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FORUM ON HEALTH AND NATIONAL SECURITY

STIGMA AND BARRIERS TO CARE  
CARING FOR THOSE EXPOSED TO WAR,  
DISASTER AND TERRORISM

CONFERENCE REPORT

Center for the Study of Traumatic Stress  
Department of Psychiatry  
Uniformed Services University of the Health Sciences  
and Defense Centers of Excellence



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DISASTER AND TERRORISM

EDITED BY

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Center for the Study of Traumatic Stress  
Department of Psychiatry  
Uniformed Services University of the Health Sciences and  
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*From the Conference Series:*

FORUM ON HEALTH AND NATIONAL SECURITY

**STIGMA AND BARRIERS TO CARE**  
CARING FOR THOSE EXPOSED TO WAR, DISASTER AND TERRORISM

Editor's Note: This transcript has been edited, however, as in most transcripts some errors may have been missed. The editors are responsible for any errors of content or editing that remain.

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## PREFACE

This Forum on Health and National Security, directed to addressing stigma and barriers to care, brought together a diverse group of leaders in order to expand our horizons on these issues of important national need in times of war, disaster and terrorism. The individuals represented national leaders, educators, researchers and health care planners across mental health, health care systems, military and disaster care and the specific issues of stigma and barriers to care. Our goal was for individuals who did not usually talk with each other or even know of each other's work, to hear new perspectives and create a new vantage point on this difficult topic. We operated under the belief that if one only talks to people that you already know we cannot maximize our joint knowledge and opportunities. We hoped that those in attendance would leave with at least two new names of people who would be helpful and of interest in pursuing our needs to address stigma and barriers to care.

Our primary goal was to better understand the issues of stigma and barriers to care as they relate to the trajectory from illness, distress and health risk behaviors after war, disaster or terrorism to care and needed help. At that point the group could translate their understanding into action through recommendations. The work of the Forum was a series of presentations followed by thinking together. Our final discussions were to formulate a set of recommendations to capture the ideas generated. The recommendations were organized into the areas of research, education and training, leadership and intervention. We hope this volume communicates the important ideas and recommended actions from this distinguished group.

*Our primary goal was to better understand the issues of stigma and barriers to care as they relate to the trajectory from illness, distress and health risk behaviors after war, disaster or terrorism to care and needed help.*



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## EXECUTIVE SUMMARY AND RECOMMENDATIONS

What is stigma? What is it that prevents people from getting help for psychological and behavioral problems after war, disasters or terrorism when they need it? What are the predictors of not coming for care and assistance? Is it because one would feel embarrassed? Is it because of inadequate transportation? Or that a person cannot get an appointment? Or are there other factors such as lack of trust in mental health professionals or people thinking treatment is not going to work, or believing “I can handle it myself”?

The Forum on Health and National Security is a conference series addressing the intersection of health and national security needs. The goal of this first conference was to better understand stigma and barriers to care in those exposed to war, disaster and terrorism and to translate that understanding into action. Stigma is associated with behavioral health in general and emergency behavioral health in particular. To address stigma and barriers to care it is important to address the marginalization and misunderstanding about what we can and cannot do in mental health and the myths about our field. Mental health stigma is not just about getting treatment. It is an attribute of many aspects of behaviors, including health and illness, and it is a part of our social interactions. It disqualifies individuals from a particular group citizenship. It can negate acceptance in the family sphere and the work place.

There are other reasons which also play a part in why people do not come forward for treatment. Perhaps most importantly if they believe that we are offering them treatment for something they do not see as a problem. Similarly, as care providers we like diagnoses — they orient our treatments and give us guideposts — but people who have illnesses do not always like them. People do not like to be placed into the ‘abnormal’ category. For mental health diagnoses, both in the military or civilian worlds, how to modify societal beliefs that psychiatric and psychological problems mean weakness is a major challenge.

Looked at from the other side of stigma— what are its consequences? What are the behavioral implications of stigma? Over the years there have been a number of efforts by community mental health to educate neighborhoods about mental health and illness. Often these messages have been that mental illness is not really an illness and not really dangerous. What researchers have discovered is that when we provide education to the community it may only help the neighborhood mobilize against those with behavioral and health problems more quickly. People who have behav-

*What is stigma? What is it that prevents people from getting help for psychological and behavioral problems after war, disasters or terrorism when they need it? What are the predictors of not coming for care and assistance?*

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ioral and health problems “know” that other people feel awkward around them. Therefore people often are reluctant to go for treatment. This is particularly true in the armed forces where the ethos is, “I don’t need help. I can handle things myself.”

There is good reason to think that embarrassment is an important cause of failure to get treatment and an important cause of dropping out of treatment prematurely. This embarrassment is based in part on the perception of the stigma associated with emotional disorders, the idea that it is shameful to have a mental illness and that it is a character flaw. The General Social Survey (GSS) conducted by the National Opinion Research Center, University of Chicago, has been monitoring attitudes about mental illness since 1972 and has documented an increase in the perception that mental illness is attributable to biological causes rather than a character flaw. There has been an increase in the perception that biological treatment is likely to be the most effective kind of treatment. Part of the reason for this is that there has been a massive increase in public information about mental illness since the early 1990’s. However, it is not always true that giving people more information creates the behavioral changes desired. Now the perception that one’s family may carry dangerous genes has become part of the stigma burden.

Mental health includes resilience as well as disorders, distress responses, and health risk behaviors. How do barriers to care affect each of these? Distress responses can also be thought of as subthreshold mild to moderate symptoms and often are early signs indicating the need for treatment or psychological rest. They also impair performance. We need to particularly better understand how barriers to care can impact the performance and health of individual service members, public health responders and other safety and security personnel as well as their organizations. It is important to address the individual’s impairment of function and how barriers to care also lead to increased disability. Complicating the issues is the fact that disability may increase with the award of compensation.

Health risk behaviors, e.g., use of cigarettes, changes in use of alcohol, accidents in particular road traffic accidents, and substance abuse, are a part of the health burden after war and disasters. They are too often overlooked in the broader public health issues after traumatic events. These are important targets for prevention and intervention in which stigma and barriers to care also impact health trajectories. For example, altering cigarette use substantially alters morbidity and mortality related to disease. In addition it is a part of the health environment of our families and our service members. We know cigarette use changes after exposures to combat, disasters, and terrorism. Our 18–25 year-olds are those who have the highest rates of cigarette use.

The individual’s perception of the need for care is an important part of the trajectory from illness, distress or health risk behaviors to care. About 17% of DoD reported a need for counseling. Approximately 4.8% of DoD has received a medication for depression, anxiety, or sleep; 14.6% have received some type of mental health counseling. Half of the counseling is from a military mental health professional. Importantly, approximately 44% describe probable or definite perceived damage to their career for seeking mental health counseling. Sorry to say but true is that this is similar for the nation as a whole. In 2004 Hoge et al. found that considerably more than half of the soldiers and marines who were surveyed and seemed to be in need of treatment, indicated that they had not received any treatment. Stigma and barriers to care were an important component in their path to care.

Families also have particular problems during war and disasters and concern

about stigma in families can prevent care to children and family members. For example, there are barriers to care related to intervention for family conflict and child neglect. We need to consider outreach to these populations. How to alter the system to better reach them and they reach us? Somatic symptom reporting is particularly important to the health care system. Unexplained and idiopathic somatic complaints increase in times of war and disasters also as shown following Katrina or in New York City after 2001. Somatic symptoms complaints raise issues of stigma and barriers to reaching the correct care, and the overtreatment of people who may not need physical health care.

In considering recommendations to address stigma and barriers to care as an impediment in the illness to treatment path, there are several models to consider. One approach is the traditional primary, secondary, and tertiary prevention. This involves response and prevention of disability. Another approach follows the IOM suggestions from 1994 which address whether an intervention is for the entire population or high risk groups. In addition, for war, disaster, and terrorism — similar to the Haddon Matrix — there are stages to consider: pre-stage, an event stage in which we operate, and a post-event stage.

How do we place disaster response, war and terrorism in these frames of reference to better address barriers and stigma? These are the issues addressed by the distinguished group of speakers and participants in this Forum on Health and National Security. Our recommendations inform and direct thoughts for research, training and education, leadership and intervention to best address stigma and barriers to care of our service members, their families and our nation as a whole in times of war, disaster and terrorism. The following summarizes the recommendations of the group.

## Research Directions

1. The stigma associated with psychological health has changed little since the start of the war despite massive education and screening campaigns. It is conceivable that the stigmatization process as a means of differentiating “in” and “out” groups plays such a central role in maintaining performance that changing the culture will continue to be a long-term goal. In order to mitigate the health and national security implications of such a phenomenon research is needed to develop alternative approaches to care. Areas for exploration include the study of the effects of relationships on altering barriers to care, coaching models of care, processes of effective care, case definition and identification, and referral and access to health care. The role of buddy care and mechanisms for fostering connection with others and support require further study.
  - Develop alternatives to diagnosis and disability-based models of care.
  - Examine the effects of buddy, leadership, and family relationships on barriers to care.
  - Examine the effectiveness of coaching models of care in decreasing barriers to care.
  - Examine the process of reaching care from case identification to referral to access.
  - Examine the role of buddy care and psychological first aid in altering barriers to care.

*The stigma associated with psychological health has changed little since the start of the war despite massive education and screening campaigns.*



*Many factors, including stigma, inhibit symptomatic individuals from seeking care following exposure to disaster, war, and terrorism.*

- Identify the role of self-help groups in promoting care seeking and adherence.
  - Examine the mechanisms of fostering connections with others as a factor in altering stigma and interpersonal barriers to care.
2. Many factors, including stigma, inhibit symptomatic individuals from seeking care following exposure to disaster, war, and terrorism. Of those who are brought to clinical attention many drop out or receive inadequate care. Research is needed to better understand vocational trajectories after care seeking, the positive effects of treatment, the process of reaching effective care, and the effectiveness of contact at various stages from symptom onset to impairment across outcomes. These outcomes include distress, disorder, health risk behaviors, and injury. There is a paucity of qualitative study of the narratives of injured soldiers who successfully negotiated barriers to care including stigma, received treatment, remained in treatment, and shared their experience of effective care. There is a need for case control or cohort studies of “declining care” with outcome variables including job function, home function, health and resilience.
    - Identify vocational trajectories after care seeking including the positive effects of treatment.
    - Examine the impact of contact across stages of psychological and behavioral responses to traumatic events on the trajectory of care seeking.
    - Use qualitative techniques to examine the narratives of trauma survivors.
    - Conduct studies of the effects of declining care across various outcomes.
  3. Research is needed to understand, develop, and make accessible high-quality, practical, evidence-based care for symptomatic individuals exposed to disaster, war, and terrorism. We need to better understand how to get rapid relief for those who enter primary or specialty care. Research is needed to examine what is effective in therapy and how to optimize primary care settings to identify and treat mental health disorders in less stigmatized settings in a manner which does not burden the primary care practitioner. We need to better understand what happens in psychotherapy in order to encourage participation in specialty care. Studies are needed to examine technologies used to get patients to treatment, get treatment to patients and to provide information and treatment in less stigmatizing settings.
    - Further develop high-quality, practical, evidence-based care for symptomatic individuals exposed to trauma.
    - Identify treatments that provide rapid and sustained relief and methods of delivery that decrease stigma and barriers.
    - Identify ways to optimize collaborative care in the primary care setting.
    - Develop qualitative methods to examine the narratives of successful treatment across the trajectories of accessing care.
    - Examine technologies to get patients into treatment that present information and treatment in less stigmatizing settings.
  4. Screening programs such as Post-Deployment Health Assessment (PDHA) and Reassessment (PDHRA) should be examined for positive and negative predictive

value, cost-effectiveness, and unintended consequences. For example, universal face-to-face mental health screening of all redeploying soldiers is difficult to implement and can deplete already overwhelmed treatment resources. In addition it may exacerbate patient concerns about confidentiality and decision-making autonomy. Selective Primary Care Screening for Depression and PTSD, as implemented in the Re-Engineering Systems of Primary Care Treatment in the Military (RESPECT-MIL) program sets the standard for optimizing access to primary health care while minimizing the potential for stigmatization associated with health care utilization. Internet-based interventions designed to get people into treatment need further development, broader implementation, and an evaluation strategy. Research is needed to evaluate the collaboration between the primary care and mental health communities in order to optimize collaboration.

- Study positive and negative predictive value, cost-effectiveness, and potential unintended consequences of PDHA, PDHRA.
- Study the unintended consequences of mandatory face-to-face mental health screening for all redeploying soldiers, irrespective of risk stratification.
- Continue implementation and evaluation of RESPECT-MIL program.
- Develop, implement and evaluate the effectiveness of internet-based interventions.
- Evaluate the collaboration between the primary care and mental health care communities' considerations in order to optimize collaboration.
- Examine the trajectory of post-traumatic reactions, including recovery, disability, and impairment.
- Examine the effects of co-morbid medical illness on barriers to care and stigma.
- Identify factors that initiate and perpetuate the illness role.

*Initial and refresher training and education of primary and specialty care providers' for encouraging service members and disaster exposed families and public health workers to enter care (e.g. motivational interviewing) are important for optimal treatment strategies, programs and goals.*

## **Training and Education**

Initial and refresher training and education of primary and specialty care providers for encouraging service members and disaster exposed families and public health workers to enter care (e.g. motivational interviewing) are important for optimal treatment strategies, programs and goals. Individuals seeking assistance need to be directed to high quality easily accessible information. A clearinghouse to establish and maintain sources of information is needed. Military leadership education and training at all ranks should include education on barriers to care (including stigma), and help seeking as an element of the service's core values and on various cultural "languages" acceptable to care seeking. In keeping with a "safety culture/safety climate" emphasis, help seeking as a means of performance optimization and training on recognizing evidence of distress should be included as an element of such curricula. It is important to maximize the extent to which this training can be provided by unit leaders to forward unit mental health providers. Leadership mastery of skills should be tested and rewarded, offering badges or special skill identifiers analogous to the Combat Lifesaver designation as potential reinforcements for soldiers developing expertise in this area. Vocational rehabilitation should be included as an element of performance enhancement. It is important to optimize, disseminate, and

*Public mental health and military mental health leadership need to integrate the message of help seeking as an aspect of performance enhancement and organizational development.*

evaluate web-based treatments for PTSD and to identify ways to inform the use of testimonials as evidence of effective care. Training in non-health care settings such as communities, work places, and jails should be provided.

