's perceptions of the health care system and health care providers influence their health seeking behavior.*

- For different groups, what are the barriers to care seeking? Do they include the availability, accessibility, acceptability, and affordability of care? Is stigmatization a reason for delay in seeking care for TB?
- Why do persons who have symptoms and known past exposure not present earlier for diagnosis? Do barriers include denial or fear?
- What factors predict initiation of LTBI treatment?
- What is the effect of using QuantiFERON testing vs. Purified Protein Derivative (PPD) on patient acceptance, especially regarding LTBI?
- From the case worker perspective, what are some patient models of disease regarding treatment-seeking behavior?
- What is the image of “public health centers” among foreign-born persons? How does this image affect health-seeking behavior?
- What are the systematic (operational) issues regarding delays in TB diagnosis? Are foreign-born TB patients (compared with U.S.-born) more likely to have longer delays in seeking care? Are they likely to utilize more health care providers than U.S.-born persons before diagnosis?
- How is a foreign-born patient’s TB treatment-seeking behavior in this country influenced by the policies and practices of his/her home country? (Suggested methodology was to conduct a linked study with the foreign-born TB patient’s country of origin focusing also on the communities, providers/programs, policy makers, etc.)
- What social and economic disparities hinder people from seeking care? Does perceived racism hinder health-seeking behavior?
- What are the effects of medical pluralism on treatment-seeking behavior? What are the delays and sources of care?
- How can we reduce aversion to venipuncture? How do we increase the value of one visit for LTBI testing?
- Will educational materials which address common misconceptions towards TB increase treatment-seeking behaviors among foreign-born persons?

## **2. Adherence to treatment**

**Treatment regimens for LTBI and TB include providing the safest, most effective therapy in the shortest amount of time and ensuring adherence to prescribed regimens. The major determinant of a successful treatment outcome is patient adherence to the prescribed drug regimen. Nonadherence can lead to inadequate treatment which can result in relapse, continued transmission, and the development of drug resistance.**

**Directly observed therapy (DOT) and self-administered therapy are two strategies commonly used in TB control. DOT, a major component of case management, is currently recommended for all patients with TB disease. In addition to DOT, research has shown the use of incentives and enablers can also enhance patient adherence. Directly observed treatment for LTBI is less common due to limited resources. Ensuring treatment completion of LTBI poses unique challenges as it is often self-administered.**

*Forum participants identified the importance of further understanding the barriers and facilitators that affect the initiation, duration, and completion of treatment of LTBI and TB disease, specifically for different populations, such as foreign-born persons and incarcerated/newly-released prisoners. Discussion focused on ways to better understand and enhance DOT. In addition, a focus of the discussion centered on how to improve patient acceptance of LTBI treatment. The discussion also posed questions on how behavior change theories and models could be utilized to better understand and overcome barriers to treatment for LTBI and TB disease.*

- Who is at high risk for non-adherence?
- What indicators predict patient adherence to treatment for TB/LTBI, particularly in groups such as Latino immigrants?
- What factors influence positive adherence, and how are these to be used to predict treatment regimens (daily/bi-weekly) necessitated in different DOT groups? (Suggested methodology is the use of retrospective studies)
- What are the barriers to completing LTBI treatment?
- What are the true “costs” of adherence (e.g., job loss, day care, and loss of social status)?
- What are some ways to address issues that relate to adherence and completion of LTBI and TB treatment among “hard to reach populations” (e.g., persons released from jail)?
- What is the relationship of patients’ capacity to engage in the TB treatment plan and completion of treatment?
- What types of framing (i.e., positive vs. negative) best promote adherence?
- Which conceptual models best explains TB adherence behavior?
- What is the relationship of the patient’s participation in health care decisions and effective TB treatment completion?
- How can we best understand and then manipulate patient risk/benefit calculations regarding LTBI initiation and completion?
- What interventions can address basic needs (e.g., housing) and treatment adherence versus those that focus only on treatment adherence through methods such as education and/or incentives?
- What cultural and educational interventions address adherence with TB and LTBI treatment?

- What interventions and activities effectively remove role model barriers to TB treatment completion?
- Can peer support (e.g., the pairing of a patient with someone who is also experiencing the disease) aid in adherence? What is the usefulness of a patient-to-peer educator match?
- Does a core team approach, which includes former TB patients who have successfully completed treatment, improve adherence and treatment completion among persons from high-risk groups?
- What is the effect and cost-effectiveness of a cultural intervention (e.g., educational intervention) on LTBI therapy adherence in Latino immigrants?
- Will the use of a standardized educational intervention guided by constructs from health behavior theories increase the number of skin test positive contacts initiating / completing treatment?

### C. Patient satisfaction

**Patient satisfaction is how individuals regard the health care services or the manner in which they are delivered by health care providers as useful, effective, or beneficial. It is often based on patient expectations of care and the self-assessment of their experiences. Patient satisfaction may play a major role in a patient's behaviors. If a patient is dissatisfied with the relationship with their provider or with the clinical setting, he or she is much less likely to be adherent to medications, keeping appointments, identifying contacts, and so forth. Research has shown that patient satisfaction can be increased with effective patient-provider communication and development of a trusting relationship.**

*Forum participants identified the importance of the relationship between a patient, provider, and health care system that serves them and the need to better understand this relationship and the role it plays, especially from the perspective of different ethnic and cultural groups. Forum participants also expressed the importance of determining how patient satisfaction may be influenced by TB care and services. They also highlighted the need to explore the influence of patient satisfaction on behavior such as adherence.*

- What patient, clinic, or service factors influence patient satisfaction with TB services? What factors correlate with patient default?
- What is the relationship between patient satisfaction with the TB treatment process, structure, and system and TB treatment completion?
- What are some ways to elicit feedback from patients about how to improve TB care? What types of exit surveys after treatment completion should be used?

## D. Social stigma

Evidenced both in research and in practice, stigma associated with TB appears to be universal. The consequences of stigma can be seen affecting care-seeking behaviors, as persons have been known to hesitate or choose not to disclose their TB status to family, friends, and co-workers out of fear of being socially ostracized, in addition to losing their employment or temporary housing. Research has demonstrated that in some cases, personal rejection occurs as a result of the stigma surrounding TB. Stigma has also been shown to hinder adherence to treatment. By identifying the consequences of stigma, social science research has illustrated the need for effective intervention strategies to mitigate it.

*During breakout discussions, the research questions surrounding stigma highlighted the continuing need to identify the effects or consequences of stigma on care seeking, adherence to treatment, and cooperation with health care providers, especially during contact investigations, to determine whether certain populations or sub-populations (e.g., foreign-born communities) are adversely affected by stigma and in which settings (e.g., residential or workplace). Forum participants also raised the issue of better understanding different perspectives and sources of stigma. Additionally, discussions revolved around the need for identifying and testing effective ways to mitigate the influences that stigma has on individuals and communities.*

- What current research exists on stigma associated with TB as well as other issues (e.g., HIV/AIDS)?
- How does stigma differ by income levels? Are low-income patients as concerned with stigma as middle or upper class TB clients?
- What effects, positive and negative, does stigma have on decisions to seek help, initiate treatment, and complete treatment?
- What are some reasons, such as stigmatization, for delays in seeking care for TB?
- What is the effect of stigma on foreign-born women with regard to TB?
- How can worksite and residential site-based outreach, such as in nursing homes and homeless shelters, be done in non-stigmatizing and non-penalizing way, so that people do not have to fear losing their jobs or the ability to stay at a site?
- How can we use what we have learned about stigma to motivate patients?
- What are some ways to reduce perceived TB stigma among patients and their families? What tests can we conduct to determine the best approaches to improving TB program efficiency and treatment completion rates?
- Would frequent media production on TB prevention and stigma increase TB awareness for government officials? African-American communities?
- Can stigma be reduced through ad campaigns? (Suggested methods include using various experimental designs)

- What survey research can we conduct in patient and provider populations to assess discrimination, stigma, and treatment issues among people with HIV/TB as well as people with TB in the home environment, community, and worksite?
- Are current conceptual frameworks (for understanding stigma) adequate?
  - If “yes” to above, what frameworks (e.g., focus groups, interviews, and surveys) can be used to collect research on providers and patients?
  - If “no” to above, what formative research can be conducted on the origins of TB stigma and its specific components?
- How do we define “stigma” from the perspectives of the patient, provider, and community? Who is the stigmatizer and why? (Suggested methods include the use of focus groups and the Delphi technique)

## **E. Providers’ knowledge, attitudes, and perceptions**

**A health care provider’s knowledge, attitudes, and perceptions (KAP) about LTBI and TB play an important role in their ability to diagnose and treat individuals with TB. A variety of factors, such as medical and health-related training (e.g., U.S.-training vs. foreign training, generalist, or specialist), cultural and ethnic background, practice settings, preferred sources of information and learning styles can influence providers’ knowledge, attitudes and beliefs about LTBI and TB.**

*Forum participants identified the need to better understand the TB-related knowledge, attitudes, and perceptions of different providers in a variety of practice settings, including private physicians, primary care physicians, civil surgeons, international medical graduates (IMG), and providers who serve foreign-born populations. Forum participants called for the further use of health behavior models and theories to be used as frameworks to better understand the factors that influence knowledge, attitudes, beliefs and practices of TB providers and how these factors influence their ability to diagnose and treat TB patients.*

- What are the current levels of TB KAP of health care providers, particularly among non-health department providers, primary care physicians, civil surgeons?
- Are provider characteristics (e.g., attitudes and knowledge) and other factors (e.g., time and workload) important in predicting adherence and successful treatment?
- What are effective methods for raising TB awareness (e.g., the index of suspicion) as a differential diagnosis among private health care providers?
- In seeking to change foreign-trained physicians’ views of Bacille Calmette-Guerin (BCG) vaccine and LTBI, is the message or the process more important?
- In what ways do gender and ethnicity preconceptions of patients affect program performance, including timeliness of diagnosis, nature of relationship with patient, and case management? (Suggested methods include using a mix of qualitative and quantitative methods, such as conducting interviews/surveys with providers\* and patients; having providers and patients keep diaries; and observations.)

\*Providers can include a broad spectrum, (e.g., outreach workers and anyone who has contact with patients).

- What specific methods or approaches are most effective in educating private health care providers about LTBI and TB?
- What are some ways to develop and test alternative modes of educating IMGs and private providers regarding disease and treatment of LTBI and TB?
- What are some ways to conduct a quasi-experimental group design with practitioners using a “standardized” approach versus a tailored messaging approach (e.g., counseling and encouragement vs. education)? Some behaviors on which to focus include adherence behavior, appointment keeping, and completion of treatment.

## **F. Provider training and practices**

**Providers serving individuals at risk for TB in the United States come from a wide range of backgrounds and perspectives. They may have differing knowledge, attitudes, and practices related to TB prevention and control based on factors such as, where they completed their medical training, residency, board certification requirements, and continuing education experiences. Personal and cultural factors may also affect their practices. All of these factors may influence the providers’ level of professional competence, cultural competency, and clinical behaviors, including their adherence to professional practice guidelines.**

### **1. Diverse training**

**Providers have different levels of knowledge, attitudes and practices related to TB prevention and control, based on factors such as where they completed their medical training, residency, board certification requirements, and continuing education experiences. Moreover, many foreign-trained providers and international medical graduates (IMG) have an increasingly important role in TB prevention and control efforts, as they may be the first point of contact for foreign-born individuals with TB.**

*Forum participants identified the need to assess the impact of working with providers of different cultural and professional backgrounds, who have undergone different types of training in the area of TB control. Participants also identified the need to improve collaborations between health department and non-health department providers.*

- How can health care workers best assess patient levels of knowledge and be trained to match educational messages and interventions to patient needs?
- How do we best train TB case workers based on lessons learned?
- What successful practices have been used to entice non-health department providers to cooperate with the health department?
- How can we get private providers and international medical graduates to do a better job of diagnosing, prescribing, and treating LTBI?
- How can we better improve foreign-trained providers’ contributions to TB control in non-health department settings?
- Can an educational / awareness campaign encouraging providers to consider TB in the differential diagnosis of respiratory symptomatic patients increase detection of disease in care settings (e.g., emergency rooms, walk-in clinics)?

## 2. Cultural competency

**The role of cultural competency in U.S. TB programs has become increasingly important, especially over the past two decades as the proportion of persons with TB who are foreign born has rapidly increased and now surpasses U.S.-born cases. In addition, widening disparities have emerged among other U.S.-born groups, such as African Americans in the Southeast. Efforts to promote health and prevent and treat disease within culturally diverse groups will involve building the capacity of programs to become culturally competent. This is extremely important in health care, as it has generally been shown that minority groups use fewer services and are less satisfied in general with their care. Furthermore, patients may avoid care out of fear of being misunderstood or discriminated against. Providers need to be aware of and understand the impact that culture can have on a patient's TB knowledge, attitudes, beliefs, and practices. By increasing the cultural competency of providers, they will be better equipped to provide the most appropriate TB care and treatment.**

*Forum participants identified the need to further understand the role of cultural competency on the delivery of services to TB patients and ways to increase cultural competency among health care providers, including public health nurses and outreach workers. In particular, participants focused on how culturally competent health care workers can influence patient's adherence to treatment for LTBI and TB.*

- Does being cultural competent make a difference? How can health departments become sensitive to patients' needs without stereotyping? (Suggested methodology is to conduct evaluation research)
- Does cultural competency have any effect on relationships with patients? Does it lead to better adherence and completion rates?
- Is further research needed on the effect of cultural competency training (evaluation and efficacy) for outreach and public health staff?
- What is the effect of cultural competency training of staff on LTBI adherence in immigrants?
- What core components would constitute a training program to enhance cultural competency among front line health care providers? Which components generate the most significant awareness of change?
- What are the cultural competency training needs of public health nurses and TB outreach workers? What are the evaluation outcomes of such training?
- From a research, treatment, and control perspective, how should the issue of "pigeon holing" stereotypes be addressed among TB control staff, providers, and patients?
- How do providers best acknowledge and incorporate traditional cultural beliefs and behaviors of foreign-born patients into patient-centered needs assessments, TB screening, diagnosis, and patient treatment plans?
- How do we, as researchers and program persons, acknowledge, utilize and/or incorporate the use of traditional methods among ethnic groups (especially among foreign-born persons from Southeast Asia) regarding TB treatment?

- Are clients more likely to complete treatment if their provider(s) is of the same ethnicity, gender, class, or language? (Suggested methodology is to conduct intervention studies research, especially on topics, such as LTBI adherence)
- Regarding message acceptability, is there a difference in knowledge and adherence behavior when the caregiver is matched with the patient on race, gender, or both, particularly in generally segregated communities?
- What specific methods should be developed for assessing cultural beliefs and behaviors that are related to TB?

### 3. Clinical Practices

**Clinical practices of providers can include TB screening and treatment, patient management, collaborating with the health department for contact investigations, and adherence to guidelines and recommendations. Just as patients are faced with individual or structural barriers to adhering to LTBI and TB treatment, health care providers also face numerous challenges and barriers to adherence to TB screening and treatment guidelines and recommendations. Providers must be aware of CDC and American Thoracic Society guidelines in order to implement them. In addition, other barriers such as provider background and practice setting may influence their adherence to guidelines. Identification of barriers to the awareness of and adherence to guidelines and ways to address these barriers can improve provider practice and lead to the provision of more effective health care.**

*Forum participants identified the need to determine ways to increase providers' awareness and adherence to TB treatment guidelines for providers in different health care settings. In these discussions, "providers" include private providers, community health workers, case workers, non-health department physicians, and foreign-trained providers.*

- What provider behaviors best prevent TB outbreaks? How can they reduce diagnostic delay in patients with TB?
- What are the effects of medical pluralism on provider response to patients' treatment models? (Special relevance should be given to foreign-born persons for delayed diagnosis and adequate treatment of LTBI and TB)
- How do opinion leaders change behavior of others? How can opinion leaders improve translation of recommended treatment standards to provider practice?
- What type of practitioner's guideline is needed to proactively identify "high-risk of drop-out" patients in order to address issues which would prevent dropping out of care? What information should be provided to reinforce and support positive health behaviors and their determinants?
- What methods should be explored for improving provider adherence to TB guidelines and recommendations?

### **III. Interpersonal**

**Interpersonal influences on behavior focus on the relationship between two individuals or units regarded as a pair. Examples include the patient-provider relationship and its impact on both the patient and provider as well as influences of a family member, significant other, or peer on a patient.**

#### **A. Communication between patients and providers**

**Communication between patients and providers is critical for effective health care. It is a fundamental element that helps to shape the patient-provider relationship and foster trust. Communication includes appropriate linguistic concordance, optimal use of interpreters when necessary, verbal and nonverbal expressions and cues, and good listening skills by providers. Communication also ultimately reflects the dynamics of the relationship between a provider and the patient. Provider-patient communication can impact trust, patient satisfaction, and treatment adherence.**

*Forum participants identified the need for additional research to understand the role of provider-patient communication in effective TB case management. Participants discussed the need to foster positive interactions and to build trusting and caring relationships between patients and providers.*

- How do we create and improve positive interactions and build trusting and caring relationships between patients and providers?
- What are the key components to building trust in the patient/provider relationship?

#### **B. Family and peer influences**

**A TB patient's family, peers, and social networks can be very influential on the patient's behavior. Family and peer influences can affect an individual's decision to seek treatment and to adhere to provider treatment recommendations. In addition, peer and social influences can impact a TB patient's willingness to identify contacts during a contact investigation.**

*Forum participants identified the need for research to further understand the family and peer in terms of whether and when a patient enters (and remains in) care.*

- How can we reach supporting populations to reduce fear of TB transmission in household/worksites?
- How does TB affect families as a whole?
- How do we better educate the coworkers, friends and relatives of the TB patient? What messages do family members and others need in order to accept and support the patient's diagnosis?
- How can TB program staff integrate the families (including extended family members) and the communities of TB patients into the TB process of education, case identification, treatment, follow-up, prevention, and re-integration into the job and community to prevent stigma and discrimination?