- Provide initial and refresher training and education of primary care and specialty care providers in optimally motivating patients to seek care as well as treatment strategies, programs and goals.
- Direct individuals seeking assistance to high quality, easily accessible information. Establish and maintain a clearinghouse of sources of accurate information.
- Establish military leadership education and training at all ranks to include education on barriers to care (including stigma), and promoting help seeking as an element of each service's core values. This should include training on recognition of signs of distress in self and others, normalization of work-rest cycles. The DCoE Real Warriors program is an excellent example.
- Reframe help seeking as a means of performance optimization and include training on recognizing signs of distress in oneself and others.
- Promote vocational rehabilitation as an aspect of performance enhancement.
- Optimize, disseminate, and evaluate web-based treatments for PTSD.
- Use individual testimonials to highlight the availability of effective care.
- Include non-health care personnel and settings in training and education.
- Study the science and processes of training in order to optimize effectiveness.

### **Leadership**

Public mental health and military mental health leadership need to integrate the message of help seeking as an aspect of performance enhancement and organizational development. Leaders should incorporate a blend of behavioral health prevention and improving capacity for evidence based service delivery in their organizations. Military leaders should integrate evidence based interventions into training and implement this at the level of operational units. Leaders need to reinforce the value of recognizing signs of distress, along with endorsing and underwriting a cultural shift toward rest and “taking a knee” when indicated. Structural efforts should be directed at improving confidentiality associated with care seeking. When highly effective treatments are available and accessible leaders need to articulate their support for care seeking and aid in dispelling myths about what happens in treatment.

- Consider a conference to expand the focus of this discussion to the broader national public mental health agenda to provide strategies and vision on behavioral public health of the nation.
- Integrate the message of help seeking as performance enhancement into all levels of leadership education and training, and policy making.
- Train leaders to incorporate a balanced blend of behavioral health prevention and improving capacity for evidence based service delivery.
- Ensure that evidence based interventions are integrated into training and implemented at the level of operational units.

- Reinforce the importance of recognizing signs of distress, along with endorsing and underwriting a cultural shift toward rest and “taking a knee” when indicated.
- Continue structural efforts toward improving confidentiality associated with care seeking.
- Leaders must be able and willing to articulate their support for care seeking, and aid in dispelling myths about what happens in treatment and after treatment is sought.
- As a preventive measure, policy makers and leaders should continue to improve deployment to dwell time ratios for military personnel.

*Many excellent programs for stigma mitigation designed to reduce barriers to care exist in the Department of Defense, Department of Veterans Affairs and civilian public health and academic centers.*

## Intervention

Many excellent programs for stigma mitigation designed to reduce barriers to care exist in the Department of Defense, Department of Veterans Affairs and civilian public health and academic centers. Leaders should foster and support ongoing evaluation of these program interventions using measurable and operational outcomes. We must consider how non-health care systems can be leveraged to reduce stigma and other barriers to care spanning the contexts of war, terrorism and disaster. Appealing to altruism, enlisting others to provide support has been an important guiding principle in the British TRIM program. Evidence informed frameworks such as Psychological First Aid should guide targeted interventions. Effective public health planning tools, such as the Haddon Matrix, can be helpful in designing phased programs. It is important to optimize the use of self-help groups to promote treatment adherence. Programs such as the DCoE Real Warriors, Bryan Doerries Theatre of War, and social media such as Twitter or Facebook are examples of creative interventions to promote “contact”, widely regarded as the most critical element of successful stigma mitigation effort. Mental health should collaborate with marketing and media experts to establish long-term public behavioral health educational campaigns and to promote collaboration between civilian and military communities.

- Leaders should foster and support ongoing evaluation of programmed interventions using measurable and operational outcomes.
- Non-health care systems can be leveraged to reduce stigma and other barriers to care in the context of war, terrorism and disaster.
- Evidence informed frameworks such as Psychological First Aid should guide targeted interventions.
- Effective public health planning tools, such as the Haddon Matrix, can be used to design public health programs.
- Self-help groups, which are known to promote treatment adherence should be optimized.
- Programs such as the DCoE Real Warriors, Bryan Doerries’s Theatre of War, and social media such as Twitter or Facebook are examples of creative interventions to promote “contact”, widely regarded as the most critical element of successful stigma mitigation efforts.

- Collaborate with marketing and media experts in establishing long-term public behavioral health educational campaigns.
- Promote collaboration between civilian and military communities.

## I

## INTRODUCTION

*Mark C. Brown, M.D., M.P.H.*

*Robert J. Ursano, M.D.*

**DR. BROWN:** Good morning and welcome to the Forum on Health and National Security meeting on “Stigma and Barriers to Care: Caring For Those Exposed to War, Disaster and Terrorism” working meeting. I stand before you today feeling as I do prior to many big events — excited, anxious if not afraid, and somewhat uncertain about what we are getting into. I am a fellow in the Disaster and Preventive Psychiatry Program at USUHS (Uniformed Services University of the Health Sciences) and a mid-career Army psychiatrist. I first became interested in this program when I met COL Chuck Engel, the architect of the RESPECT-MIL (Re-Engineering Systems of Primary Care for PTSD and Depression in the Military) program. COL Engel encouraged me to see mental health problems through a population-health lens and inspired me to sign up for the disaster psychiatry fellowship, which has been a great experience.

Sadly, I am near the end of that journey and want to take a couple of minutes to thank some important people. First I should comment on the origins of this conference. The idea was born during a meeting about a year ago when I was waxing philosophical about my research findings and the secondary analysis of COL Hoge’s land combat study data. A smile came across Dr. Ursano’s face and he said, “Mark, you’re going to lead a conference on this topic next year.”

So here we are. Thankfully, when he made that statement, he had also hired a wonderful woman named Mary Lee Dichtel. Without her, I could not have done this. Mary Lee is a former ICU and pediatric oncology nurse who is exceptionally caring and who has a very gentle touch. She was extremely well qualified to help me orchestrate this meeting. Along with Mary Lee, Julie Grieco did much of the hard work. Dr. Jamie Naifeh is responsible for the conference website, which some of you have joined and contributed to. All of the talks will be posted on the website, which will remain available after the conference.

I want to thank COL Chuck Engel for his mentorship and friendship over the last couple of years. In addition, I want to personally thank Dr. Alisha Creel, who has a Ph.D. in Public Health, Social and Behavioral Science, and is a great student of stigma. As my key mentor during the MPH year, she guided me through directed readings on stigma, most written by people who are in the room today.

Indeed, we have convened the world’s experts on stigma and we will soon hear

*Our first goal is better understanding and then to translate that understanding into action in the areas of dealing with stigma and barriers to care for our three populations: those exposed to war, disaster, and terrorism. We have representatives from all of those areas of study.*

from them. We also have experts from a variety of other areas. Together we are going to think across disciplines to try to better understand this topic.

COL Hoge graciously allowed me to analyze his dataset to develop some new skills under the expert supervision of Dr. Creel. Dr. Bob Ursano has been an absolutely great mentor and a real gentleman, leading me through a mid-career learning experience. I would like to take this opportunity to thank him for all that he has done.

**DR. URSANO:** Thank you, Mark. I would like to thank all of you for being here. We brought together a diverse group of leaders in their fields who may or may not know each other's work and that is why you are each here. If you are only talking to people that you already know we are not accomplishing one of our goals. We want you to leave here with at least two new names of people who will be helpful and of interest to you in pursuing these topics. To help with this, in your packets we have provided a list of the e-mail addresses and affiliations of all attendees.

Our primary work today is a series of presentations and thinking together. Our work tomorrow is to formulate today's discussion into a set of recommendations, so you should capture ideas generated today that you want to bring up tomorrow. Specifically, the goal tomorrow will be to take what we have learned and translate it into a series of recommendations in the areas of education, training, leadership, and research. Our first goal is better understanding and then to translate that understanding into action in the areas of dealing with stigma and barriers to care for our three populations: those exposed to war, disaster, and terrorism. We have representatives from all of those areas of study.

It is a great pleasure to have as our first speaker Ron Kessler. Ron is not only one of the brightest people I have ever met, he is also one of the most gracious. As you all know Dr. Kessler is a professor at Harvard. He has done most of the epidemiologic studies that we all cite in our papers, including the National Comorbidity Study, the National Comorbidity Study-Replication, and the related Adolescent Study. He is the head of the ongoing World Health Organization (WHO) studies. He is also the driving force in the Army STARRS (Study to Assess Risk and Resilience in Servicemembers) study, which is our ongoing study of suicide within the Army looking at risk factors and resilience. He is gracious and brilliant, and he is here to talk with us today as well as to join the discussion. Welcome, Ron.

## MENTAL HEALTH, STIGMA AND BARRIERS TO CARE

*Ronald C. Kessler, Ph.D.*

**DR. KESSLER:** There are a couple of reasons, at least, for studying stigma. One is, of course, that we are interested in discrimination, the behavioral implications of stigma, for example, discrimination in housing and jobs and in research. I do not know how many of you have seen Ben Druss' interesting paper in Health Affairs which had a rank ordering of the societal burdens of different classes of illness and a rank ordering of how much money is given to research on those illnesses. The biggest discrepancy is mental disorders.

Quite a bit of interesting work has been done in diverse ways concerning behavioral implications and discrimination. Rich Hogan, who is one of my former students, has done this fascinating work on the question of, "How do the community mental health centers decide where to put a group home?" Essentially, what happens is that it is done in the middle of the night by stealth. When they discover that a group home is going to be put at the end of the block, communities mobilize, go and get their local councilmen and lobby against it.

Over the years there have been a number of efforts by community mental health people to meet with the neighborhood and tell them how mental illness is not really an illness and not really dangerous. What researchers have discovered through considerable practical research on this topic is that when they provide education to the community in advance it only helps the neighborhood mobilize against them more quickly. They discovered the best thing to do is rent the place, get in before anybody knows, and then fight people off after it is too late. That is the practical implication of the perceptions of mental illness in the community.

The aspect that I have been most interested in has to do with the other side of it. That is, people who have mental illnesses know that other people feel this way about people living with mental illnesses. One of the implications is that people have a great deal of reluctance to go for treatment. This is nowhere more true than in the armed forces where the ethos is, "I don't need help. I can handle things myself." There is good reason to think that embarrassment is an important cause of failure to get treatment and an important cause of dropping out of treatment prematurely. Premature dropout is a massive problem and I will discuss some data on that in a



little while. This embarrassment is based, at least in part, on the perception of the stigma associated with emotional disorders, the idea that it is shameful to have a mental illness, and that it is a character flaw.

There is reason to think that some of these attitudes might be changing. For a number of years now the General Social Survey has been monitoring attitudes about mental illness and has documented an increase in the perception that mental illness is attributable to biological causes, rather than a character flaw. There has been an increase in the perception that biological treatment is likely to be the most effective kind of treatment. Part of the reason for this, presumably, is that there has been a massive increase in public information about mental illness since the early 1990s when Prozac became the first prescription drug to be advertised on TV.

I do not know how many of you are familiar with this but it is really not coincidence that in the last 15 or 20 years there has been this boom in understanding of mental illness. I was, as it so happens, working as a graduate student at the National Broadcasting Company in New York at the time that it became illegal to advertise cigarettes on television. The television networks in their eagerness to improve public health and also, as an aside, to get a little bit more money, decided that it was a terrible thing that prescription drugs could not be advertised on television and started something called the Prescription Drug Advertisement Coalition. They came together with a bunch of pharmaceutical companies to lobby to make it legal to advertise prescription drugs on television.

As it turns out there is some interesting economic evidence about this. Advertising on TV for eyeglasses, which also require a prescription, is illegal in some states. It turns out that when you look at the states where you can advertise prescription eyeglasses on TV, the cost of eyeglasses is only about 60% as high as in the states where you cannot advertise. The result is that all of these eyewear shops only go into the states where they can advertise because they make their money on volume. In fact, being able to get this information out has a positive impact on getting people access. That is not always the case, though. If you look at over-the-counter medications, like Bayer aspirin versus aspirin, the companies that spend most on advertisement raise the prices of their products more.

It is not always true that giving people more information is a good thing. For one reason or another, the networks and the pharmaceutical industry combined to convince the FDA that there should be direct-to-consumer advertisement for prescription medications. It just so happened that ruling occurred at exactly the time that Eli Lilly developed Prozac, the very first drug that was advertised direct-to-consumer. As you know, Prozac had this unbelievable uptake. The idea that depression is an illness and that treatment was available was compelling. We now know that the effectiveness of SSRIs and SNRIs is not that much greater than TCAs. There is a side effect profile advantage. But the dramatic change in the number of people who were getting treatment for depression was really unprecedented. It is hard to know which was the horse and which the cart. It is true that direct-to-consumer advertising of Prozac coincided with front page feature stories about Prozac on the covers of *Time* and *Newsweek*, and all of a sudden we became inundated with Prozac.

Subsequently, we have had many front covers of *Time* and *Newsweek* that have talked about PTSD, stress, trauma, and suicide in the Army. Various famous people have gone on the Tonight Show to talk about their depression and their drugs and how they overcame it. There are lots of tell-all books, etc. If you look at the mass media archives, the number of stories about mental illness in the past 15 years has

increased dramatically. Based on that dramatic increase it is probably no surprise that the treatment of mental illness has skyrocketed since the early 1990s.

I want to discuss aspects of the National Comorbidity Survey (NCS) and the National Comorbidity Survey Replication (NCS-R). In 1992 and 2002, we did national surveys and looked at rates of mental illness and treatment for mental illness. There was no increase at all in the prevalence of mental illness over the decade. When you see changes in treatment it is not because there are more people who need it. It is the same people who are changing their probability of getting help.

In 1992 we looked at specialty treatment, general medical treatment, and human services treatment for mental illnesses among people who have a severe mental illness and those who have a less severe mental illness. The treatment went from about 4% to 6% in a decade, up 50%. It is actually about a 60% increase overall in specialty treatment from a psychiatrist, psychologist, psychiatric social worker or psychiatric nurse. General medical treatment increased from 3% to 9%, about a three-fold increase in treatment in 10 years. The human services treatment, which is treatment by a minister, priest, rabbi, social worker, or counselor increased by about 50%.

What is striking about this is when you look at the people who have a serious mental illness such as schizophrenia, other nonaffective psychoses, bipolar disorder, atypical psychosis, severe depression, and severe OCD, the changes are quite different from people who have more garden variety disorders. Those who watch television a great deal are influenced by this advertising. If you look at specialty treatment, the percent of people with a severe mental illness who received treatment from a psychiatrist did not change much. However, treatment for the people with less severe illnesses doubled. What may be happening due to the advertising boom is that people who may not need treatment are going to see their psychiatrist. When you look at the general medical sector, people with a severe mental illness are twice as likely to get treatment with their family doctor. The percent of people with less severe disorders who sought treatment almost tripled.