- What are some ways to develop culturally sensitive and appropriate strategies to educate families and coworkers and communities about TB?
- What is the effect of family member influences, especially women, on their family member's health seeking behavior?
- How can TB programs assist and support female patients in fulfilling their familial roles given their illness?
- How can social networks be involved in positive and facilitating ways regarding a patient's TB experiences?
- What are the community influences on health behaviors? What is the impact of community health workers (peers) on treatment initiation and completion?
- What is the role of social support in LTBI adherence in Latino immigrants?
- What is the application of a social network framework to at-risk TB populations?
- What is the relationship of the patient's role models to effectively completing TB treatment?
- Who are the best, most effective role models or opinion leaders of high-risk patients?

## **IV. Health Systems and Organizations**

**Influences of health systems and organizations on behavior focuses on how structural, economic, and other organizational forces can affect the views of individuals, small groups, and communities. Examples include the availability, accessibility, and use of health care services by individuals, and collaboration between and among provider communities and other systems.**

### **A. Organizational structure**

**The way in which the health care system is organized may play a role in affecting both patient and provider behaviors. Whether the system has a vertical or horizontal structure, whether services are integrated with other health and social services or are part of a collaborative network, and how the health care system is impacted by other systems within a society may impact availability, delivery, and acceptability of services.**

#### **1. Collaborations between provider communities and systems**

**There are many different social and behavioral determinants involved in TB transmission, identification, and treatment success. Certain factors that place individuals at high risk for TB, such as poverty, substance abuse, and homelessness can be greatly impacted by the availability and quality of social services. Both private and public collaborations between and among existing social service agencies and TB control efforts, as well as timely and appropriate social service referrals for individuals with TB, may play an important role in the efforts to successfully eliminate TB.**

**There are also a number of relevant collaborations between TB services and other health-related entities that may need to be better understood and cultivated. Given the high rate of TB/HIV co-infection among certain populations, collaboration between or integration of TB and HIV services may lead to better treatment outcomes and improved satisfaction among persons receiving these services. Collaborations with mental health and substance abuse services, homeless shelters, and correctional facilities hold equal promise.**

*Forum participants identified the need to determine ways to increase collaboration between TB programs and other health and social service agencies for related conditions (e.g., HIV/AIDS, mental health, and substance abuse) to improve TB diagnosis, case management, and integration of services. Specific areas for increased research include focusing on patients with multiple/varied needs, U.S.-Mexico border issues, and collaboration with correctional systems, Immigration and Customs Enforcement, and other agencies.*

- What mix of TB and other services are most effective in different communities, and what are the difficulties encountered in providing such a mix? What mix is best for the patient and provider?
- What are some ways to develop collaborations with the justice system (e.g., county jails)?
- What are some ways to increase U.S. (south of border) and Mexico/Central America collaboration through the use of the government, health care providers, academic institutions, and community agencies? How should the community of origin be factored into this?
- What are the country specific TB prevention and control strategies of Mexican, Central, and South American health departments and communities?
- How can TB control and prevention partnerships be developed between U.S. and Mexican local health departments, specifically in Mexican communities?
- What are the barriers that health providers and health departments face when doing TB control and education with labor and services providers?
- What are some ways to identify and compare better methods on increasing collaboration between TB control programs and other health and social service agencies?
  - How can coordination of care (i.e., systems of care) be increased for patients with multiple health issues, such as co-morbid conditions?
  - How can coordination of mental health care with TB treatment and adherence interventions be increased? How can patients with mental health problems best receive care?
  - What can be applied from HIV practices to TB with regard to incorporating screening and care into jail settings?
  - How can TB be integrated into HIV provider and community planning group activities? What about substance abuse provider activities?

- How can constraints, such as environmental ones, be overcome in the implementation and provision of HIV counseling and testing in TB programs and clinics?
- What specific interventions would positively impact the fact that clients in correctional facilities are referred to the community [health center] for follow-up of LTBI therapy?
- What strategies or models for collaboration lead to better patient outcomes, not only for TB, but for a patient's holistic health? (Suggested methodology is to conduct operational research using case studies.)
- Using an HIV case model, what type of comparison can be made on the following: 1) an increase in the number of those who know their TB status; and 2) the number who receive appropriate treatment?

## **2. Impact of sharing patient information**

**Patients who have other health and/or social issues such as TB/HIV co-infection, diabetes, substance abuse, and mental health issues, in addition to TB or LTBI, may have multiple providers. The sharing of patient information becomes a crucial component in the provision of proper and effective health care, especially as it relates to a patient's TB treatment regimen and follow-up care. Providers who take a holistic approach to their patient's health and who thus have a complete picture of their patient's health and well-being are better equipped to make well-informed decisions that ensure the most appropriate TB care and treatment.**

*Forum participants identified the need to focus upon the impact of sharing (or not sharing) patient information on case management, service coordination, and health outcomes among managing providers in varying settings, such as health departments and correctional, mental health, and substance abuse facilities.*

- What is the impact of sharing and not sharing of patient information on provider behavior and treatment outcome?
- Does the sharing of client records among managing providers (e.g., county health departments, jail system, mental health facilities, and substance abuse facilities) increase the quality of case management for clients with TB?
- What are the key elements of a medical record that health providers need to start and continue care?
- What type of retrospective analyses of clinical medical records can be conducted to develop a patient profile? How can factors and determinants be identified for patients who completed care and for those who dropped out, based on their medical charts?
- What types of evaluation can be conducted on health data transfer systems currently in place for TB?

## **B. Service delivery**

**The delivery of health services plays a major role in how patients receive TB care and treatment. From an organizational perspective, accessibility and acceptability of services, cost of services, and quality of care can often delay or prevent a person from seeking TB care and treatment. Through the use of patient-centered approaches and effective case management, these systematic barriers can be reduced or alleviated, resulting in improved provision of care and better treatment outcomes.**

### **1. Patient-centered approaches**

**Patient-centered approaches focus on bringing together compassion, empathy, responsiveness, and resources to the needs, values, and expressed preferences of individual patients. Effective patient-centered care is essentially a partnership between the provider and the patient. It involves determining individual patient needs and expectations while ensuring that efforts are made to address those needs and expectations by the health care provider(s).**

*Forum participants recognized the potential benefits of delivering TB control services which embody a patient-centered approach, and suggested that additional research is needed to identify, compare, and standardize different methods and models for patient-centered care.*

- What are some patient-centered approaches that can be tested, standardized, and replicated?
- What are some ways to develop and compare different methods for conducting patient needs assessments?
- How are client-centered needs assessments best utilized in developing client-centered interventions? Do we need to restructure needs assessment tools to be holistic?
- How do we demonstrate the added value of patient-centered TB treatment? How can this be applied to other services? What are the synergistic influences of TB control programs on those other services?

### **2. Case management**

**Quality case management is an important component of effective TB care. It holds the potential to increase treatment adherence and treatment outcomes by tailoring case management to the patient, by making appropriate referrals to needed health and social services, and helping to remove barriers to treatment success. However, little empirical evidence exists that systematically confirms the effect of the various types of case management practices. Part of the reason for this may be that many case management practices are not standardized and vary based on case management models and institutions.**

*Forum participants identified the need to determine the influences of case management on multiple outcomes (e.g., treatment outcomes, reduced homelessness, care for substance abuse, receipt of other appropriate social and other health resources) as well as approaches to strengthen case management practices.*

- How can negative outcome expectations be overcome in order to provide HIV counseling and testing in TB clinics?
- What is the impact of using case management strategies in homeless shelters (and also jails) on multiple outcomes, including LTBI adherence, reduced homelessness, and increased access to mental health care and substance abuse treatment?
- Would the quality of case management improve if addressing social needs was a standard part of the model?
- What types of demonstration projects can be used to apply case management strategies that are effective with patients with active TB to LTBI patients?
- What are some ways to conduct theory based experimental or quasi-experimental studies that test specific methods to improve efficiency and effectiveness of TB control programs?

### **3. Advantages and disadvantages of directly observed therapy**

**Directly observed therapy (DOT), in which a health care worker or other qualified individual watches the patient swallow every dose of the prescribed drugs, is an extremely effective strategy for making sure patients take their medicines. DOT is strongly recommended as part of a patient-centered case management plan because it is difficult to reliably predict which patients will be adherent. Successful treatment programs are dependent upon public health programs and providers accepting responsibility for a patient's care by ensuring that DOT is appropriately administered.**

**As TB incidence declines and programs are turning their attention to the treatment of LTBI, more TB programs are trying to use DOT for LTBI patients. Data indicating low completion rates among patients on treatment suggests the importance of determining the appropriate use for DOT with LTBI patients.**

*Forum participants identified the need to conduct further research on the effectiveness of varying DOT modalities for LTBI and TB, such as clinic, home, or field-based DOT. Forum participants also raised the need to identify patient-centered DOT strategies that are most appropriate to the particular needs of patients, questioning the one-size fits all mentality. Participants also focused on the need to further delineate the usefulness of DOT in treating TB and other co-morbid conditions, such as HIV.*

- What are the most effective DOT strategies based on existing research?
- How can DOT services be most cost effectively delivered?
- Given that directly observed preventive therapy (DOPT) is an expensive modality, what are cost-effective models for achieving treatment of LTBI?
- Does the initial education of the infected patient regarding the use of DOPT affect the completion of treatment? Are factors, such as advising not to use alcohol, initially emphasized? Is the lack of a health department's legal power to enforce LTBI important to why clients drop out?

- What case control studies can be conducted to identify predictors of persons who succeed and persons who fail in self-administered programs for LTBI, and who may benefit from DOPT?
- What additional research is needed on DOT with regard to TB treatment adherence? Are there parts of the DOT process that interfere with adherence?
- What method, clinic-based versus home-based DOT for TB treatment, works best and for which patients?
- Can changes be made to the DOT process that will aid in adherence (e.g., increase in patient participation, feelings of control)?
- Is selective DOT a viable option? What components of DOT can be delivered separately?
- What are some ways to test and evaluate different directly observed therapy-short course (DOTS) “flavors” for appropriateness?
- How can patients be screened in terms of determining 1) what basic needs will enable them to complete therapy, and 2) what flavor of “DOTS” (e.g., observation, control, or medicine pick up) works best for them?
- Is DOT for HIV and TB helpful in treating both diseases?
- How should a randomized clinical trial (RCT) of full vs. selective DOT with a detailed protocol for patient management be conducted? What specific components (e.g., home visits, clinic visits, or self-management) are effective? What specific outcomes, such as completion rate, failure and relapse rate, multi-drug resistance, and cost-effectiveness, are important to measure?

#### **4. Role of incentives and enablers**

**Research has shown that the use of incentives and enablers can enhance patient acceptance as well as adherence to treatment for both TB disease and LTBI.**

**Incentives and enablers help patients continue and complete treatment and are widely used in facilities providing TB services. Incentives and enablers are most beneficial when they are tailored to the patient’s special needs and interests. Learning as much as possible about individual patients through the use of patient-centered approaches will help to identify their needs and better assist them in completing treatment.**

*Forum participants identified the importance of further understanding the barriers and facilitators that affect the initiation, duration, and completion of treatment of LTBI and TB disease, and the role that incentives and enablers can have in achieving TB treatment goals, specifically for diverse populations such as foreign-born persons and incarcerated or newly released prisoners.*

- What are some ways to identify and distinguish basic needs from incentives and their impact on treatment completion?
- What is the role and effectiveness of incentives in completion of treatment, particularly with DOT and without DOT? What about the use of DOPT?

- What incentives are effective with different foreign-born populations? With African-Americans in the southeast? With the homeless?

## 5. Contact investigations

**The contact investigation is an important component of TB prevention and control efforts, as it is a process for identifying persons exposed to someone with infectious TB, evaluating them for LTBI and TB disease, and providing appropriate treatment for LTBI or TB disease. In TB programs in the U.S., there is wide variability in the way in which contact investigations are conducted. Furthermore, the contact investigation can be sensitive for TB patients as they are required to elicit personal information, such as who they interact with, how often, and where. Little is known about the social and emotional impact of these investigations on the individuals involved and on the identification and follow-up of contacts.**

*Forum participants identified the need to determine ways to improve contact investigations by, for example, gaining a better understanding of patient and contact perceptions and being more sensitive to involved parties to enhance contact investigation outcomes. Finally, more research is needed with providers to examine their perspectives on contact investigations.*

- What are the perspectives of patients, contacts, and providers of contact investigations? What are the problems associated with contact investigations? How can the yield and patient satisfaction with contact investigations be increased?
- How can contact investigations be improved? How can the process be better explained and made less intrusive to patients? What is the distinction between TB control and TB care? How can these be differentiated, and what would it look like? How can the process be made less punitive without jeopardizing public health?
- Why do some contacts not want to be examined? For patients with TB disease who were unidentified but knew they were contacts, what barriers did they encounter that prevented them from getting tested?
- What are some ways to systematically collect data on TB control and other programs in various settings, (e.g., prisons and homeless shelters) during investigations of TB outbreaks in order to identify “missed opportunities?”

## 6. Health communications

**Health communications can be used to share information on TB with the general public, local communities, patients and contacts, as well as providers. Research has demonstrated that misconceptions about TB and the stigma associated with the disease still abound, suggesting the continuing need to increase knowledge and awareness of TB through effective channels of communication. Further research to better understand informational needs, identify appropriate and effective media for channeling information, and testing health messages related to many aspects of TB for a variety of audiences will enhance the effectiveness of TB control efforts and hopefully mitigate the stigma associated with TB.**

*Forum participants identified the need to identify specific and tailored messages and messengers for improving communication about LTBI and TB diagnosis and treatment among patients and providers, as well as among family members and within the community.*

- What messages do family members need to accept and support the patient's diagnosis?
- What type of message will increase the completion of LTBI treatment?
- How do we integrate messages with traditional health beliefs of foreign-born patients and of the community?
- What are current media messages in TV news and programs, newspapers, and magazines about TB and people with TB? Do these messages in daytime/primetime programs, newspapers, and magazines need to be improved or changed to be more effective?
- Regarding message acceptability, is there a difference in knowledge and adherence behavior when the caregiver is matched with the patient on race, gender, or both, particularly in generally segregated communities?
- What is the role of peers and other messengers in the delivery of health messages for patients, contacts, and providers?
- Does a core team approach, which includes former TB patients who have successfully completed treatment, improve adherence and treatment completion among persons from high-risk groups?
- How do opinion leaders change behavior of others? How can opinion leaders improve translation of recommended treatment standards to provider practice?
- What are the best places to advertise to high-risk groups?
- What specific educational interventions are most effective in reaching clients in terms of type of delivery, type of message, time entailed, messenger, and cost-effectiveness?

## **7. Special challenges of high risk settings and populations**

### **a. HIV/TB**

**Co-infection of TB and HIV presents challenges for both patients and the providers serving them. One challenge is related to the potential lack of collaboration among TB and HIV programs. It is important that TB providers offer HIV voluntary testing and counseling to both TB patients and high risk contacts, and that HIV providers offer TB screening and follow-up. Patients who have both TB and HIV may also face challenges associated with the burden of taking medicine for both diseases, as well as with the stigma associated with both illnesses.**

*Forum participants identified the need to conduct research on patient, provider, and agency barriers to the integration of voluntary HIV testing and counseling in TB programs as well as the incorporation of TB services in HIV/AIDS programs.*

- How do the views of disease and patient agencies differ between TB as a single disease and HIV/TB co-infection?
- Regarding HIV testing of persons with TB and LTBI, how can we better understand why TB and LTBI clients resist testing for HIV? What motivators can be used to get TB and LTBI clients to get tested?
- How can the provision of HIV counseling and testing in TB programs be improved?
- How can we help TB program managers and front line staff integrate HIV volunteer counseling and testing (VCT) into their TB program activities? What are the barriers and how can we reduce them?
- Is there a way that TB can be better integrated into HIV community planning group activities?
- How can we overcome the *environmental constraints* to implementing HIV counseling and testing in TB clinics? How can we overcome the *negative outcome expectations* to providing HIV counseling and testing in TB clinics?
- What survey research can we conduct in patient and provider populations to assess discrimination, stigma, and treatment issues among people with HIV/TB as well as people with TB in the home environment, community and worksite?
- What are some effective models that can be used to increase HIV testing of TB patients?

**b. Homelessness, unstable housing, and mental health issues**

**TB control also faces significant challenges when dealing with homeless populations or with individuals who may also be experiencing mental health or substance abuse issues. These issues, combined with a lack of stable housing, make TB screening and follow-up, diagnosis, contact investigations, treatment initiation, adherence, and completion of treatment extremely challenging.**

*Forum participants identified as important the need to assess the TB knowledge, attitudes, and perceptions (KAP) as well as other influences on behavior of homeless populations. Participants also identified the need to consider using patient-centered case management strategies to identify and address competing health and social issues for this population.*

- What are the TB KAP and influences of homeless people?
- What is the impact of using case management strategies in homeless shelters (and also jails) on multiple outcomes, including LTBI adherence, reduced homelessness, and increased access to mental health care and substance abuse treatment?
- How do we address the impact mental illness and addictions have on TB? (Suggested methodology is to conduct intervention research.)
- What research is needed on mental health issues in regard to client behavior? What are some effective interventions that address mental health issues (co-morbidities) of people with TB?