One big difference is that in the early 1990s, of the people with severe illness, more were being treated by a mental health professional than by a general medical doctor. It flipped and it stayed flipped. If you look at more recent data, people who have a serious mental illness are much more likely to be treated in the general medical sector than in the specialty sector. As a result, the proportion of people in treatment has gone up over time. Conversely, the quality of treatment has gone down over time. There has been a decrease in the quality of care for mental disorders since the early 1990s.

As people with severe disorders have gone to see their family doctor there has been a dramatic increase in the proportion of those in treatment who are being treated with pills and not with talk. As we know, combined therapy works better than either alone but there has been a big shift toward treatment with psychopharmacology, particularly for men. It is clear that men do not want to talk about it: "Just give me the pill. Thank you." That is probably better than nothing, but it has implications. Now, we need to ask, "How much of this dramatic increase in treatment was due to a decrease in perceived stigma?" Were people less embarrassed about going to care? "Everybody has this illness. After all it is on the front page of Time magazine and I read this article that says that zillions of Americans have it. Treatment is available. Why am I letting myself suffer?"

We were also interested in the possibility that people recognized that they had an illness more so than in the past. In our early work with the NCS one of the most

*If you pull the NCS and NCS-R data and put in a variable for time you see an 80% increase in the odds of getting treatment in the decade, controlling for the disorder.*

striking things we found was that when we asked people with disorders, “How come you didn’t get treatment for this problem?” They said, “What problem?” This is more true for some illnesses than others, such as excretion disorders. The real poster child for this is social phobia. People who are painfully shy tend to say, “I’m shy. I’m not sick.” That is not coded as an illness. Many people who have depression before it gets severe feel that it is not an illness. Rather, it is simply, “I have an awful life.” People who have panic disorder, on the other hand, go for treatment. They might think they are having a heart attack so they get evaluated because it is clear that there is something wrong. For many mental disorders it is not so clear.

Now, we looked at three things in our data that might have influenced this change. First, to determine increases in recognition of a problem we asked people, “Was there ever a time in the last year when you thought that you might need treatment for some kind of emotional problem?” Second, to assess perception that effective treatment was available we asked people, “How much do you think these treatments for mental disorders help? Out of every hundred people who have an emotional problem and go for treatment, what number out of a hundred is helped?” Third, to assess perceptions about stigma we asked people, “How embarrassed would you be if your friends or neighbors knew you had a mental illness? How much do you worry that you would be discriminated against by your coworkers or you wouldn’t get a promotion?”

We found that after a massive amount of money was spent on direct-to-consumer advertising in the 1990s the perceived helpfulness of treatment had not changed much a decade later. Forty percent of people versus 38% said it was very effective. Thirty-five percent versus 37% said it was moderately effective. “It doesn’t really help many people at all” changed from 5% to 7%. The perception that you have a problem did go up even though the percent of people in the population who had a mental disorder did not change. What we are calling stigma, i.e., these perceptions of concerns about somebody knowing about you having a problem, showed only a modest reduction but it was not statistically significant.

If you pull the NCS and NCS-R data and put in a variable for time you see an 80% increase in the odds of getting treatment in the decade, controlling for the disorder. The more serious your disorder, the more likely you are to get treatment. Getting treatment from a psychiatrist, other mental health professionals, and general medical providers all moderately or robustly increased. Treatment from human services and self-help groups remained flat over the decade.

The question is, if we introduce measures of perceived need, stigma, and perceived effectiveness, does this change? The answer is no, which is not surprising given that these things have not changed much over time. To review, the more severe your disorder, the more likely you are to get treatment. If you are not worried about what people think, you are more likely to get treatment. Perceived need for treatment is an enormous factor. Perceived helpfulness of treatment is not very salient in getting people the treatment. It is noteworthy that whether you have a serious disorder or not the perception is obviously more important than the reality.

Turning to the second of our two surveys, we found that many people are in treatment. Among those with a disorder in the last year, 41% were in treatment. Of the people with a serious disorder, nearly two thirds were in treatment. Treatment rates were actually quite high.

We asked the people who did not get treatment, “How come you didn’t get treatment?” You see that a very high percent of them said, “I didn’t need it. It wasn’t

really bad enough. What problem are you talking about?” This is less likely to be a response among the people with a severe disorder than those with a mild disorder. To the people who say they have a snake phobia, we ask, “Why didn’t you get treatment for that?” They answer, “I live in an apartment in Manhattan. What do I need treatment for my snake phobia for?” People who had suicide plans, who were actively ruminating about killing themselves and were having a hard time functioning on a day-to-day basis, but who did not get treatment were asked, “So how come you didn’t get treatment for this problem?” They said, “What problem?” One out of every four of them responded this way.

Structural things such as not having insurance, not knowing where to go, long waiting lists and so forth were not really all that important. Structural barriers become more important for people who have severe disorders, because if it is severe enough your inclination is to go and get help. The only reason you are not going to get help is if there is something that really gets in the way. Thus, it turns out that attitudinal barriers are not as important among people who have severe disorders. “I want to handle it on my own,” is something that people frequently say. They do not say as much, “I’m embarrassed,” but they say, “I want to handle it on my own.” If we try this with a person with a broken arm it does not happen so much.

These comments do not really come up among people who say, “I don’t have a problem.” Really, what we should be doing is looking at the people who recognize that they have a problem. When you survey the people who do recognize they have a problem, structural barriers become a little more important and attitudinal issues are overwhelming. These people have all kinds of good reasons why they cannot go into treatment. If you figure out a way of refuting one, they have another one handy. Elderly people, men, and those with more education are less likely to say they have a problem. It is middle class people who say, “Oh, this is not a problem.”

Structural barriers are more prominent for young people who do not have insurance, do not know where to go, or are married with obligations, and for people who have more severe disorders. As I said, as the disorder gets more severe people do not say, “I don’t need it.” They recognize they need it and practical stuff gets in the way. These attitudinal barriers are there across the board.

Getting people to treatment is not the only place where stigma issues play a part. For the typical person who goes to a family doctor for treatment of a mental disorder, the average number of visits is 1.7. There are not many evidence-based therapies that work in 1.7 visits. We reviewed our data about whether respondents were getting medication alone, psychotherapy alone, or both in combination, as well as who provided the treatment. We then went to the literature to define appropriate treatment.

There are quite a few people who have a major depressive disorder who are getting benzodiazepines alone, or people who have a bipolar disorder who are getting Prozac without a mood stabilizer. That is not appropriate treatment. We discovered even in these newer data that the quality of care for mental disorders in America is absolutely abysmal. A big part of the problem is treatment dropout with people quitting treatment before they get an adequate course of care.

For example, the median number of visits to a general medical doctor among people who got treatment is one. They went once and they never went back. The inter-quartile range is one to two, so one standard deviation above the mean is two visits to the family doctor. We looked to say, “So where are you now? Are you still in treatment? Did you complete the treatment? You’re cured or did you drop out?”

*Structural things such as not having insurance, not knowing where to go, long waiting lists and so forth were not really all that important.*

We discovered that for most sectors the percent that dropped out is pretty close to the percent who completed treatment and said they were cured. We found a dropout-to-cure ratio of 15% to 23% for psychiatrists, and 19% to 27% for other mental health specialists. In the general medical category, 30% dropped out compared to 22% that continued what they thought was an effective course of treatment. Dropout is an enormous problem.

When we asked, “How come you quit?” sometimes people said it was not effective but very often they said, “It was not as painful anymore as it was before. I can function at least minimally. As soon as I can function at least minimally I can handle it myself.” There is this embarrassment about getting treatment and people get out very quickly. Dropout tends to occur early in the treatment course, particularly in general medical. The more providers you have the less likely you are to drop out. If you have a self-help group you are very unlikely to drop out. When you look at the average number of visits to a self-help group in America it approaches 17 times a year. Close to 50% of all visits for a mental health problem each year are visits to a self-help group. It is a small number of people going a large number of times.

We originally thought self-help groups were competing with professional treatment but that is not the case. It is worth noting that most people who are in a self-help group are in for reasons other than substance problems. The people who are in self-help groups for emotional problems are often also seeing a mental health professional of some sort. If you do both of those things your probability of dropping out of professional treatment is substantially lower than if all you are doing is seeing a professional.

It is interesting that in the mental health world we have not done much with self-help. There is not a great deal of coordination between self-help and professional treatment. That is quite different in other areas of medicine. If you go to Sloan Kettering in New York for example, people who are getting treatment for cancer are deeply invested in self-help groups. Nurses often run them for patients and their families.

People who fly in from California for treatment are in treatment eight hours a week. Five of those hours are with a facilitator in a self-help group, one hour is with social workers, a half hour is with a resident, and two and one half minutes are spent with a doctor. The idea is a pyramid of care where self-help is integrated into the system and people feel that they are connected. The dropout problem is considerably lower in some areas than it is in psychiatry. It could well be that we should focus our energy on some combination of these concepts.

What do we take away from this? The NCS-R and NCS comparisons demonstrate a dramatic increase in treatment with no real reduction in mental illness stigma. Why did that occur? We originally thought recognition that help was available caused it. Clearly that is not going on. Then we thought there was an increase in the recognition of a problem. That does not seem to be it either. At this point we honestly do not know the answer. Clearly some dramatic increase in treatment occurred without changes in stigma and perceptions of treatment effectiveness. One possibility is that there actually was a change in perception of stigma that we did not pick up.

Sociologists in the audience may remember the work of Richard LaPierre. In the 1950s, LaPierre studied discrimination by calling hotels and asking if they would be willing to have a black person stay at the hotel. The vast majority said no. Then he, a black person, showed up and registered. The vast majority of the hotels let him

in. What people tell you and what they actually do are not always the same thing, and the disparity is not always in a bad direction. It could be that our simpleminded questions just did not work very well.

You might be familiar with Charles Turner's work published in *Science* a number of years ago which used ACASI interviews to get information about stigmatizing behaviors. These interviews are administered with a laptop at a person's house. You plug in a little headset on it, turn around the computer and let people answer the questions privately. Essentially the computer will digitally ask a question such as, "How often do you have sex with small animals - often, sometimes, rarely, or never?" You just punch in the answer and then the computer will follow up with a series of questions.

Turner did a series of experiments in which a random half of the respondents were asked, "How often do you have sex with small animals?" Then the other random half of the people had the question asked privately on the computer. They found that when you ask the questions in a private, less embarrassing way, more people admit to stigmatizing behavior. They found that people were more willing to admit drug problems, sexual things, illegal things, but not mental illness. There was no change. Does that mean that mental illness was less stigmatizing, or does it mean that it was so much more stigmatizing than having sex with a small animal that people would not admit to it? There is good reason to believe that it was the former— that actually mental illness is becoming less stigmatizing than it was in the past.

These techniques represent an interesting paradigm that we have not tried in studies of stigma. To the best of our knowledge it looks like people are willing to tell you that they have these problems if they are asked in the appropriate way. We know from the work of Greg Simon and colleagues that when you pose mental health screening questions in a primary care waiting room, patients will check off the boxes in very high proportions, even though most of them are likely not there for treatment of the emotional problem.

We also know from those same studies that when you do thoughtful outreach with stages of change interviewing, you can get a substantial proportion of those people into treatment. If you use thoughtful case management, such as that being implemented in RESPECT-MIL, you can keep them in treatment. The problem we have is that case management does not often happen, and when they get typical treatment it is so lousy that it is not worth the effort to get them into treatment. What I conclude from this is that stigma is not that big of a deal, at least for the things I am interested in. Stigma, as a practical matter, is probably doing quite a bit to get people not to reach out for help.

I did not show you the data about reasons for dropping out of treatment but it is clear that we can implement structural processes to reach out to people, get them into treatment, and keep them in treatment. The question is, "Do we want to get a worldview change in the way the world sees mental illness, or do we want to make practical changes to get them to enter and stay in the treatment?" My guess is that the latter is going to be more effective in the short run. To the extent that we can work on the former, that is great—but I would not hold my breath. I think the action is in trying to do outreach, recognize that there are embarrassment issues and that they do not go away when the person gets into treatment. They are still there—sometimes bigger—so you have got to keep holding their hand. We could

do much better, at least on the treatment side, if we address those things in a more proactive way rather than a societal way. Thank you very much.

**DR. BELL:** Do you have any idea about how people are welcoming prevention?

**DR. KESSLER:** Yes, we have done rigorous research and discovered beyond a shadow of a doubt that people want to quit smoking after they have cancer. It is much more difficult before they have cancer. Prevention is a very tough sell. Further, early intervention is something that is in a woefully neglected state of affairs in the mental health arena. Hendricks Brown can tell you from his work at Hopkins with behavioral researchers that at the age of four, children already have mental illness. So we could try prevention and early intervention, but you have got to start at about six months of age if you want to do that.

What is more important is that the vast majority of people with a mental disorder do not get into treatment. In our data if you look at age of onset of your first mental illness and age of first contact with a treatment system, the difference is 12 years. Most people who have serious disorders in adulthood have onset in childhood and get treatment when they go to college, join the military, or get into a relationship that falls apart at the age of 22. I wish we could do a better job of early intervention with mild disorders when people are in pain and are interested in getting treatment. There are lots of kids out there, usually sitting in the back of the room, the quiet kids who are scared to death, who would love to have somebody reach out to them. They are not going to seek care of their own volition. That is the biggest bang for the buck. Early intervention, primary prevention of secondary disorders to try to influence the course of illness, is really where the action is. Of course, we know exactly where these kids are five days a week, nine months a year, from 9:00 to 3:00. It is a crime that we are not doing more in the schools.

**DR. HENDRICKS BROWN:** Ron, do you have any information on changes in stigma associated with mental disorders after September 11th?

**DR. KESSLER:** We do, however I have never looked at that. It turns out that we were in the field then and half of our survey was done. We could see a clear blip in 30-day prevalence of disorder. We did not see any blip at all in lifetime disorder which is comforting. It likely means that most of the people who had the extreme distress reactions were people who had a history of disorder in the past, but we never looked at the stigma issue.

## STIGMA AND BARRIERS TO CARE IN MILITARY & VETERAN POPULATIONS

*Charles W. Hoge, M.D.  
Paul S. Hammer, M.D.  
Matthew J. Friedman, M.D., Ph.D.*

**DR. URSANO:** I am pleased to introduce our first panel, Charles Hoge, Paul Hammer, and Matt Friedman. Charles Hoge has led much of the effort in military psychiatric epidemiology throughout this war. He is an epidemiologist and psychiatrist by training. Matt Friedman is the Director of the National Center for PTSD. Paul Hammer is the Director of the Naval Center for Combat and Operational Stress Control in San Diego.