### c. High mobility jobs and migrant labor

**Given their mobility, migrant farm workers and other migrant populations present unique challenges to TB prevention and control programs with respect to diagnosis, treatment, continuity of care, and contact investigations. U.S.-Mexico border issues, such as immigration and frequency of border crossings, create additional challenges.**

*Forum participants suggested conducting descriptive and ethnographic research using case studies as a possible method, among this special population. This type of research might help to determine ways to access migrant networks, mechanisms for tracking patients in a non-stigmatizing way, and ways to increase completion of care.*

- In what ways does TB affect migrant groups vs. the general population?
- How can we “track” migrant TB patients so that we follow-up on their treatment but don’t stigmatize them?
- What data sources can be utilized to identify sites with high rates of migrant populations including Mexicans?
- What survey tools can be used to access migrant populations within networks, such as employment settings, clinics, etc.?
- What descriptive research can be conducted that tracks a small sample of mobile, high-risk populations?
- How can migrant “pockets” (i.e., locations with significant populations) be identified?
  - What types of ethnographic research studies using quantitative and qualitative methods need to be conducted?
  - How should patients be screened for disease? How can persons with TB/LTBI be placed into care?
  - How should patients in care be followed to completion? (Suggested method: Interview patients at 18 months)
- How should the following be conducted with mobile or migrant populations:
  - Targeted testing for significant percentages of TB?
  - Placing patients on TB treatment?
  - Enrolling patients in Migrant Clinician Network’s TBNet program?
  - Following patients through to treatment completion?
  - Following up with patients upon treatment completion, including reviewing for ease of contact, ease of tracking, percentage complete, and percentage lost?

#### d. Incarceration

**Jails and prisons pose a unique challenge for TB prevention and control. Efforts have been made to improve the relationships between health department TB programs with jails and prisons to enhance TB screening and follow-up among inmates and correctional personnel. In addition, continuity of care can be a particular challenge for TB patients who are incarcerated during treatment and who are later released from prison or jail while on treatment.**

*Forum participants discussed the need to conduct further research to identify ways to improve TB screening activities, as well as adherence to and completion of treatment for incarcerated persons and newly released prisoners. In addition, participants called for further research to examine how screening and treatment for TB can be incorporated into the diagnosis and treatment for other diseases such as HIV.*

- How can we provide demonstrations and conduct evaluations of programs intended to improve TB testing and follow-up in jails?
- What ways can we improve adherence and completion of TB/LTBI treatment among “hard to reach populations” (e.g., persons released from jail)?
- How do we address TB for incarcerated populations returning to the community?
- What specific interventions would increase referral of clients in correctional facilities to community facilities such as health centers for follow-up of LTBI therapy?
- How can we evaluate the use of incentives and educational based interventions aimed at increasing adherence to LTBI and TB treatment for persons being released from jail?
- What can we learn and apply from HIV to TB with regard to incorporating screening and care into jail settings?

#### e. Substance use

**Substance abusers are at increased risk for TB. Substance abusers may have competing priorities that may prevent them from being diagnosed with TB, accepting and adhering to treatment regimens, and identifying contacts.**

*Forum participants identified the need to better understand the TB knowledge, attitudes, and perceptions (KAP) of substance abusers as well as determine the best ways to address these issues, so that this population will receive the most effective TB care and services.*

- What are the TB KAP/influences of substance abusers?
- How can patients with substance abuse problems best receive TB care? (Suggested methodology is a call for basic research)

## f. Foreign born

Although TB case rates have steadily declined since 1992, TB in foreign-born persons represents a significant challenge for TB control efforts in the United States. In 2002, TB case rates among the foreign born comprised 51% of reported TB cases in the United States.<sup>2</sup> Foreign-born populations may have unique cultural characteristics, practices, and circumstances related to their re-settlement and adjustment to the U.S. that may influence their TB treatment and care.

*Forum participants identified the need to acknowledge, understand, and incorporate different health-related cultural beliefs and practices of foreign-born patients. Other issues that warrant exploration included foreign-born persons' perceptions of the U.S. health care system and/or the providers who deliver care, determining the role of gender and ethnic differences between patients and providers, and identifying and addressing the wide range of barriers foreign-born persons encounter when accessing services related to LTBI/TB diagnosis, treatment initiation, adherence, completion, and follow-up.*

- What are the effects of knowledge and attitudes among different ethnicities and nationalities on LTBI treatment initiation, adherence, and completion?
- What are the health education needs (and KAP) of newly arrived immigrants and/or “transient” foreign-born persons (e.g., Latino immigrants) with respect to TB transmission, treatment and adherence?
- Are immigrant males at higher risk of contracting TB due to labor and environmental issues?
- What is the image of “public health centers” among foreign-born persons? How does this image affect health-seeking behavior?
- What is the effect of stigma on foreign-born women with regard to TB?
- What are the systematic (operational) issues regarding delays in TB diagnosis? Are foreign-born TB patients (compared with U.S.-born) more likely to have longer delays in seeking care? Are they likely to have more or less access to health care providers than U.S.-born persons?
- What are the effects of migration patterns on foreign-born persons with regard to stigma, beliefs, social support, access to care, and ensuring continuation and completion of treatment? What happens at other end? How does a patient’s social support structure change with his or her relocation?
- What are the barriers that immigrants face when accessing TB prevention, case identification, education, treatment, and follow up?
- Will educational materials, which address common misconceptions towards TB, seen regionally throughout the world, increase treatment-seeking behaviors among foreign-born persons?
- What factors predict adherence to treatment in Latino immigrants?
- What is the role of social support in LTBI adherence in Latino immigrants?

- How do we best incorporate cultural beliefs and behaviors into patient treatment plans, especially for Mexican and other foreign-born populations?
- What incentives work with various foreign-born populations?
- How do we integrate messages with traditional health beliefs of foreign-born patients and their community?
- What is the effect of new immigration policies on TB case identification, follow up, treatment, and adherence, especially for Latino immigrants?
- What type of research is needed to maximize screening of new and recent arrivals? How is access to these populations gained? How can collaboration with Immigration and Customs Enforcement (ICE) and other similar agencies that focus on foreign-born persons be increased?
- What are some ways to help undocumented persons overcome their fear of government agencies and institutions?
- What is the explanatory model of TB in Latino immigrants? (Beliefs about health and sources of illness from Kleinman)
- What type of bottom-up education package can be used for educating patients of different cultural groups about TB questions they may have, such as on TB medication, while also being sensitive to influences, such as the patient's gender and age (e.g., family generation)?
- What is the effect and cost-effectiveness of a cultural intervention (e.g., educational intervention) on LTBI therapy adherence in Latino immigrants?
- How is a foreign-born patient's TB treatment-seeking behavior in this country influenced by the policies and practices of his/her home country? (Suggested methodology was to conduct a linked study with the foreign-born TB patient's country of origin focusing also on the communities, providers/programs, policy makers, etc.)

#### **g. Pediatrics**

**Children with LTBI and TB represent another population with unique characteristics and needs. The diagnosis and treatment of children is often dependent upon the role of the parent, primary care giver, and other adults.**

*Forum participants felt it was important to conduct research to test alternative models to increase LTBI and TB screening and treatment among children.*

- What provider behaviors can lead to more efficient LTBI diagnoses in children? Can the tuberculin skin test (TST) be avoided for low risk children? What tests should be conducted for the use of new testing tools for children? How do we get providers to use these screening tools, if effective?
- What alternative models can be used for delivery of LTBI treatment among children? An example of an alternative model is the use of school-based parent administrators with and without prompts (e.g., phone call reminders).

## V. Community

Influences that are community-related affect behavior on both small and large-group levels, such as those in community settings. Examples include influences of family and social networks on individuals, the relationship between local health services and individuals and communities, and the impact of social stigma of TB on groups.

### A. Impact of TB services on communities and patients

Whether defined by a geographic region, a common interest or shared ethnic or cultural background, communities play an important role in people's lives. Because a community typically shares a set of common interests and values and gains strength from this collective entity, it is important for health care providers to understand the communities they serve to effectively meet the community's needs. Developing a respectful, collaborative relationship with communities may strengthen the delivery of health services and improve the general health and well-being of communities as a whole.

*Forum participants identified the need to determine the perceptions of TB within communities and to understand the origins of those perceptions and the influence of forces that affect people's perceptions, such as the media. Participants also expressed the need to develop tailored, culturally-specific interventions to increase understanding of TB and reduce the stigma associated with TB.*

*Participants across all groups discussed the need to determine the optimal relationship between health departments and the local communities they serve, as well as the role of community groups like community-based physicians in increasing TB awareness and delivering TB services. Suggestions were made to conduct more participatory action research and to define and determine how local communities can become involved in locally driven research.*

#### 1. Influences of family and social networks

Family groups and social networks have been shown to be extremely influential on many different health outcomes. In terms of TB outcomes, this influence can manifest itself positively by facilitating or supporting, for example, care-seeking, treatment adherence, and other patient behaviors. Conversely in other cases, misconceptions held by those close to individuals with TB can have negative effects such as increasing the level of stigma attached to the disease resulting in social ostracism or isolation. Furthermore, family units and social networks are often adversely affected by the introduction of TB and the consequent stressors into their networks. Successful TB control efforts based on a strong understanding of these issues may maximize the positive influences of social networks and minimize disruptions to family and social networks.