**DR. HOGE:** In 2004 we put the stigma discussion on the map by observing that considerably more than half of the soldiers and marines who we surveyed, and who seemed to be in need of treatment, indicated that they had not received any treatment. Based on the responses to the survey, it appeared that stigma and barriers to care were important components to that. We did not have a causal relationship, but there has since been other work on that question.

I will present some of the data from the Land Combat Study. One of the earlier observations was that those soldiers who met screening criteria for PTSD, depression, or generalized anxiety had a much higher rate of endorsing stigma items than soldiers who did not have a mental health problem. We surveyed attitudes that might represent barriers to care using questions such as, “I’d be seen as weak by members of my unit.” Or, “leadership might treat me differently.” “Members of my unit might have less confidence in me.” We also explored barriers of an organizational sort, such as can you get an appointment, can you get to the appointment, and so forth. Tom Britt did factor analysis and confirmed that those two categories of questions related to stigma and barriers differentiated into two nice groups.

Some of the work conducted since then indicates that there is actually a third component, and Ron Kessler alluded to this in his work. It begs the question, “What is stigma?” What is it that prevents people from coming in to get help when they need it? What are the predictors of not coming in to get help? Is it because I would feel embarrassed? Is it because I don’t have adequate transportation? Or that I can’t get an appointment? Other factors may also play a role, such as I don’t trust mental

*In 2004 we put the stigma discussion on the map by observing that considerably more than half of the soldiers and marines who we surveyed, and who seemed to be in need of treatment, indicated that they had not received any treatment.*



*“Has stigma changed since the start of the war?”— the answer appears to be “no,” at least based on in-theater Mental Health Advisory Team (MHAT) data collected since the start of the war.*

health professionals or I don’t think it’s going to work. Or, I think I can handle it on my own, which is the construct that Ron was talking about.

We have looked at several questions. One is whether stigma has decreased since the start of the war. We have had massive education campaigns. We have a post deployment health assessment process and post deployment health reassessment which came into effect a couple of years after the start of the war. Has it made a dent in stigma? Are there differences between the Reserve and Guard with respect to stigma and changes in stigma since the start of the war? Finally, what other constructs should be considered?

So in the first question — “Has stigma changed since the start of the war?”— the answer appears to be “no,” at least based on in-theater Mental Health Advisory Team (MHAT) data collected since the start of the war. I think this is very consistent with what Ron showed in the civilian population between 1992 and 2002. We have done three samplings in Afghanistan and every year since the start of the war in Iraq.

There are some Reserve and National Guard differences. We are finding that the active component seems to have higher rates of stigma than in the National Guard. I think that may have to do with organizational differences in terms of the higher OPTEMPO deployment cycle, short dwell time, and the fact that there probably are some cultural differences to seeking care in the active component compared to the National Guard. Once the National Guard members come back and demobilize, they are particularly interested in getting care after they have been home for several months.

There are other relevant constructs around receiving help that are in need of investigation. Mark Brown and Alisha Creel have done analyses of these constructs in their work recently, as has Tom Britt. There are some other interesting things including perception of how I would be viewed versus how I would view others who seek help from a mental health provider. This is work that Sebastian Schnellbacher did during his residency at Tripler Army Medical Center. It is very interesting that the perception that I would be seen as weak does not correlate with the perception that I would see another soldier as weak if they sought mental health care. Again, the perceptions of stigma are very individual and personal.

There are three factors to consider when we talk about the concept of stigma: stigma, barriers, and then attitudinal perceptions. Then there is the difference between perceptions of how I would be treated versus how I would treat others if they seek treatment. We have not seen much of a dent in stigma over time. How is stigma going to change, in society at large or in the military culture, if we have not made much progress since 1992, despite a large change in the way in which we perceive mental illness?

One of the questions I am grappling with now in my clinical practice is, “Just what is mental illness, exactly?” For instance, if you believe Ron Kessler’s data from the National Comorbidity Study, half of everyone in this room will in their lifetime have a mental illness.

How many people in this room have a close relative who has a mental health problem?

This means that mental illness is part of the fabric of what it means to be human. Then the question arises: Is there anything that we can do as mental health professionals to change the way in which society views mental illness, and in what way are we as mental health professionals contributing to the problem?

It is possible that we are contributing to stigma at times in subtle ways which

we do not even realize. For instance, consider the soldier in Iraq who experiences a devastating loss of his buddy from an IED explosion. When he cannot get out of bed the next day, his commander thinks he should be able to get out of bed and his unit peers think he should be able to get out of bed.

Eventually, he gets air evacuated back to Walter Reed for “PTSD” and is put in the WTU where there is some sergeant whose job is to make this guy get out of bed and come in and get care.

Then he meets the mental health professional who says, “You’ve got 17 out of 17 PTSD symptoms and you need treatment. There are two treatments of choice that are approved and certified in our treatment facility. These are prolonged exposure therapy where you can talk about your worst traumatic event in present tense repeatedly until you feel better. Or you can reframe your thinking, your ‘distorted’ way of viewing the world that has resulted from this experience.”

The soldier is incredulous. He does not want to get out of bed because of the devastating impact the loss and grief has had on him and the awareness of the pointlessness and senselessness of the situation he has been through. He does not want to get out of bed to come see a mental health professional who says he is “crazy.” Who is “crazy” here? Is he the one who is “crazy” or are we “crazy?” I submit that he is actually the one who has the more accurate perception of reality. Every message, implicit and explicit, that he receives from the medical professionals who treat him reinforces societal perceptions. That is not necessarily going to lead him or encourage him to continue with treatment, and this may be contributing to our high dropout rates from therapy.

The overall effectiveness of most of the treatment that we have for PTSD is relatively poor. The recovery rate is around 40%, maybe 50%. You may get some symptom resolution in a higher percent of people, but not full recovery.

The data show that one principle reason we do not see higher recovery rates is because people drop out of treatment. Then I think the question for our patients is, “Who is crazy?” Is it them or is it the folks who are around them? Until we start to look at mental illness as part of what it means to be human, there is not going to be any change in stigma.

If you want further information on any of my comments, please see my new book, *“Once a Warrior, Always a Warrior.”* Thank you very much.

**DR. HAMMER:** The title of this particular segment is, *Stigma in Military and Veteran Populations*. I would like to propose that we change the word “populations” to “culture.” I think the context of culture is critical when we start talking about stigma and barriers to care.

I think about stigma in three ways. First we have the institutional factors that we talk about with stigma, such as policies, rules and regulations. Rules tend to promote things that may not make sense from a scientific or rational point of view but we follow them because they are rules.

For example, you cannot take an SSRI and be on a submarine. Why does that rule exist? Or you cannot carry a weapon if you are on an SSRI. There is actually no rational basis for that other than we do not want “crazy people” carrying weapons. Those institutional things are relatively easy to fix. You simply change the rules.

The other two parts to consider are the external and the internal factors impacting on military context and culture. An example of an external influence is seen in the misperceptions of people, the images in the media, and the terms that are in common use. Last night, while watching *Law and Order SVU*, I was amazed to hear

*The problem comes when we have to deal with the invisible wounds of war, the wounds from psychological trauma, from fatigue, from loss and grief, and even from moral injury of having to deal with the ambiguous, difficult, and untenable situations into which we place our young men and women when we send them to war. The treatment of these unseen, invisible wounds is difficult.*

the portrayal of a serial killer described as having schizophrenia brought on by his PTSD. Who wrote that! In this day and age, when we understand so much more about mental disorders, a writer carries on this wild old Vietnam veteran stigma of the crazy Rambo who is going to go out and kill everybody.

I think that what happens internally is most important. Charles Hoge and others have alluded to the relationship of the individual and how she perceives herself within the culture. What is her identity as a member of a larger group and does her perception of having something that we define as mental illness make her separate from her larger perceived group? As a former Marine, I like to use the example of Marines because they are so clear and distinct in many ways. What makes a Marine a Marine? If you take a kid who is 18 years old, shave his head and put him in the right uniform is he a Marine? No. It is not until he has gone through boot camp and had that collection of shared experiences, taken on values, taken on particular attitudes, and taken on a certain level of training that he becomes a Marine. It is not just Marines. It is the same with soldiers, sailors, airmen, Coast Guardsmen, police officers, fire fighters and disaster workers. You become that person. You incorporate that training as part of your identity. You take on the warrior code and you incorporate that external set of cultural norms and external experiences into your identity.

When a warrior is wounded, we have warrior transition units, wounded warrior barracks, wounded warrior regiments in the Marine Corps, and Safe Harbor in the Navy. These are places where wounded warriors go to recover and they wear their stigma of physical injury with pride. Their amputated limbs or the scars that they have from the numerous surgeries are worn proudly as badges of honor.

The problem comes when we have to deal with the invisible wounds of war, the wounds from psychological trauma, from fatigue, from loss and grief, and even from moral injury of having to deal with the ambiguous, difficult, and untenable situations into which we place our young men and women when we send them to war. The treatment of these unseen, invisible wounds is difficult. While it may not require great physical pain, numerous surgeries, or refitting prostheses on amputated limbs, it demands dealing with the questions, “Who am I now? Where do I belong? What have I become? Has this turned me into somebody who is no longer a warrior? Am I now a member of some other group?” In the mind of the warrior, that other group may include that guy who is living in the park homeless. “Am I going to become that burned out guy who is hopelessly cynical and going to numerous self-help groups? Am I no longer a warrior? Am I no longer a proud, fit, active, engaged, fired up, strong young man or woman? Am I now a wounded, damaged person? What have I become?”

Regarding PTSD, there are many tasks in treatment and most require integrating the experience of what happened to the Marine in war into her current identity. The treatment often requires a certain level of “mature intimacy,” a term I have borrowed from Bessel van der Kolk’s book about traumatic stress. Successful treatment requires the capacity to bear pain in the presence of another human being. Together, patients and therapists must confront the conflicts, ambiguities, inconsistencies, and difficult issues, and tolerate them while going through this process of recovery—to look at them openly, honestly, and drop that “image armor” of a warrior long enough to address those deeper issues requires that you become vulnerable.

As I have implied, vulnerability is the antithesis of the warrior ethos. As a warrior you rarely want to talk about vulnerability. You only talk about that in terms of infantry tactics and addressing vulnerabilities to the security and protection of

the unit. As a warrior you never want to be vulnerable because we have asked our people to do incredibly difficult, insane things in the name of serving their country. Nobody enlists saying, “I think I’m going to get a job requiring that I go out and get killed.” They say, “I’m going to serve my country, and I’m going to be proud.” They are going to do this wonderful thing and we collude in disguising the true nature of their job with its inherent risks.

The question is, “Can we make this process of dropping the image armor and allowing for vulnerability part of what happens within the culture?” My vision is that two Marines are walking along on base and one says to the other, “I’m going over to the hospital for my therapy.” His battle buddy asks, “Is it physical therapy for your knee?” He replies, “No, no. My psychotherapy.” His buddy replies, “Okay. See you at 1500 when you get back.”

That is the conversation I want to hear, but I do not think it is going to happen anytime soon. When we reach that point, we will have incorporated psychotherapy into the larger culture. We need to discover how we can make vulnerability and care-seeking an acceptable part of the culture, part of their identity, in a way that does not make people feel weak, excluded or part of the “other” group. The individual Marine, soldier, sailor, airman, and veteran will not be reassured that his status within the group is secure until we really make it part of the culture.

**DR. FRIEDMAN:** My job is to talk about VA (Veterans Affairs) work on stigma. I have identified two good studies that I think will expand the context of the discussion that we have started.

First is a study by Tom Britt which raises the issue of social support and social context. This was done in the setting of a post-deployment screening for mental and physical problems. One finding was that people expressed more discomfort disclosing mental problems than physical problems. In this survey sample, some of the people were there with their units and others were by themselves. Those that were by themselves felt more comfortable disclosing psychiatric or psychological problems. I think that social context, as others have begun to suggest, is very important.

Tom Britt’s work shows some of the predictors of people not coming in for treatment: younger age, being male, nonwhite, active duty, with no social support, and a strong need for personal control, “I can do it myself. I don’t need help from anybody else.”

The second study I want to talk about was done by Nina Sayer and her colleagues at the Minneapolis VA. This was a structured interview given to 44 veterans, some from Vietnam, some more recent, some male, some female. All of them had filed a disability claim for PTSD. They all had recognized that they were somehow disabled and wanted to be compensated, yet only about half of them were actually in treatment. The other half were not in treatment but their opinions were fairly comparable.

There are several barriers to care that were identified from these structured interviews. The first one has not been mentioned yet, but is important to note, although perhaps limited to PTSD. Part of the PTSD construct is the avoidance symptoms, which extends to treatment-seeking. People do not want to talk about what happened to them. They do not want to have to relive it. That is why rape victims do not press charges. Well, the same thing is true for servicemen and service-women regarding their military experiences. This tendency has been addressed by some of the previous speakers. That is, the individual’s values and priorities stand in

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opposition to treatment-seeking. A pride in self reliance exists, and the mental health problems are much less important than maintaining a job or a family.

Treatment-discouraging beliefs get into the perception that those who have not shared in the combat experience simply cannot understand it. “If they haven’t been there, they just aren’t going to be able to understand and help me.” Some other beliefs include, “Treatment doesn’t work,” “I’m relinquishing control,” and “They could lock me up if they knew how crazy I feel sometimes.” This view was prominent among the older veterans, the Vietnam vets that need treatment.

Some of the other stigma issues you have heard about include, “Treatment is for those who are weak, incompetent,” or “It’s only for the really disturbed and I certainly don’t fit in that category.”

There are system concerns, including limited resources. However, perhaps for the first and only time in history, the different veterans groups have agreed that they do not want their mental health treatment outsourced. They do not think that a community-based civilian provider could possibly provide the kind of treatment that a VA practitioner could provide.

Knowledge barriers also pose a significant problem. Veterans do not understand what treatments and resources are actually available. Many OIF and OEF vets do not know that they have five years of eligibility at the VA, no questions asked. The area of military sexual trauma is an important issue that has not been mentioned yet, and it is very stigmatized. Access barriers have also been highlighted. The onerous paperwork one must complete, taking time off from a job, and, particularly for women, childcare issues are all cited as access barriers.

Finally, the authors described the “invalidating post-trauma social environment” affecting people who have had bad experiences becoming unwilling to take another chance that they may not receive support. Vietnam vets in particular who had a very negative homecoming are not going to risk outing themselves and going for treatment. This may represent PTSD withdrawal, but it is partly related to suffering with a stigmatized health condition.