*Forum participants identified the need to better understand the role of social networks on health behaviors and determine strategies for strengthening the positive influences of social networks. Specific focus was given to identifying ways in which TB programs can work with families to better understand and mitigate the impact of TB services on social networks.*

- How can we reach supporting populations to reduce fear of TB transmission in households and worksites?
- How does TB affect families as a whole?
- How do we better educate the coworkers, friends, and relatives of the TB patient? What messages do family members and others need to accept and support the patient's diagnosis?
- How can TB program staff integrate the families (including extended family members) and the communities of TB patients into the TB process of education, case identification, treatment, follow-up, prevention, and re-integration into the job and community to prevent stigma and discrimination?
- What are some ways to develop culturally sensitive and appropriate strategies to educate families and coworkers and communities about TB?
- What is the effect of family member influences, especially women, on their family member's health seeking behavior?
- How can TB programs assist and support female patients in fulfilling their familial roles given their illness?
- How can social networks be involved in positive and facilitating ways in a patient's TB experiences?
- What are the community influences on health behaviors? What is the impact of community health workers (peers) on treatment initiation and completion?
- What is the role of social support in LTBI adherence in Latino immigrants?
- What is the application of a social network framework to at-risk TB populations?
- What is the relationship of the patient's role models to effectively completing TB treatment?
- Who are the best, most effective role models or opinion leaders of high-risk patients?

## **2. Social stigma**

**Evidenced both in research and in practice, stigma associated with TB appears to be universal. The consequences of stigma can be seen affecting care-seeking behaviors, as persons have been known to hesitate or choose not to disclose their TB status to family or friends out of fear of being socially ostracized. Research has demonstrated that in some cases, personal rejection occurs as a result of the strong stigma surrounding TB. Stigma has also been shown to hinder adherence to treatment. By identifying both the sources and consequences of stigma, social science research has illustrated the need for effective intervention strategies.**

*Social stigma was an issue raised in all of the breakout groups, highlighting the shared perception of the need to better understand its sources and identify effective ways to address it. During breakout discussions, forum participants specifically noted the need to define stigma from various perspectives, identify existing research to understand the impact of stigma, and propose specific measures to address and reduce stigma. Among*

*these measures, it was suggested to identify ways in which the public health community can alter its presentation of epidemiologic data to avoid the perpetuation of existing stigmatizations and to reinforce that TB is a curable disease.*

*Proposed research questions focused on identifying the effects or consequences of stigma on care seeking and adherence to treatment, and determining whether certain populations or sub-populations are adversely affected by stigma.*

- How does stigma differ among different ethnic groups? How does it vary with demographics? (Suggested methodologies include conducting formative and quantitative research).
- How can stigma be reduced among certain groups? (Suggested methodology is to provide massive education to those groups.)
- What are some ways to enhance the presentation of epidemiological data in order to avoid stigmatization and to increase community empowerment?
- What are some ways to avoid stigmatizing a community and to avoid essentialism of TB stigma and discrimination?
- How can the families and the communities of TB patients be integrated into the patient's treatment, follow-up, and re-integration into the job and community to prevent stigma and discrimination?
- How do we define "stigma" from the patient's perspective? ...The provider's perspective? ...And the community's perspective? Who is the stigmatizer and why? (Suggested methods include the use of focus groups and the Delphi technique)
- What are general community perceptions about TB and people living with TB? Where do they derive their understandings? What, if any, media influences exist that affect the community's perceptions? (Suggested methodologies include conducting surveys [e.g., mail surveys] among university and high school students; and conducting focus group discussions with church groups and other existing community groups.)
- Are current conceptual frameworks (for understanding stigma) adequate?
  - If "yes" to above, what frameworks (e.g., focus groups, interviews, and surveys) can be used to collect research on providers and patients?
  - If "no" to above, what formative research can be conducted on the origins of TB stigma and its specific components?
- What survey research can we conduct in patient and provider populations to assess discrimination, stigma, and treatment issues among people with HIV/TB, as well as people with TB in the home environment, community, and worksite?
- What are some ways to conduct an intervention study on the impact of locally developed education and messaging within communities on decreasing stigma?
- What are some ways to develop and test community based culturally specific interventions to increase awareness and knowledge of TB and to reduce stigma associated with treatment?

## VI. Public Policy

**Public policy influences focus on the implications that public policies have on the behaviors of individuals, groups, communities, and organizations, with special emphasis on issues relating to government commitment, funding, health insurance, and immigration policies.**

### A. Government commitment and funding

**Governmental entities, from federal to local, play a critical role in TB-related services. From federal-level research funding to service delivery at local health departments, TB control is affected greatly by policy decisions. Given these arrangements, the development of a better understanding of the policy process and greater engagement of decision-makers by those working in TB control may lead to improvement in TB services.**

*Forum participants identified as important the need to focus on identifying appropriate decision makers, potential advocates, and strategies to influence TB-related policies. They also specifically addressed funding issues such as the identification of effective ways to advocate for TB funding as well as possible models for allocation of funds within the TB framework.*

- Who are the TB local, state, and national policy-makers? What are their interests? How can TB be made a policy agenda item?
- How can state programs be influenced to advocate for TB? Where are the decisions being made?
- Who are the best advocates for TB control? (i.e., What is the role of state programs in advocacy?)
- What are the best ways to advocate for TB funding?
- What are some ways to conduct a demonstration in which TB funding is allocated similarly to Ryan White Care Act dollars? What are some ways to test an HIV model (e.g., Ryan White Care Act) within the TB framework?
- Which cultural interventions can be practically integrated into TB programs with limited resources?

### B. Health insurance

**As of 2002, data from the U.S. Census Bureau indicated that 43.6 million people were uninsured in the United States.<sup>3</sup> The lack of health insurance among people in the U.S. creates a serious impediment for those who seek or wish to seek health care for LTBI or TB disease, especially as it relates to TB testing and treatment. It is unknown to what extent a lack of appropriate insurance coverage or fear of treatment costs hinder care-seeking, but it is suspected that this economic deterrent has clear negative implications.**

*Forum participants identified the need to determine the effect of health insurance or lack of appropriate coverage for TB services on health behaviors and health outcomes, including access to TB diagnosis and treatment. Further research is needed to determine the impact this has on TB patients and their families, in addition to finding alternative funding solutions to increasing health care costs and expenses.*

- What is the effect of health insurance (or lack thereof) in regards to early interventions for the treatment of TB?
- How can the poor get health access (e.g., insurance)?

### **C. Immigration policies**

**With over half of TB cases in the United States occurring among individuals born outside of the country, the link between immigration and TB services has become increasingly important in recent years. Efforts to coordinate public health efforts with immigration activities pose an evolving challenge as changes occur to immigration policy and enforcement agencies. Understanding the impact of these specific changes as well as developing a broader body of knowledge of immigrant issues in general, will likely lead to improved TB services and better health outcomes.**

*Forum participants identified as important the need to focus on the effect of immigration policies, specifically regarding recent changes to policies, on TB services. Additional discussion focused on the need to develop strategies for collaboration with immigration authorities to increase access to immigrant communities.*

- What is the effect of new immigration policies on TB case identification, follow-up, treatment, and adherence? What about their effect on TB control among Latino immigrants?
- What types of research are needed to maximize the screening of new and recent arrivals? Issues to address include access to the population and collaboration with Immigration and Customs Enforcement.
- How can undocumented persons be helped to overcome their fear of government agencies and institutions?

## Appendix D: Participant List

### Tuberculosis Behavioral and Social Science Research Forum December 10-11, 2003 Atlanta, Georgia

**Rita Ailinger, PhD**

Professor  
George Mason University  
MSN: 3C4  
Fairfax, VA 22030  
Phone: 703-993-1926  
Fax: 703-993-1942  
E-mail: [railinge@gmu.edu](mailto:railinge@gmu.edu)

**Rachel Albalak, PhD**

Senior Epidemiologist  
Centers for Disease Control and Prevention  
Division of TB Elimination, SEOIB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-2385  
Fax: 404-639-8959  
E-mail: [Rka3@cdc.gov](mailto:Rka3@cdc.gov)

**Guadalupe Munguia-Bayona, MD**

Clinical Research Coordinator  
UNTHSC  
1101 S. Main Street, Suite 1600  
Fort Worth, TX 76104  
Phone: 817-321-4913  
Fax: 817-321-4920  
E-mail: [gbayona@hsc.unt.edu](mailto:gbayona@hsc.unt.edu)

**Gabrielle Benenson, MPH**

Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-5320  
Fax: 404-639-8960  
E-mail: [Gkb6@cdc.gov](mailto:Gkb6@cdc.gov)

**Regina Bess**

Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8987  
Fax: 404-639-8960  
E-mail: [RDB1@cdc.gov](mailto:RDB1@cdc.gov)

**Henry Blumberg, MD**

Professor of Medicine  
Emory University  
Division of Infectious Diseases  
69 Jesse Hill Jr. Drive  
Atlanta, GA 30303  
Phone: 404-616-6145  
Fax: 404-880-9305  
E-mail: [hblumbe@emory.edu](mailto:hblumbe@emory.edu)

**Cristina Booker, MPH**

Analyst  
Abt Associates, Inc.  
55 Wheeler Street  
Cambridge, MA 02138  
Phone: 617-349-2681  
Fax: 617-349-2497  
E-mail: [Cristina\\_booker@abtassoc.com](mailto:Cristina_booker@abtassoc.com)