The third study I am going to talk about was done at the National Center for PTSD by Rob Pietrzak and Steve Southwick. This study involved a questionnaire that was mailed to a thousand military returnees in Connecticut. They had a 27% response rate to questions on a wide variety of issues including barriers to care and beliefs in mental health treatments. The majority of the population were aged 20 to 30, white, with some college, married, serving in the Army, mostly Guard and Reserves, and in theater during 2004 and 2006, having completed one or two deployments. Most of them were working, so it was a fairly functional group of people.

The findings showed that on both the perceived stigma scale and the perceived barrier scale, the people with PTSD were much more likely to endorse these items. Interestingly, those people who were positive for depression or substance misuse were not more likely to endorse items on these scales. At least in this cohort, PTSD seemed to be uniquely predictive of endorsement of stigma and barriers to care.

Another element that was done very nicely by these investigators was asking specific questions about psychotherapy and psychotropic medications. Again, the people with PTSD, in contrast to people with the other mental health problems, were much more likely to express negative beliefs about psychotherapy and psychotropic medications.

Despite these stigma issues, people are coming in for treatment. The VA’s market penetration has traditionally been about 20% of veterans. It is now over 40% and

heading toward 50% among the OIF and OEF cohort. Whatever their belief system is about stigma, mental health, or psychotherapy, people are coming in for treatment. That may have some very interesting effects in terms of how they feel about themselves for doing this.

I found it interesting that if you thought that medication did not help, you were more likely to seek counseling. If you thought that therapy did not work, you were more likely to go for medication. Again, beliefs are clearly affecting behavior. It is also interesting that the beliefs about medication and psychotherapy, and beliefs about treatment were completely independent of perceptions of stigma or barriers to care.

When they did a multivariate analysis, they found that the people who had reported greater unit support in theater and good unit cohesion were less likely to endorse those barriers to care or stigma items. People who had negative beliefs about mental health care were more likely to endorse them. This group is now looking at some data about social support among families, and it seems important in treatment-seeking, so this social support factor is something we ought to talk about as well.

To summarize, we need to understand the unique contribution of PTSD to suppressing treatment-seeking in terms of the avoidance, the alienation, and the lack of social support. Erroneous beliefs about treatment further exacerbate this.

I am going to finish with results from Nina Sayer's structured-interview study of 44 veterans. In addition to asking why they did not seek treatment, researchers also asked, "What would make things better? What would make it easier for you to come in for treatment?" Remember not everyone in this group was treatment-seeking even though they all perceived themselves as having a PTSD related disability. One of the key items was a recognition and acceptance that PTSD is a treatable problem and that help is available. Secondly, recognition that getting help is socially acceptable, and that the system of care is trustworthy, delivering confidential care, would encourage help seeking. Finally, social networking with other vets, peer-to-peer programs, as well as incorporating family and employers, are very important areas of emphasis.

Hopefully I have added a few things on the table for our discussion. Thank you very much.

**DR. ESTROFF:** Part of what I have been thinking about for the first two sessions is this emphasis on getting people into care, that this is what we need to do. We have already agreed that the system needs to be improved, the care is not optimal, and we do not have capacity. Despite this, we have emphasized, "This is what they need to do. They need to come to us." If we want to do something concrete, I would argue that we need to improve the quality of care and have greater capacity. To me there is an obvious disconnect. If they come to a place that is not so good they are not going to come back. It is a question of what you are foregrounding and what you are backgrounding. Coming to care in a system that you perceive as toxic or ineffective is sometimes worse than not coming. At least in our research, people talk more about symptoms of treatment rather than symptoms of illness.

**DR. BELL:** One other serious problem I have seen is this notion of media epidemiology. I think the public gets its ideas about prevalence not from science, but from distorted media reports. This drives people in the wrong direction which is a serious problem in terms of help seeking behavior. My sense is that we scientists do not market our knowledge well, so people are walking around with the wrong ideas about what is going on.

**DR. HOBFOLL:** I want to follow up on Dr. Estroff's comment. At an important

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level it is as simple as this: if people who walk into a room get poked in the eye with a sharp stick, they do not walk into the room anymore and they tell their friends, “Don’t go to that room.” That is especially true in military or other predominantly male and performance-directed contexts.

To expand it a step further, psychology and psychiatry are both professions based on what is comfortable for the provider, which is to be in a room and to write scripts. That is really easy to do compared to say, going into a coal mine. Or, even worse, you conduct psychotherapy on a comfortable couch because you get to sit with coffee and talk to people as opposed to working with the media on the consultant level. We need to consider being much more multi-faceted in the kinds of things we train mental health professionals to do. If we moved more toward education and skill-building in our continuum of care we could become de-stigmatized as a profession. As we help people become more resilient, then everyone goes for that at some level, and we are easily moved to the next step.

I would also say that we have known all this throughout my whole career. I was trained as a community psychologist so it was pushed on me a little more. The question is, “Why don’t we do those things?” Why are we stuck doing the same things wrong and looking at societal stigma and other things that we already know from the past how to change?

**DR. HAMMER:** Part of the problem is that there is a perception that we should just give a pill and it will be alright. Treating PTSD is hard work both for the patient and for the therapist. If you are going to do it you had better get down in the mud with the patient and be willing to get dirty. It is not going to be comfortable. It is not going to be easy. Our responsibility is to acknowledge that and to dig in and get better at it.

**DR. FRIEDMAN:** I do not agree with some of the comments that have been made. I think that many people in this room do know about getting down in the mud and going where the patient is. I do not think we need to be preached to about some of that. I also do not agree that we have nothing to offer. If we get people to come in, I think we have a great deal to offer. However, there are two different levels on which we have to have this discussion. One is on the traditional patient/doctor clinical discussion.

However, the other discussion that is in some ways more important is at the public health level, where the mental health team is not a psychologist, a psychiatrist, a social worker or nurse.

It is someone who understands how to use the media, someone who is a sociologist or an anthropologist. We are starting to learn that. It is not what we were trained to do but many of us realize that it is what we have to do.

I do think there have been efforts to increase capacity. The treatment that is available is better, so I cannot agree with some of these negative characterizations of what we have to offer and what we are trying to do.

**DR. ESTROFF:** I do not want to be misunderstood. Most of us who work, and have done research in the public mental health system in the US know that the quality of care is not great. I have to say in the several weeks that I have been trying to learn about what goes on in the armed services, I am pretty impressed. I have been to all the websites including Wounded Warriors and Battlemind. These are amazing so I am not saying that the armed services do not have things to offer people. It is part of the general situation when you are out of theater and back home. Sure, there are people who can do it but it is not widespread. We know the quality varies

tremendously so it is about making sure that when we are working so hard to bring them in they are going to have a good experience.

**DR. HOGE:** I think it is both. The reality is that there is a huge benefit in seeking treatment. What we do in mental health and the incredible programs that have been stood up in DoD and VA in particular, is extraordinary. The reality, though, for many individuals who seek treatment within our system is that they have negative experiences. There are some fundamental assumptions we make about the nature of treatment, treatment effectiveness, and the application of evidence-based practices. For many individuals evidence-based treatments are inflexible and end up being detrimental because every individual has an extremely personal experience requiring a tailored approach. There is no way we can tell that individual what they need in order to get over that experience, to integrate it into who they are now, to once again have meaning, joy, and purpose in their life. I sometimes try to get my residents and cofacilitators in PTSD groups to do a moratorium on the terms, “You need to. It’s important to consider. You need to consider.” They almost become completely incapable of speaking when you do that.

**DR. RUZEK:** I work in the VA system at the National Center for PTSD. There are people who actually do engage in treatment. In many different treatment programs within the VA the normative experience is an attitudinal change. It would be very interesting to see studies of people moving through the treatment process and how that affects their views of mental health participation. In fact, what we usually find in VA PTSD treatments are a range of experiences, including negative ones. People who pass the threshold of five or six visits end treatment with tremendously positive views of the treatment experience, the treatment providers, the caring of the providers, their views about the importance of disclosure, and their willingness to disclose.

One of the untapped tools for us to change attitudes towards treatment is to better capture those success experiences, to magnify the perceptions of benefit, and change the perceptions of what happens in treatment. We ought to be videotaping testimonials about treatment. It is possible that the stigma of treatment inhibits those successfully treated individuals from having conversations with the body of veterans who are not seeking treatment. We want to get veterans and active duty treatment participants talking about their treatment experiences.

**DR. LINK:** I am speaking as a stigma researcher and coming back to the exchange that Sue Estroff and Matthew Friedman had. Perhaps the facts about treatment capacity are disputed, but the extent to which capacity has not developed through history could be due to stigma. Also, regarding the concern that if everybody came to treatment we would not be able to take care of everyone, we might consider a shift in our frame of reference. I was interested in thoughts about the culture and whether you can imagine helpful interventions that have to do with the culture of the soldiers and how they deal with each other. We could explore not just what clinicians can do, but what the context can do to help with these kinds of problems.

**DR. RADKE:** I am the State Medical Director for the Minnesota Department of Human Services and Chief Medical Officer for State Operated Services. We run all the disability programs in the state. My perspective is from the public mental health sector. Obviously, we know we are running a fragmented, discontinuous, gap-filled system, or lack of a system. In spite of that people come to treatment or they are brought to treatment. The point I want to make is that a person with schizophrenia does not come to treatment or get brought to treatment because of their psychosis.



*We have a threshold, a barrier, stigma, a fear of the system that has to be overcome by tremendously difficult and painful behaviors.*

They never end up in the hospital because they are psychotic. They end up at the hospital because of their behaviors. Those behaviors have either become overwhelming for the individual or overwhelming for the society. Those behaviors have gotten so painful and have produced so much suffering for the family or the individual that stigma is overcome by the fear of loss of control.

That is a powerful point because it is not what we should be doing in our society, but that is what we do. We have a threshold, a barrier, stigma, a fear of the system that has to be overcome by tremendously difficult and painful behaviors. You would not say that about somebody who needs surgery or an internal medicine clinic, but you can say that about somebody coming to the mental health system. That worries me a great deal because no matter what we do—fill all the gaps, become continuous, comprehensive, resolve the fragmentation—if we do not resolve the barrier of stigma and the fear of the system, we will only bring people in when their pain and suffering is such that they cannot resist coming.

**DR. URSANO:** Alan Radke's comments also touch on the differences between internalizing and externalizing disorders, and how they may be affected. I know Ron Kessler has data on some of those issues.

## STIGMA AND BARRIERS TO CARE IN DISASTER

*Dean G. Kilpatrick, Ph.D.*  
*Sandro Galea, M.D.*  
*Stevan E. Hobfoll, Ph.D.*

**DR. URSANO:** I am pleased to introduce our next panel. We are shifting from military to disaster with the leading epidemiologists and social scientists in the world on this topic. Dean Kilpatrick and Sandro Galea have led the way on the issue of psychological first aid (PFA) and understanding resource loss and its contribution to recovery, illness, and disease.

**DR. KILPATRICK:** As we have heard this morning, the notion that there is stigma and that many people who could benefit from treatment do not seek treatment, is not limited to disaster victims. I am going to address several questions about disaster victims per se. One of them is, “What do we know about help seeking for mental health problems among disaster victims who have PTSD?” What special characteristics of disasters create unique barriers to care that are not present in some of these other situations? What do disaster victims tell us about stigma and other barriers to care? Why do disaster victims have concerns about getting mental health treatment and whether it works? Most importantly, what are some of the new ways to address stigma and overcome barriers?

Sandro Galea and I have conducted several studies with support from NIMH about various types of disasters. All the studies got information about PTSD and several of them also gathered information about help seeking from mental health professionals after disasters. I want to briefly run through some of the disasters and present some of the data about help seeking among PTSD sufferers after these events. First, I am going to talk about some relevant older studies including Hurricane Hugo, which first peaked my interest in disasters and mental health. Later, I will touch on the Oakland Hills fire, the Sierra Madre earthquake, and the Los Angeles civil disturbances, so an array of different types of disasters will be discussed.

Hurricane Hugo was a category 4 storm with very strong winds which produced a fair amount of physical damage over a very broad area, including where I live. The Oakland Hills fire storm happened in 1991 and destroyed a great deal of acreage and many homes. Again, this was an expensive storm in terms of the amount of

*“What do we know about help seeking for mental health problems among disaster victims who have PTSD?” What special characteristics of disasters create unique barriers to care that are not present in some of these other situations?*

*The leading response was they do not think mental health counseling would help.*

damage. Many people narrowly escaped with their lives and little else. There were some people who were killed. We located people who had been affected by the fire storm and interviewed them three to eight months after the fire.

An earthquake occurred in 1991 in the San Gabriel Valley of California. Even though it was a moderate earthquake in terms of deaths, injuries, and economic damage, it was particularly difficult psychologically because there had been four earthquakes in that same general area within a short period of time. We were interested in the cumulative trauma that might magnify the effect of a moderate earthquake. Again, involved adults were screened and interviews were conducted between four and seven months after the earthquake.

The final disaster I will discuss is the L.A. Riots project. It was the largest civil disturbance in quite some time in the United States. There were a number of people killed, many injuries, and much damage. Due to widespread media coverage, the effects were not limited to South Central L.A. but incorporated the whole of L.A. County. We over-sampled from South Central L.A., the main area of civil disturbance. Then we conducted these interviews in both English and Spanish. There were 1,200 people interviewed overall, with a high participation rate in this study. What I want to illustrate here is that among these people with PTSD across a range of different disasters, fewer than 50% in each of those four studies sought mental health care.

I am poaching on terrorism territory here, but we were involved in a study of the Pan Am 103 bombing and it was a disaster initiated by terrorists. I want to spend a little time going over the predicate for this. Before 9/11 there were more deaths associated with this act than any terrorist attack in U.S. history. The Office for Victims of Crime, which is part of the Justice Department, developed some special services for family members in this case. They approached us at the National Crime Victims Research and Treatment Center to do an assessment study of the service utilization and how satisfied people were with services to make recommendations for changes in policy. The salient point is that to get into this study, every single one of these people had had at least one relative killed in that plane crash. For me, this is as bad as it gets in terms of suffering a loss, because there is no way anybody can ever bring that person back. Secondly, if you are looking for a blameless victim situation, this would probably be it. Nobody is going to blame a parent for their child's death in this context. Further, the circumstances are so tragic that you could argue that maybe mental health stigma would not be such an issue. Who is going to blame somebody for coming forward to get treatment under these conditions?

Notwithstanding, only 6% of these family members said they had utilized unlimited, conveniently located, free counseling, covered by the Office for Victims of Crime, despite 48% of the sample reporting emotional or behavioral problems severe enough that they considered mental health counseling. Most people who got unspecified treatment thought it was helpful.

We asked, "People don't always seek mental health counseling even after losing a family member in this type of terrorist crime. What do you think are the most important reasons family members do not seek mental health counseling in a case like this one?" The leading response was they do not think mental health counseling would help. They have negative attitudes about mental health counseling. Secondly, they have good support from family, friends, religion, etc. Thirdly, denial, inability to admit they need help. Stigma is not far from the top, followed by, "they don't want

help,” and “prefer to handle it on their own.” “Insurance or cost concerns” was an issue for some. I think these are instructive and they fit in nicely with some of the other data that have been presented earlier about other contexts.

It seems that stigma is less of an important issue than just having negative expectations about counseling. Why might that be? Why would it be that some people feel negatively about counseling? Sam Goldwyn, the film producer, said, “Anyone who would go to a psychiatrist ought to have his head examined.” That is an old quote but I suspect that many people would extend that to psychologists and other mental health professionals, too. It is probably still operative.

Then there are some highly marketed treatments that make fairly radical claims. This is the kind of material that might help us understand why people have some misgivings about treatment.

Many of you may have seen a recent *Newsweek* front cover reporting the depressing news about antidepressant studies suggesting that the popular drugs are no more effective than placebo. In fact, they may be worse. I am not getting into debating whether antidepressants work or not. I am presenting this because many people probably read this and when their doctor says, “You should undergo a course of antidepressants,” they might have some questions about it. The way these things are presented in the media does have an effect.

There are some things about disasters that may be different in terms of barriers to care. One is the disruption in services. Secondly, basic needs are probably more important than mental health needs and so if you are attending to those you cannot attend to the other. Then, as I have said before, there may be less blaming of disaster victims.

I would like to leave you with some ideas about ways that we might address this. Stigma issues associated with web-based things might be less prominent. Web-based interventions may provide a way of tapping into some of our self-help oriented, rugged individualist tendencies, such as, “I can do it on my own. I don’t have to go forward. I don’t have to label myself as being a psychiatric or psychological patient.” Long story short, these things represent self-help opportunities and mechanisms. They have videos with them, and good information about utilization suggests that people seem to like these things. Some preliminary data suggest that people who go through this compared to controls actually get better on some measures.

In conclusion, ways of addressing stigma and barriers include crafting a way to spread the word about effective treatments in ways that people can understand them. We also need to be more careful in how we discuss resilience. Without question, most people after disasters are resilient. However, when we stress that, which may be a good thing to do, suppose I am not resilient? What does that say about me? Is that stigmatizing me? Is that going to make it more likely for me to come in and get treatment? I think we need to figure out a way to hit the sweet spot as opposed to the way we do it now. I do think that the web-based psychosocial self-help interventions may have a great deal to offer because they get around some of the barriers.

**DR. GALEA:** Good morning. It is an honor to be here. As Dean said, we have done a great deal of work together and we agreed that I would present some new data from one of our recent studies. Before I do that I want to talk a little bit about disasters because there are some of us who have done a fair amount of work on disasters and some of you who understandably do not think as much about disasters. I want to make a point as to why we should think about disasters.

This is the bad news from the best database that exists about disasters worldwide

*In conclusion, ways of addressing stigma and barriers include crafting a way to spread the word about effective treatments in ways that people can understand them.*

*In the context of stigma, there are things we can learn from disasters that can assist us in thinking about the military context and culture.*

in the past 100 years: the frequency of disasters is increasing. Everybody asks, “Why is the frequency of disasters increasing?” Meteorological and hydrological disasters are probably linked to changing global and environmental conditions. Another reason is probably due to urbanization, concentrating more people in smaller areas. The same natural events that were happening 200 years ago perhaps resulted in trees falling into forests with no human injury toll. Now, when trees fall in the forest there are a thousand people underneath it so disasters are increasing. We are packing more people into areas where these large scale traumatic events are happening. The good news is that more people are surviving disasters. One more piece of bad news is that many more people are being affected.

An interesting phenomenon from an epidemiologic point of view is that every time a disaster passes we have an unerring ability to forget all about the disaster and think another one will not happen. We see this time and time again including recently with Haiti. Of course, these events attract a great deal of attention and breathless reporting in the news like, “Wow, this is shocking and surprising and we don’t know anything about it.” Then two months later you forget all about it. In fact, Haiti was not predictable but it is entirely predictable that some other big event was going to happen and something else will happen again.

Having said that, it is well worth the effort to make epidemiologic inquiry into disasters. In the context of stigma, there are things we can learn from disasters that can assist us in thinking about the military context and culture. When thinking about barriers and stigma to mental health care after disaster, three central domains are pertinent: predisposing characteristics, enabling factors, and need. I am going to focus my comments around the health behavior model. I am going to show you some data related to predisposing characteristics, enabling factors, and need as associated with barriers to care and stigma after one particular event.

I want to talk about Hurricane Ike in the Galveston Bay recovery study. Hurricane Ike is one of those neglected events. On September 13, 2008, it essentially wiped out Galveston on the Texas gulf coast. The interesting thing about Hurricane Ike is that much of the impact on the population was a combination of the winds as well as the flood. This was an event that we studied as part of a consortium. It is a National Center grant funded by NIMH that is co-directed by Dean Kilpatrick, myself, and Fran Norris at Dartmouth who works as part of the National Center for PTSD. We were able to launch a study soon after Hurricane Ike to look at the consequences. The study is called the Galveston Bay Recovery Study.

It was a fairly large event with substantial impact. Then it faded from public awareness soon afterwards because it occurred just before the national election and our attention span is short.

We made a big effort to recruit a population representative sample of people who were living in the area before the disaster. This is no easy task when you think about the population displacement. We reconstructed sampling frames and found people all over the country. We ended up talking to 658 people, 80% by phone, 20% in person. Of particular interest is that we asked about mental health service need, utilization, and reasons for not using services. We used a fairly structured instrument, the primary care needs questionnaire, which allowed us to study some of the barriers that were discussed in the previous discussions. We looked at concerns around stigma, preferences for care, expectations, and resource barriers. About 40% reported mental health service need, which is fairly consistent with the previous presentations. It is astonishingly consistent in these samples that we have a little

more than a third of the people reporting need yet only about a third of those who report need actually obtain service.

Let me start with predisposing factors including gender, race, ethnicity, social support, stigma concerns and preference for mental health services. The only thing associated with perceived need was social support, with a very dramatic increase in reporting need among people with low social support. Looking at those who actually sought services, men were more likely to seek services than women, which is unusual in large, population-based samples. In the group seeking services, age and social support do not seem to matter much. Different factors are associated with reporting need and getting services. One reason people did not obtain services is embarrassment or shame and not wanting friends or family to know. Note that this is only about 17% of the individuals who did not seek services. Expectations and preferences actually explain 70% of the reluctance to seek services in this group.

I am struck how this resonates with Ron Kessler's talk from this morning. He pointed out that stigma in many ways is not our biggest concern. It actually pales when you look at other barriers to care, and we see it again here. People want to solve problems on their own, prefer to rely on family or friends, and want to pray. Again, applying the useful metaphor of a broken limb, I do not know many people who pray as a primary means of addressing a broken limb. However, it does seem to be a preferred approach to coping with mental illness.

I want to pause on this point because it is emerging as a common theme in many presentations. I thought it was very smart of Mark Brown and Bob Ursano to label this meeting Stigma and Barriers to Care. Stigma has gotten a great deal of play as a label but it is instructive to think of it as part of a bucket of barriers to care. There could potentially be different interventions that are required for people with different barriers to care, stigma or otherwise.

Looking at gender, race, and social support, we see that men are much more likely than women, by about 60%, to report stigma as the reason they did not seek care. Dramatic racial differences, bigger than anything I have shown so far, are evident. Black and Latino subjects were actually four-and-a-half times more likely than whites to report stigma as a barrier. Similarly, low social support was related to concerns about stigma. Looking at expectations of treatment, most factors do not seem to matter, but race does matter. Minority races are much more likely to report negative expectations about treatment. Age and social support also seem to matter. Older individuals with high social support are more likely to prefer to deal with it themselves.

The summary from the predisposing factors is that men were more likely to obtain services than women, and low social support is associated with a perceived need for services, but does not predict whether people actually get services in the context of a disaster. Men, minorities, and those with low social support are likely to report stigma, while those who are older with high social support prefer to take care of the problem on their own. That concludes the discussion of the predisposing factors.

Let me show you two enabling factors in the interest of time. I want to talk about income and health insurance. I have to discuss health insurance given the contentiousness of the debate on this issue of late. Regarding need, there is absolutely no association with employment and health insurance in the sample. In the group of people who actually did get services, you see once again no association between employment, health insurance, and getting service. When we study the people who

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need and did not obtain services, we find that employment does not matter but insurance does. Insurance does not matter for perceiving need, but it does differentiate between those who get service and those who do not. What you find is that those who have public insurance or no insurance are much less likely to get services than those with private insurance.

Moving now to perceived need for mental health services I am going to discuss factors that are much more objective than people reporting perceived need. I am going to look at event exposure, stressors, PTSD, depression, and generalized anxiety. The good news is that the people who we might think objectively would need services are the people who do actually report needing services. We found about a threefold greater likelihood of reporting need in those who have PTSD, depression, anxiety, a number of stressors, and a number of traumas. There is a dose-response relationship between being exposed to traumatic events and actually getting services among those who report need. This is likely due to the availability of services arranged by government and not-for-profits for the people who are most severely exposed.

What emerges from this event is that men, minority groups, and persons with low social support are the people who are expressing concerns about stigma overall, while minority racial groups report low outcome expectations. Health insurance and psychopathology matter in this context, while predicting need is actually not predicting access to services, and this is quite concerning. Across these varied contexts of disaster, trauma and war, if we are to make a difference in this area we need to get more sophisticated in parsing out the barriers to care among different vulnerability groups in order to identify just what we need to overcome. Thank you.

**DR. HOBFOLL:** First, I would like to thank Drs. Brown and Ursano and Mary Lee Dichtel. I want to begin by stating that I think the first point of this meeting may be some meaning that is beyond what we could get by reading the important presentations of Dean Kilpatrick and Sandro Galea. If someone as smart and experienced as Matthew Friedman and myself and a few others disagree, that is really an interesting point to get at, to advance. I want to get us to argue a bit more, therefore I am going to try to say a few things that will cause argument.

Uncle Sam is getting older, and America is facing some large problems in dealing with disasters, terrorism, and trauma on the world stage. The FALLS model expands the principles and parameters of the adaptation process in the Conservation of Resources model and stands for Fitting, Adaptation, Limitations, Leniency, and Selection. First is fitting. Resources do not just fit demands. Humans are active and our institutions and culture are active in fitting. Fit is a verb. Resources often need to be molded or altered to fit. How do we mold and alter our institutions and our culture itself in order to fit demands? The distance of resources of any group to new demands makes this fitting more or less difficult. If you are in the group that has lots of resources, you make the transition rather quickly and easily. If you are in the group that does not, there will be many more impediments. A great example of unexpected fitting of resources is when the Mohawk Indians moved from Canada in the early 1900s to build skyscrapers. Someone realized that although they had never been up in a skyscraper or even seen one, hardly anyone had at that time, they were not scared of heights and they needed jobs. They had a little bit of a resource, but a great deal of adaptation was required to go find them, bring them in, and train them.

Second is adaptation. Adaptation is a process of successive approximations, not

an outcome. It is hard to get publications on process but that is what adaptation is about.

Adaptation is bound by expectations on the part of any special group or class of people to the host culture. If you are wealthy in this society and white, you can do just about anything and get along. That is equated with adaptation but that is not adaptation. When an inner city woman who is black or Hispanic with some language difficulties and lack of education feeds her family, that is adaptation. Adaptation follows the allocation of resources and can be rapid. If you move resources around, rapid adaptation will follow those resources. When adaptation is blocked, when people are blocked from services, conflict will arise. There is conflict in the military right now, between most senior commanders who are not very interested in mental health, and Congress and parents and the press who are bugging them about it, because a lack of adaptation leads to conflict. Of course commanders care about every suicide, but it is not their main care because it is not their primary mission. The mission is protecting the United States against its enemies. It is the same situation I have when I meet with my dean. He says, "I really think your ideas are important here." I say, "Yes, but how are my concerns ranked compared to the other chairs of departments? If you only have three rooms to give out and I'm number five, it doesn't matter if you like me among 20. You're only giving out three rooms." Another example of a movement of adaptation with conflict was the civil rights movement. Blacks were well adapted to very difficult situations, but corridors leading to success and a less stressful life were to a much larger degree blocked to them.

Third is limitations. We know about limitations from sociology. The resources of those who are disenfranchised have reduced currency. A dollar is not a dollar. It takes about a \$1.30 for an African American person to get the same credit as it does a white person in the United States. Certain neighborhoods are redlined. I was looking for a house in the Cleveland suburbs and I am Jewish. That has not been a big obstacle for me in the period of my growing up in the United States, but I was told by the realtor as we went to several neighborhoods, "This street has a housing association. They vote and you will not get a house on this street." What that means is any dollar I have is not exchangeable. The housing association did not say, "It will cost you more for the house." They said, "You will not be voted to be allowed to enter this house."

Some pathways are blocked or bottlenecked. A great deal of mental health pathways are not entirely blocked, but we see some people getting through while there are huge bottlenecks and obstacles for others. Some resources that people have are rejected outright in this limitations process. For example, many areas of government and medical assistance say, "You cannot pay for psychological care." That policy was put in place by psychiatrists who wanted to block psychologists from giving care, even though those psychiatrists know the literature and know that both kinds of care are important. There are turf battles that play a role.

Fourth is leniency. Positive status confers extra value on resources. For example, you can be not terribly bright and get into Harvard or Yale as a legacy. That is the opposite of limitation. That is a leniency that occurs. One of the major leniencies of our society, in economic terms, is the *intra alia* distribution of funds. As an upper/middle class child you receive about a million more dollars from your parents, without paying any taxes on that turnover of money, than a child in the inner city in the United States. That is a million dollar grant per upper/middle class child for allo-



*I would end with this point: The reason the military has problems is that it is still using a mental health diagnosis to categorize and get certain people out.*

cation to all kinds of resources such as better schools, mental healthcare, medical care, and so on. Courts, jobs, and universities treat those of higher status with greater leniency. We know, for example, the greater distance you are from a judge in social status the more likely you will be incarcerated and receive a stiffer sentence, and also the more likely you will be found incompetent and put into mental health care. Said another way, public defenders lose all their cases in the mental health court, almost 100% of their cases. I got a call from a friend of mine's son the other day who won his first mental health case in Los Angeles after a year as a public defender.