**Leslie Boss, PhD**

Epidemiologist  
Centers for Disease Control and Prevention  
National Center for Environmental Health,  
EEH Division  
1600 Clifton Road, NE, Mailstop E-17  
Atlanta, GA 30333  
Phone: 404-498-1002  
Fax: 404-498-1088  
E-mail: [LPB1@cdc.gov](mailto:LPB1@cdc.gov)

**James Carey, PhD, MPH**  
Behavioral Scientist  
Centers for Disease Control and Prevention  
Division of HIV/AIDS Prevention, BIRB  
1600 Clifton Road, NE, Mailstop E-37  
Atlanta, GA 30333  
Phone: 404-639-1903  
Fax: 404-639-1950  
E-mail: [jcarey@cdc.gov](mailto:jcarey@cdc.gov)

**Betsy Carter, MPH, CHES**  
Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8386  
Fax: 404-639-8960  
E-mail: [Bkc9@cdc.gov](mailto:Bkc9@cdc.gov)

**Kenneth G. Castro, MD**  
Director  
Division of TB Elimination  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8120  
Fax: 404-639-8604  
E-mail: [Kgc1@cdc.gov](mailto:Kgc1@cdc.gov)

**Patrick Chaulk, MD, MPH**  
Senior Associate for Health  
Annie E. Casey Foundation  
701 St. Paul  
Baltimore, MD 21202  
Phone: 410-547-3672  
Fax: 410-547-3613  
E-mail: [pchaulk@aecf.org](mailto:pchaulk@aecf.org)

**Paul Colson, PhD**  
Program Director  
Charles P. Felton National TB Center at  
Harlem Hospital  
2238 Fifth Avenue  
New York, NY 10037  
Phone: 212-939-8241  
Fax: 212-939-8259  
E-mail: [Pwc2@columbia.edu](mailto:Pwc2@columbia.edu)

**Nick DeLuca, MA**  
Lead Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8988  
Fax: 404-639-8960  
E-mail: [Ncd4@cdc.gov](mailto:Ncd4@cdc.gov)

**Beverly DeVoe, MS**  
TB Program Director  
Georgia Department of Human Resources –  
TB Program  
2 Peachtree Street, NW, Suite 12-493  
Atlanta, GA 30202  
Phone: 404-657-2597  
Fax: 404-463-3460  
E-mail: [bdevoe@dhr.state.ga.us](mailto:bdevoe@dhr.state.ga.us)

**Agatha Eke, PhD**  
Behavioral Scientist  
Centers for Disease Control and Prevention  
Division of HIV/AIDS Prevention, BIRB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-1906  
Fax: 404-639-1950  
E-mail: [AEE2@cdc.gov](mailto:AEE2@cdc.gov)

**Kimberly Field**  
President NTCA, TB Controller  
Washington State Department of Health  
Services - STD/TB Services  
P.O. Box 47837  
Olympia, WA 98504-7837  
Phone: 360-236-3447  
Fax: 360-236-3470  
E-mail: [kim.field@doh.wa.gov](mailto:kim.field@doh.wa.gov)

**Hsin-Hsin Foo, MPH**  
ASPH Fellow  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8337  
Fax: 404-639-8960  
E-mail: [Hdf9@cdc.gov](mailto:Hdf9@cdc.gov)

**Maria Fraire, MPH, CHES**  
Lead Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-5317  
Fax: 404-639-8960  
E-mail: [Mff8@cdc.gov](mailto:Mff8@cdc.gov)

**Victoria Gammino, PhD, MPH**  
EIS Officer  
Centers for Disease Control and Prevention  
Division of TB Elimination, SEOIB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-1572  
Fax: 404-639-8959  
E-mail: [Vmg0@cdc.gov](mailto:Vmg0@cdc.gov)

**Deliana Garcia, MA**  
Director, International Research and  
Development  
Migrant Clinicians Network  
P.O. Box 164285  
Austin, TX 78716  
Phone: 512-327-2017  
Fax: 512-327-0719  
E-mail: [dgarcia@migrantclinician.org](mailto:dgarcia@migrantclinician.org)

**Judy Gibson, MSN, RN**  
Nurse Consultant  
Centers for Disease Control and Prevention  
Division of TB Elimination, FSEB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-5322  
Fax: 404-639-8958  
E-mail: [Jsd0@cdc.gov](mailto:Jsd0@cdc.gov)

**Stefan Goldberg, MD**  
Medical Officer  
Centers for Disease Control and Prevention  
Division of TB Elimination, CHSRB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8123  
Fax: 404-639-8961  
E-mail: [SSG3@cdc.gov](mailto:SSG3@cdc.gov)

**Greg Guest, PhD**  
Senior Research Associate  
Family Health International  
2224E NC Highway 54  
Durham, NC 27713  
Phone: 919-544-7040  
Fax: 919-544-7261  
E-mail: [Gguest@fhi.org](mailto:Gguest@fhi.org)

**Theodore (Ted) Hammett, PhD**  
Vice President  
Abt Associates, Inc.  
55 Wheeler Street  
Cambridge, MA 02138  
Phone: 617-349-2734  
Fax: 617-349-2497  
E-mail: [Ted\\_Hammett@abtassoc.com](mailto:Ted_Hammett@abtassoc.com)

**Yael Hirsch-Moverman, MS, MPH**  
Epidemiologist  
Charles P. Felton National TB Center at  
Harlem Hospital  
2238 Fifth Avenue, Room 163  
New York, NY 10037  
Phone: 212-939-8240  
Fax: 212-939-8259  
E-mail: [Yh154@columbia.edu](mailto:Yh154@columbia.edu)

**Harold Jaffe, MD**  
Director  
National Center for HIV, STD, and TB  
Prevention  
1600 Clifton Road, NE, Mailstop E-7  
Atlanta, GA 30333  
Phone: 404-639-8000  
Fax: 404-639-8600  
E-mail: [Hwj1@cdc.gov](mailto:Hwj1@cdc.gov)

**Nikki Johnson, LSW**  
Social Services Provider  
Georgia Department of Human Resources –  
TB Program  
2 Peachtree Street, NW, 12th Floor  
Atlanta, GA 30303  
Phone: 404-656-6254  
Fax: 404-463-3460  
E-mail: [njohnson@dhr.state.ga](mailto:njohnson@dhr.state.ga)

**Heather Joseph, MPH**

Health Scientist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CHSRB  
1600 Clifton Road, NE, Mailstop -10  
Atlanta, GA 30333  
Phone: 404-639-2636  
Fax: 404-639-8961  
E-mail: [Hbj7@cdc.gov](mailto:Hbj7@cdc.gov)

**Elizabeth Kalayil, MPH**

ASPH Fellow  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Atlanta, GA 30333  
Phone: 404-639-6469  
Fax: 404-639-8960  
E-mail: [Ehk2@cdc.gov](mailto:Ehk2@cdc.gov)

**Masae Kawamura, MD**

ACET Chairperson  
Director, TB Control Section  
San Francisco Department of Public Health TB  
Clinic, Ward 94  
San Francisco General Hospital  
1001 Potrero Avenue  
San Francisco, CA 94110  
Phone: 415-206-8524  
Fax: 415-648-8369  
E-mail: [Masae\\_kawamura@sfggh.org](mailto:Masae_kawamura@sfggh.org)

**Amera Khan, MPH**

Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-6428  
Fax: 404-639-8960  
E-mail: [AJK5@cdc.gov](mailto:AJK5@cdc.gov)

**Kathleen Kolaski, MSN**

Nurse Consultant  
Georgia Department of Human Resources –  
TB Program  
2 Peachtree Street, NW  
Atlanta, GA 30303  
Phone: 404-656-6250  
Fax: 404-463-3460  
E-mail: [kokolaski@dhr.state.ga.us](mailto:kokolaski@dhr.state.ga.us)

**Kayla Laserson, ScD**

Team Leader  
Centers for Disease Control and Prevention  
Division of TB Elimination, IRPB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-5334  
Fax: 404-639-1556  
E-mail: [Kel4@cdc.gov](mailto:Kel4@cdc.gov)

**Brandon Long, MPH**

Consultant  
Abt Associates, Inc.  
26 Cordis Street, #2  
Charlestown, MA 02129  
Phone: 617-241-8343  
E-mail: [Blong777@yahoo.com](mailto:Blong777@yahoo.com)

**Joan Mangan, PhD, MST**

Educational Research Consultant  
Gorgas TB Initiative  
1665 University Boulevard  
Ryals Bldg., Suite 217  
Birmingham, AL 35294-0022  
Phone: 205-934-1752  
Fax: 205-934-1746  
E-mail: [jmangan@ms.soph.uab.edu](mailto:jmangan@ms.soph.uab.edu)

**Suzanne Marks, MPH, MA**

Senior Epidemiologist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CHSRB  
1600 Clifton Road, NE, Atlanta, GA 30333  
Phone: 404-639-5343  
Fax: 404-639-8961  
E-mail: [Sqm3@cdc.gov](mailto:Sqm3@cdc.gov)