If you are of certain classes or groups in society, you go up on a glass escalator to whatever you want, including mental health care. All of my friends that need mental health care get it. I do not know if they feel there is a stigma. Those in need may not be blocked by prejudice but may not qualify, as others are treated and fill the rooms. All psychologists and psychiatrists are very busy. But those who are treating the poor see a patient every two minutes in community mental health centers, and those who are seeing wealthy patients spend an hour to an hour-and-a-half with each one. The Institute of Psychoanalysis in Chicago is still very active with people coming to treatment for five days a week seeing psychiatrists.

Finally, there is selection. People select into certain roles, and the host culture will select individuals for certain roles. Certain roles will be prohibited. The role of doctor and patient is relevant here. I actually think what Matt Friedman's center has done is create a full continuum of care including prevention, education, and early intervention, and it has gotten away from the role of doctor, expert, and sick patient in terms of how they are approaching the problem. Diagnosis is a big devil in all of this. We are still pushing a diagnosis as something that is meaningful. Recent data, for example, a study by Kubzansky and her colleagues (2009) showed that women, who were rather resistant to heart disease, with minor PTSD symptoms have about a threefold increase in coronary heart disease. There was nothing about reaching diagnostic levels. The sorting of selection occurs differently if we look at the continuum beginning when someone starts getting symptoms and focus on preventing symptoms from occurring and skill building, rather than on treating disorders. The role of a mental health patient is used for selection by those in power, creating stigma and barriers.

I would end with this point: The reason the military has problems is that it is still using a mental health diagnosis to categorize and get certain people out. The seeds for change are already in the military culture, in which the focus is shifting to training soldiers to become more resilient and not breakdown with PTSD. When you talk about resilience you are talking about performing better at all levels, and then going back home to be a spouse and a more effective parent. That will make a soldier who continues service for an entire career as opposed to being pulled out. I think we are spending upwards of \$30,000 per recruitment right now for the military. If you are highly trained there are some categories of training for which the reenlistment bonus is over \$100,000. Those are good things, by the way. You have to incentivize, but you will also have to change the barriers, take the data, and place them into the context of theory in order to know where to go.

**DR. ZATZICK:** I wear a number of hats. I am a clinical investigator in trauma center settings. My academic pedigree derives from Greg Simon and Wayne Katon in collaborative care and primary care. We have been trying to adapt those models working with Chuck Engel here on a large military trial for acute care in post-trauma populations. I am also Chair of the Services in Non-Specialty Settings, NIMH

Study Section. In that capacity, I am often in a room like this reviewing grants with folks from multiple disciplines, and we have the potential to get into arguments that we are trying to resolve to come to some sort of agreement. I think we need to fastidiously think through the different disciplines that are around the tables and come up with higher order constructs that may help us have dialogues over the course of the next day-and-a-half.

Sandro, I just came back from nine days in Haiti earlier this month. You have talked about, from an epidemiologic perspective, how population impact and safe population impact is related to the effect, the quality and the reach of an intervention. Say I am the frontline provider delivering care after a hurricane in my trauma center in Haiti. I am like Charles Hoge, screening a veteran after a buddy has been blown away the day before. I realize that there is treatment effect heterogeneity. The issue of tailoring that intervention is key. How would you take the goal of wanting to have a large population impact and meld it with my desire to tailor and deliver care in a very unusual context very far from where the interventions were developed?

**DR. GALEA:** Doug Zatzick and I have had this argument for about a decade and I think we are never going to resolve it. We did a paper together trying to resolve it but it seems to somehow not have stopped the argument. There is a tension between improving population mental health and improving individual mental health. We have to be very careful about conflating the two. The evidence around the drivers of population mental health suggest certain approaches that would improve the mental health of everybody, both those who are at the high end of disability versus the low end of disability. For example, given the data I showed here, one would think that improving social support across the board would improve people's access to care. Other data from many other areas including HIV in marginalized populations shows that people who are networked and have social support actually get care. If you improve networks and supports in populations, I would expect us to see increase in the utilization of mental health services. This is population-based information.

You are asking about the individual level. At the individual level, the fact that I have low social support has relatively poor predictive value for the outcome of having barriers to care, because the population of observation is not necessarily telling us about a given individual. Epidemiologists and population health scientists have been poor at providing guidance to clinicians who need algorithms for tailoring interventions. You cannot state from my data the characteristics of the individual that should be targeted for care. We need specific studies that identify the features that are most likely to predict poor access to care among individuals. Nothing that I showed can tell you that.

**DR. ZATZICK:** The VA is refining and honing and delivering evidence-based treatments. To increase population access, would you think about generating on the fly, in-setting kinds of treatments that focus on engagement? How would you think about this notion of reach?

**DR. GALEA:** It depends on what you mean by the word treatment. If you have a "population-wide treatment" that improves networking, linkage, and support among everybody then my data would support that. If by treatment you mean you are targeting a particular subset of the population, nothing from my data can tell you that a treatment is going to work and you actually need separate trials to tell you that it is going to work for a particular subset of individuals.

**DR. FRIEDMAN:** Putting these issues in a public health preventive context

challenges the title of this conference. In a preventive context, the outcome is not necessarily clinical utilization. The goal is to abort situations where one exceeds a clinical threshold at which mental health treatment becomes necessary. We can use social media, Twitter, Facebook, and websites to provide education that may help people recognize that they are starting to take on water. They are not necessarily exceeding a clinical threshold but they are not functioning as well at work and with their families. It is not a clinical issue, it is a public health issue unless left unattended. If you can provide sufficient education, monitoring, and corrective steps early on in a preventive way, that will reduce stigma issues that we have been talking about in a more clinical context.

**DR. KILPATRICK:** Populations are made up of individual people and some will need more help than others. A website may not help those at the top of the pyramid of care who have major mental health problems. But for many people education may desensitize them to getting treatment if they need it. It gives you the opportunity to provide information to many more people than if you are talking about mental health professionals meeting with people individually or even in groups. Web-based self help tools may help get around some of the stigma of having to label yourself as being so bad off that you need the services of a mental health professional. It may also be a tool for self assessment to help people see they need something more and maybe there is some education that can be included about that.

**DR. WESSELY:** Dean Kilpatrick mentioned Pan Am 103 and Lockerbie and the research on the families. A professor of psychiatry at Dundee wrote a very good account of what happened in the village of Lockerbie itself. He organized a mental health response based on the local town hall. There were policemen who were upset by having to stand by body parts all night right after the event. There were also 13 killed in the town and others injured, and many people were very shaken by Pan Am 103 disintegrating above them. Without exception, none of them came to the mental health center. They all came to the primary care center, which was run by three general practitioners who they knew and were people they could talk to. I thought Ron Kessler was a bit mean to primary care, because in most health care systems, primary care will be where the vast majority of mental health care is going to be delivered. It is an existing structure. It is much freer from stigma because they are the same people you also talk to about childbirth and other things.

In the U.K., general practitioners will deliver 90 to 95% of the mental health treatment for common mental disorders, not schizophrenia or bipolar disorder. Given that they actually will deliver the bulk and they are acceptable to the population, we should think more about supporting the primary care practitioners who actually are trusted and will deliver much less stigmatized service than I am afraid the folks around this table will, including me.

**DR. KILPATRICK:** First of all, the families who lost somebody on the ground in Lockerbie were included in the sample because they were included in the services that the Office for Victims of Crime provided. Secondly, it is true that most people go to primary care. The question is whether, aside from giving medications, primary care doctors really are equipped to handle serious PTSD and other disorders. The advantage is people will go to them. The disadvantage is that if you have got two, three, or maybe 10 minutes for a complicated case, primary care doctors do not even have the time to handle the issues for which people go to primary care in the first place.

**DR. URSANO:** We have introduced the question of primary care. We have intro-

duced the question of access. We have introduced the question of whether primary care is prepared to use the latest treatments and whether they have the time. If not, what do they need?

**DR. LINK:** We have discussed the different reasons people do not seek care, and comments have been made that reasons related to stigma are less common than ones like, “I can handle it on my own.” If you imagine a respondent reacting to a question suggesting “Why aren’t you doing something that would be good for you?” they are less likely to say, “I would be embarrassed” than “I can handle it on my own.” There could be demand characteristics in the questions that shape the responses.

The second point is that if you ask the respondent why do they want to handle it on their own, you might see that there are identity issues about what that would mean about them. You would see stigma issues rolled in with respect to beliefs about what kind of person needs treatment. Put another way, imagine us saying that we would go out and change people’s beliefs about that one narrow thing, “I can handle it on my own,” to say, “No, I can’t handle it on my own.” Do we really think that we would make them come into treatment?

**DR. KESSLER:** One important aspect of disasters is that stigma can get flipped. If you look at national data among people who have a mental illness and predict whether they got into treatment in the last year, having trauma is a very strong predictor of them getting into treatment, and the reason is that there is a good reason to get into treatment. “This terrible thing happened to me that is beyond the range of normal human experience.” Anybody would be upset by that. It gives you a license to talk about it in a way that you would not otherwise. Very often the people who get into treatment after being in a car crash or a natural disaster are talking about their mother not loving them 30 years ago. The trauma is an occasion for getting into treatment, so many of the people you see have chronic, ongoing problems.

We did a study looking at the impact of the Virginia Tech shootings on students, and there were 32 students killed in a population of 30,000. There was a massive increase in the number of kids who got into treatment for mental health problems. The main reason reported was that a close friend of theirs died. However, each of the kids who died had to have had 370 close friends for that to be true, which is pretty unlikely. Twitter studies of close friendships show that people tend to have around eight.

Trauma is an occasion for going into treatment. One problem with trauma treatment setups, particularly in natural disasters, is that they are set up on an acute disease model. A team swoops in for two weeks with Cipro and these chronic schizophrenics are wandering in with this little bag of pills that are sort of purple. “I don’t have my pills.” “What’s it called?” “I don’t know.” They do not have any antipsychotic medications or antidepressant medications in the strategic drug file.

We have to figure out some way of giving longer term treatment and mass treatment after a disaster because this is the opportunity to reach an enormous number of people. They feel it is okay to come in a way they normally do not. They do not want to come in for two weeks. They want to come in long term, so we have to figure out some way of doing something. One possibility is to work more on telemedicine. There have been some movements in that direction in the last few years. For a couple of natural disasters recently, the American Psychiatric Association and the American Psychological Association had people who were volunteering to see two patients a week for free forever on the telephone. The problem was that if the patient was in

New Orleans and the physician lived in Cleveland, malpractice insurance did not cover the treatment because insurance is defined under state laws. There are federal ways of overriding that.

Once the crisis is over, people stop thinking about mental health. We need more people thinking about how to get long term treatment in place in a mass way. There is no way that the people in the local area can handle it all. The primary care people would be swamped. You have to figure out how to have a decentralized method of treating these people. That means innovative approaches with group treatment or community treatment or more likely some kind of triage system on the telephone so the treating provider does not have to be in the same physical place as the patient.

**DR. URSANO:** That model is also talked about in terms of clinicians in San Francisco talking to soldiers in Afghanistan, so it works across other domains.

**DR. SHALEV:** One thing that should be raised is the threshold issue. What is the actual threshold above which you need treatment and below which you do not? People are identified as needing help because of exposure or from endorsing symptoms. Questionnaires often do not include the disability impairment component, just a list of symptoms. We had a study showing that under the threat of terror only one-fifth of those who endorse the full set of symptoms for PTSD also have impairment and disability. So do they need treatment? In discussing whether diagnosis is useful or not, are we diluting our own message about when people should seek treatment? We can become very confused and very ambiguous in terms of recommending what to do in a specific setting. I wanted to put on the table the notion of a threshold that should be used for inferring need for treatment and eventually inferring that without treatment there will be no recovery.

**DR. GALEA:** I do not disagree with the need for a threshold, but let me add another view. In this country in the 1950s there was an epidemic of a particular disease that was largely driven by a particular kind of person. One option was to intervene with those people, meaning to figure out the threshold and to try to make the disease go away by focusing on them. The option that was instead taken was to change the context for everybody and, in fact, levels of the disease dropped dramatically. What I am talking about, of course, is motor vehicle accidents. The decrease in motor vehicle fatalities is one of the largest public health successes of the 20th century, and we did not do that by targeting bad drivers and giving them driver training. We did it by improving roads and cars.

There are two separate issues here. Issue A is identifying a threshold and identifying people who we want to treat. Issue B is, how do you change population level factors to improve population mental health separate and apart from the thresholds? I think these are two equally important issues. Going back to Ron Kessler's point, the current model for disasters certainly is an individual-based parachuting in intervention. The model of improving population-based context to shift mental health sub or supra threshold does not really exist right now. In a group like this with a nice mix of clinicians and population health scholars, we need to push on both approaches.

## 5

## STIGMA AND BARRIERS TO CARE IN TERRORISM & PUBLIC HEALTH EMERGENCIES

*Simon Wessely, M.D.*

*Brian Flynn, Ed.D.*

*Dori Reissman, M.D.*

**DR. URSANO:** Our next panel is on stigma and barriers to care and is particularly focused on terrorism and public health emergencies. Simon Wessely is the provost and vice dean from the Institute of Psychiatry at King's College and directs the Center for Military Health. Brian Flynn is a retired Rear Admiral, Public Health Service, and a member of our Center, and has probably spent more time on disasters from the public health side than anybody else I know. Dori Reissman is from CDC and NIOSH, and is now detailed to the Center for the Study of Traumatic Stress with us.

**DR. WESSELY:** I am going to divide the talk into two parts. I will talk about people who have been exposed to disaster, terrorism, etc., who actually do not need help or do not want help and then I will talk about those who do and the differences between them. I will use two examples from London, the city in which I live and work. The first example is when Alexander Litvinenko was poisoned with polonium in a London sushi bar, or possibly a London hotel, and subsequently died, triggering a radiation alert. Our Home Office, equivalent to your Department of Homeland Security, was very interested in this incident for obvious reasons. They wondered if this was a good model for all of the various exercises that we had been doing about population reactions to dirty bombs. We were asked to carry out a very rapid study in the first few days of the crisis of reactions of ordinary Londoners, and also to interview most of the people who had been in direct connection with Litvinenko and the other Russians in the bar and hotel. For everyone living in London, this was a completely normal time of the year and the incident made no difference to anything. The further away you got from London the more people seemed to think this was some form of crisis. A general observation I have is that the further away people are from the epicenter where very many things happen, the more they assume that things are going wrong and there is a sense of panic. Russian television viewers, who are not disinterested observers in this

particular episode, were talking about panic on the streets of London and the evidence was that there were police on the streets.