**Holly Massett, PhD**

Senior Research Scientist  
RTI International  
1615 M. Street, NW, Suite 740  
Washington, DC 20036  
Phone: 202-728-2472  
Fax: 202-728-2095  
E-mail: [hmassett@rti.org](mailto:hmassett@rti.org)

**Kelly McCarrier, MPH**  
ASPH Fellow  
Centers for Disease Control and Prevention  
Division of TB Elimination, CHSRB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8415  
Fax: 404-639-8961  
E-mail: [Bke4@cdc.gov](mailto:Bke4@cdc.gov)

**Scott McCoy, MEd, Eds**  
Health Education Specialist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8992  
Fax: 404-639-8960  
E-mail: [Smccoy1@cdc.gov](mailto:Smccoy1@cdc.gov)

**Shawna Mercer, PhD**  
Health Scientist  
Centers for Disease Control and Prevention  
Public Health Practice Program Office, OD  
1600 Clifton Road, NE, Mailstop K-56  
Atlanta, GA 30333  
Phone: 770-488-8475  
Fax: 770-488-8200  
E-mail: [ZH15@cdc.gov](mailto:ZH15@cdc.gov)

**Jane Mezzoff, DrPH**  
Behavioral Scientist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CEBSB  
1600 Clifton Road, NE, Atlanta, GA 30333  
Phone: 404-639-8043  
Fax: 404-639-8960  
E-mail: [Jsm0@cdc.gov](mailto:Jsm0@cdc.gov)

**Donald Morisky, ScD., M.S.P.H., Sc.M.**  
Professor  
UCLA School of Public Health  
Department of Community Health Sciences  
650 Charles E. Young Drive South  
Los Angeles, CA 90095-1772  
Phone: 310-825-8508  
Fax: 310-794-1805  
E-mail: [dmorisky@ucla.edu](mailto:dmorisky@ucla.edu)

**Lauren Moschetta, MA**  
Health Educator  
NJMS National TB Center  
225 Warren Street, 1st Floor, West Wing  
Newark, NJ 07101  
Phone: 973-972-1261  
Fax: 973-972-1064  
E-mail: [Moschelb@umdnj.edu](mailto:Moschelb@umdnj.edu)

**Mark Nichter, PhD, MPH**  
Professor  
University of Arizona  
Department of Anthropology, Haury Bldg.  
Tucson, AZ 85716  
Phone: 520-621-2665  
Fax: 520-621-2088  
E-mail: [mnichter@u.arizona.edu](mailto:mnichter@u.arizona.edu)

**Rick O'Brien, MD**  
Chief, Clinical and Health Systems Research  
Branch  
Division of TB Elimination  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8123  
Fax: 404-639-8961  
E-mail: [Rjo1@cdc.gov](mailto:Rjo1@cdc.gov)

**Jessica Ogden, PhD**  
Technical Specialist  
International Center for Research on Women  
1717 Massachusetts Avenue, NW  
Suite 302  
Washington, DC 20036  
Phone: 202-797-0007  
Fax: 202-797-0020  
E-mail: [jogden@icrw.org](mailto:jogden@icrw.org)

**Alawode Oladele, MD, MPH**  
Medical Director, TB & Refugee Health  
DeKalb County Board of Health  
445 Winn Way, Suite 150  
Decatur, GA 30030  
Phone: 404-294-3768  
Fax: 404-491-8655  
E-mail: [axoladele@gdph.state.ga.us](mailto:axoladele@gdph.state.ga.us)

**Kathryn O'Toole, MBA**

Associate Director of Management and Operations  
Division of TB Elimination  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8120  
Fax: 404-639-8604  
E-mail: [Keh3@cdc.gov](mailto:Keh3@cdc.gov)

**Marian Passannante, PhD**

Associate Professor  
UMDNJ Medical School & National TB Center, Department of Preventive Medicine & Community Health  
185 South Orange Avenue, MSB F588  
Newark, NJ 07103  
Phone: 973-972-4775  
Fax: 973-972-7625  
E-mail: [passanna@umdnj.edu](mailto:passanna@umdnj.edu)

**Paul Poppe**

Deputy Director  
Division of TB Elimination  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8120  
Fax: 404-639-8604  
E-mail: [Pop1@cdc.gov](mailto:Pop1@cdc.gov)

**Carol Pozsik, RN, MPH**

Director, TB Control Division  
South Carolina Department of Health & Environmental Control  
1751 Calhoun Street  
Columbia, SC 29201  
Phone: 803-898-0539  
Fax: 803-898-0685  
E-mail: [pozsikc@dhec.sc.gov](mailto:pozsikc@dhec.sc.gov)

**Noreen Qualls, DrPH**

Lead Health Scientist  
Centers for Disease Control and Prevention  
Division of TB Elimination, CHSRB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8195  
Fax: 404-639-8961  
E-mail: [NLO0@cdc.gov](mailto:NLO0@cdc.gov)

**Cathy Rawls, MPH, CHES**

ASPH Fellow  
Division of TB Elimination, CEBSB  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-6291  
Fax: 404-639-8960  
E-mail: [Cvr8@cdc.gov](mailto:Cvr8@cdc.gov)

**Alyssa Robillard, PhD**

Senior Associate  
Rollins School of Public Health-Emory University  
1518 Clifton Road NE, Room 546  
Atlanta, GA 30322  
Phone: 404-727-9823  
Fax: 404-727-1369  
E-mail: [arobill@sph.emory.edu](mailto:arobill@sph.emory.edu)

**Ximena Urrutia-Rojas, Dr.PH**

Assistant Professor, Department of Social and Behavioral Sciences  
University of North Texas Health Science Center, School of Public Health  
3500 Camp Bowie Boulevard  
Fort Worth, TX 76107-2699  
Phone: 817-735-0325  
Fax: 817-735-0255  
E-mail: [xurrutia@hsc.unt.edu](mailto:xurrutia@hsc.unt.edu)

**Rachel Royce, PhD, MPH**

Senior Research Epidemiologist  
Research Triangle Institute  
P.O. Box 12194  
Research Triangle Park, NC 27709-2194  
Phone: 919-485-5649  
Fax: 919-541-7384  
E-mail: [rroyce@rti.org](mailto:rroyce@rti.org)

**Robin Shrestha-Kuwahara, MPH**

Behavioral Scientist  
Division of TB Elimination, CHSRB  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8314  
Fax: 404-639-8961  
E-mail: [Rbk5@cdc.gov](mailto:Rbk5@cdc.gov)

**Esther Sumartojo, PhD, MSc**

Deputy Associate Director for Science and Public Health  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-87  
Atlanta, GA 30333  
Phone: 404-498-3072  
Fax: 404-498-3070  
E-mail: [esumartojo@cdc.gov](mailto:esumartojo@cdc.gov)

**Wanda Walton, PhD**

Chief, Communications, Education, and Behavioral Studies Branch  
Division of TB Elimination  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8319  
Fax: 404-639-8960  
E-mail: [Wxw2@cdc.gov](mailto:Wxw2@cdc.gov)

**Charles Wells, MD**

Chief, International Research and Programs Branch  
Division of TB Elimination  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-8120  
Fax: 404-639-1566  
E-mail: [CCW2@cdc.gov](mailto:CCW2@cdc.gov)

**Mary Castle White, PhD, MPH**

Professor  
University of California, San Francisco  
2 Koret Way, School of Nursing  
Box 0608  
San Francisco, CA 94143-0608  
Phone: 415-476-5213  
Fax: 415-476-6042  
E-mail: [mcwhite@itsa.ucsf.edu](mailto:mcwhite@itsa.ucsf.edu)

**Maureen Wilce, MS**

Behavioral Scientist  
Centers for Disease Control and Prevention  
Division of TB Elimination, FSEB  
1600 Clifton Road, NE, Mailstop E-10  
Atlanta, GA 30333  
Phone: 404-639-5330  
Fax: 404-639-8958  
E-mail: [MUW9@cdc.gov](mailto:MUW9@cdc.gov)

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the 1990s, the number of people with a mental health problem has increased in the Netherlands. The prevalence of mental health problems in the Netherlands is estimated to be 15% (Van Tilburg *et al.* 2000). The prevalence of mental health problems is expected to increase in the future because of the ageing of the population (Van Tilburg *et al.* 2000).

People with a mental health problem are often dependent on others for their daily needs. This dependency is often caused by a lack of insight into their own condition and a lack of insight into their own needs. People with a mental health problem often have a low self-esteem and a low confidence in their own abilities. This can lead to a lack of motivation and a lack of initiative. People with a mental health problem often have a low social skills and a low ability to solve problems. This can lead to a lack of social support and a lack of resources.

People with a mental health problem often have a low quality of life. This is caused by a lack of insight into their own condition and a lack of insight into their own needs. People with a mental health problem often have a low self-esteem and a low confidence in their own abilities. This can lead to a lack of motivation and a lack of initiative. People with a mental health problem often have a low social skills and a low ability to solve problems. This can lead to a lack of social support and a lack of resources.

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