A telephone random sampling study found that only 11% of London residents perceived any threat to their health and only 2% thought they actually had been affected. The vast majority of people were unconcerned by what had been going on. We found that concern depended on the motives the respondent attributed to the perpetrators. Ninety percent of Londoners thought this was just Russians killing each other; they did not think it was of any relevance to them. The small minority of people who thought this was an act of terrorism directed at the population found it much more distressing and were the only ones who felt it was likely to affect their health. Keep in mind that the actual medical risks of polonium are completely independent of the motivation of the perpetrator. We concluded that this was actually a rather bad model for a dirty bomb and a terrorist incident because people did not think that was what it was.

We interviewed people who had been either in Itsu, the sushi bar, or the Millennium Hotel, where it actually turned out he had been poisoned. Of the 130 people who had been identified by the police and had their names passed on to the Health Protection Agency, only two were upset; the vast majority were remarkably unconcerned by the whole thing. At the same time this was occurring, there was a launch of the new James Bond movie, *Casino Royale*. Nearly everyone described the incident at the Millennium hotel as like an episode of James Bond. As they did not work for the KGB, they did not think it was at all relevant to them. We looked at the possible stigmatization of the people who had been exposed to the radiation source. One person said, “Yes, before Christmas we went to some parties. One or two people asked us to stand outside. They wanted us to illuminate the parking lot so people could see where they parked their cars.”

I will move on to an event that had a broader impact on London, the London bombings of 2005. These bombings had a death toll of 68 and paralyzed London for some time. Again, we spoke to ordinary Londoners, not the people who were involved in the incident. This was a random sample of people in the city. We used the same questions that had been used in the *New England Journal of Medicine* Shuster papers about September 11th. Despite the considerable difference and the impact of the two episodes, people’s emotional reactions were rather similar. Negative responses were higher in New York, but not as dramatically as you might think. We are talking about normal emotional reactions in the few days following, not PTSD or psychiatric disorder.

Those most dramatically upset by the London bombs were Muslims. Twelve percent of the population of London is Muslim, as were 10% of the victims killed in the bombs, excluding the suicide bombers. The second most distressed group were people who were uncertain of the safety of others and who could not reach their family or friends or loved ones by telephone. The mobile system was partially switched off to reduce the risk of secondary devices being used and partially due to call volume. Studies in Israel have shown that those who can immediately make contact with their family and friends are less distressed than those who cannot. The surprise was that the effect persisted six months later. Those who had not been assured of the safety of their family and friends were still significantly more upset by what had happened. We are still not talking about PTSD, but about a normal range of emotional reactions. So what did people do about their distress? Many did want to talk about the event. It was a major attack on our city. It was repeated three weeks later, albeit unsuccessfully. It was a time of great uncertainty, with concern and anxiety on the streets of London. The vast

majority dealt with the event within their own social networks. Only 1% had actually gone for professional help.

Neal Greenberg, a Royal Marine, studied peacekeepers coming back from Bosnia in the days of the UN intervention and the results were very similar. Many people wanted to talk first to their peers and to their family. Psychiatrists are down at the bottom of the list. For every person who wanted to see a psychiatrist, five or six wanted to see the chaplain. In general most people prefer to seek other sources of help, predominately in their own social networks. As Sandro Galea said, encouraging social support is very important and people are mobilizing their own sets of social support.

The home office asked us to assess how much penetration there had been of the various systems and services that had been set up in the aftermath of the London bombs. They asked us to see how many people knew about the different responses that had been organized by the NHS and by the government. There were actually three government responses and one we made up. Anyone guess which one we made up? Yes, it is the one that was the most popular: the London Rescue Programme. The one that did not exist got a higher rating and was better known than the three that did. This leads me to be quite skeptical about many of these studies. We should be very careful when we assess the impact of services. The Home Office was not pleased that we asked the fake question because they wanted to publish data saying how successful they had been with reach for the first three services. But that is not the way that we should be assessing success.

We believe that what is important is that people are talking to each other; we should pay much more attention and try to assist with that. The advice we are going to give in the next terrorist incident in London is not to tell people not to use their phone but instead to keep it short. In those first few weeks we should simply help people mobilize their own social support. That is what people want to do, it is what comes naturally, and for the majority of people, that is sufficient. But of course it is not sufficient for everyone.

Let us have a look at the people who do need and want help. What happens to them? Chris Brewin and his group did a screen-and-treat program of the 540 or so people who were in the three tube trains or the buses. These are the people who were actually there, many of them injured. Dr. Brewin and colleagues set up a program and waited eight to ten weeks, following our standard policy. The vast majority got better, but around 20%, as predicted, did not and then they got treated very successfully.

The first problem was bureaucracy. They did not contact all who were affected, namely those who went to St. Mary's hospital. The authorities there refused to release the names of those who had been involved, citing the Data Protection Act. That meant that immediately one quarter of those who had been affected could not benefit from the research because the hospital erroneously felt patient confidentiality meant that they could not tell Ehlers and Brewin who they had treated for physical injuries. Later the decision was challenged and the hospital officials admitted that they got it wrong but it was far too late by then.

We will move on to examine data from our health surveillance studies on the armed forces during the wars in Iraq and Afghanistan. For the last seven or eight years, we have followed a large random sample of all three of our armed forces, including those who have left the services as well. We just completed a follow-up of over 10,000 of them. We also conducted follow-up interviews by phone, adding information about changes over time that is not typically available. For these interviews, we over-sampled those whom we knew from the study had mental health problems. We managed to



interview 75% of these individuals directly. I often talk about the differences between Britain and the USA, but with respect to stigma and barriers to care there was absolutely no difference at all. You could not put a cigarette paper between our responses and Charles Hoge's when we repeated exactly the same questions as Charles had in the Land Combat Study.

We looked at these 800 veterans to see what had happened to them. Many of them have left the services, and many have mental health problems. But very few of them actually come to see us. Only one-third of them get any care at all. For those who see a health professional, they are four times more likely to see a non-mental health person. Health professionals themselves are not that popular; however mental health professionals are even less popular. Of those who are seeking help, very few get adequate treatment. Only 1% receive the best standard of treatment, CBT. I do not suppose that is an entire surprise to you but the scale of it may be somewhat surprising. It could also be that the military is a very macho organization, in the UK as in the US, and that particular culture is what prevents help seeking. But is this unique to military culture?

We compared data from the military with those in the rest of the population using data from our psychiatric census, which takes place every ten years. We managed to ask who had served in the armed forces, something they had never done before. Comparing veterans and non-veterans, we confidently predicted that veterans would have worse mental health, be worse in treatment seeking, and have more problems the longer they served. In fact, that is not what we found. When you compare veterans with the rest of the population, there were no differences in their treatment seeking, except for alcohol problems. They did not have more mental health problems compared to the population. The longer they had served, the less likely they were to have problems.

Veterans' rates of help seeking behaviors are actually comparable to the rest of the population. It is not true to say, certainly for the UK, that they are worse help seekers than others. Actually, everyone is bad at help seeking. Having a mental disorder is bad news wherever you are, but it probably is not any worse if you are in the armed forces. Concentrating on stigma only within the military misses the point. It is a broader social issue.

My final point is that part of our job is to reduce the number of people who come to see us and who need to see us by providing less stigmatizing alternatives. I have already mentioned primary care, but we also need to put a great deal of effort into building up peer support. Neal Greenberg and I train one in two of all the Royal Marines with a very simple two-day course on mental health measures. That has been repeated across the whole of the British Army. The idea is to put us out of business. I think it is highly unlikely to happen, but the idea is that the fewer people who come to see us, the more pleased we will be. Thank you very much.

**DR. FLYNN:** Let me provide some context before making my comments. My background is primarily in disaster and emergency, mental health and behavioral health issues. The organizational home for most of my career was the U.S. Public Health Service. I am not a researcher, but I have had a great deal of experience in government and in the field. I made a career out of going to the nicest places at the worst possible times. I think I have learned something in the process.

I want to use a different lens and talk about systems issues because that is really where most of my work and my familiarity lie. Stigma involves a number of factors. There are individual and cultural factors. Stigma and barriers differ depending on the disorder or the context, such as whether the disorder derives from a war experience or a disaster or a rape. Then there is stigma about the field of behavioral health in general

and disaster and emergency behavioral health in particular. I want us to think about the issues of stigma as it pertains to our field and about what we do, but we should not equate that with the stigma that individuals feel. They are not comparable. Those of us who choose to be in this field choose to be in this field. People do not choose to have a mental illness. The magnitude of problems for individuals should not be trivialized in any way.

I want to talk particularly about disaster and emergency behavioral health as a subset of our field, particularly about how it interacts and intersects with health and medical and emergency management issues. If I were to redo my slides based on my thinking today, I would probably add a couple of more pieces about the need to consider stigma and barrier issues with primary victims and survivors and also with workers and helpers, because while I think there is overlap, there are also some separate issues. As we move away from the more traditional areas of health and into behavioral health and then into disaster and emergency behavioral health, there is increased marginalization, misunderstanding about what we can and cannot do, and myths about our profession along with stigma. The irony is that if you get into a major public health disaster, some of this may shift. When we talk about emergency management, we again have the same problems of marginalization and stigma.

I worked with the Federal Emergency Management Agency (FEMA) over the years. The health component is not really central to their operation and they sometimes do not know how to handle it. Once you get into the health and medical emergency support function, they do not know what to do with the mental health component. There are increasing issues of stigma and marginalization that happen as you move away from the core. In a public health emergency, emergency management may not be at the center; rather, public health and medicine will be central. When the shoe is on the other foot, we need to be careful that we do not trivialize the emergency management function. It may be just as important to get vaccines in place and out to people, or whatever kind of medical interventions are appropriate.

We also want to make sure that we have people who understand human behavior and who understand the importance of social functions and community continuity. We need to make sure that the food supply is maintained if there are blockages of borders and that the guy who fills the ATM machine gets there. These functions may be just as important as getting people inoculated or immunized. For those of us who choose to be in this field, if we are going to escape with our egos intact we need to share some delusions. One of those delusions is that emergency management always values what we do in this field. That has not always been my experience when I get out in the field in disasters.

The other delusion is that I am always a full-blown part of the team. Many times when I have been out working on disasters, I felt like a lonely cat in the presence of a row of dogs, the emergency managers. In 2004 I was invited to be part of a CDC process to develop an operations manual for what to do in the first 48 hours of an event that had public health consequences. The process used computer-based decision making. Everyone in the room had a computer, you were asked a question, you typed in your response, and it appeared on a big screen in front of the room. It was anonymous so people were more candid. There were only two of us in this group of about 60 people who had a behavioral health background. Because of my bias I kept injecting comments about behavioral health because I feel it has a role in everything.

Apparently that view was not shared. A public health official said, "I understand and empathize with your concerns about mental health and public health emergencies.

However, the issues I have to deal with and the decisions I have to make in the first 24 hours are life and death issues. Mental health concerns, while important, do not rise to that level of importance.” Well, excuse me. When I got over the narcissistic injury of this, I realized that this was a problem. My colleagues and I have not been doing the job that we should do in defining where we can contribute and what our behavioral health concerns are. In fact, the behavioral choices that people make in these kinds of situations are very much life and death decisions. I realized then how important it was to make sure that we correct some assumptions about what our jobs are and can be in these situations.

I have been in this field for many decades and my view is that things are improving. One of the ongoing frustrations I have is that much of the improvement in the field does not seem to be systemic. It seems to be personality dependent: who is sitting in what chair at what time and who is sitting in the chair across from him or her at that same time. When that constellation changes, a great deal of good work gets undone or forgotten. I am not sure what to do about that. It has gotten better but we have a long way to go.

I want to end with some suggestions. One is that we need to more broadly define our contribution. Getting in and doing individual interventions with people is important work, and I do not want to trivialize it. We also need to do more consultation and leadership training. One of the areas that I have been involved with more intensely in the last couple of years is trying to integrate behavioral health principles with messaging and communication. I think that is where there is a whole lot of bang for the buck and where I want to put some of my energies. It is an exciting area. Systems design and preparedness is another area where we have something to contribute.

We need to continue to increase the evidence base. When you look at where the evidence basis comes from and how it has advanced, probably 90% of it comes from the people in this room; we need to keep doing that. The more our consultation and systems design is based on evidence rather than on marketing or belief, the better off we will be. We need to get to and stay at the table somehow. We need to have a presence in discussions about systems issues, whether it is in emergency management or public health. If you are not invited, go anyway. If you do not make a fool out of yourself, you might get invited back. Get there and stay there somehow.

I also think that part of what we need to keep in mind when we are dealing with these other systems is how to make other people’s jobs easier. That will get us incorporated and invited back. The FEMA-funded program that I administered for many years is now almost 40 years old, and once you work with people long enough, they begin to tell you the truth. This program was not generated by a humanitarian concern. It was generated because at that point there were one-stop shops for people to come in and apply for FEMA assistance. People were getting upset and crying in those situations, and FEMA personnel did not know how to handle them. People were so distraught that they could not fill out the forms. They wanted us to solve that stress based administrative problem for them and it was the birth of something that has gone on for many decades.

There are many fantasies about what we do, including a belief that our job is going to make other people’s jobs more difficult or complicated. We always need to go into these systems discussions with an eye toward how we are going to solve a problem for the people who we are doing business with. And then we need to push for parity. We need to continue to advocate within these other systems to ensure that behavioral

health consequences get their due in terms of money, respect, recognition, and inclusion in plans and strategies.

With respect to stigma, I think of the State Department after the bombings in Nairobi and Dar es Salaam. Many people needed care very desperately. They were very traumatized, but they would not go anywhere for care due to the fear of jeopardizing their security clearances. We have situations in which the stigma may not be just in the individual. We need to consider that it may be in our processes. We need to be aware that there are stereotypes about this field and we have to go the extra mile to make sure that our help is practical, legitimate, and evidence based, and that it helps other people do their jobs. We must take care not to reinforce negative stereotypes of behavioral health.

**DR. REISMAN:** I would like to thank Drs. Ursano and Brown for having me here. It is quite daunting to be here talking to you because I view you as the experts and see my job as carrying your flag. According to Erving Goffman, who did some of the earliest work on this, stigma is “an attribute that is deeply discrediting,” and the attribute of the person in some way reduces the bearer “from a whole and usual person to a tainted discounted one.” If we think about stigma, whether it is barriers to care, stigma, or negative attitudes toward the care that is available, you can see that everything answers to culture and power. Power of labeling others and making them feel bad about their labeling. People’s beliefs may be within culture but also may be based on life experience as separate from culture.

Social conditions are often captured in our epidemiology studies by using socioeconomic status as a proxy. You are potentially more exposed in lower SES environments to crime, infections, poor diet, pollution, and other lifestyle factors that are not very health-promoting. Access to quality of care and capacity for that care may be compromised. Transportation to get out of your environment to access that care may also be problematic. Thinking about this in terms of public health emergencies, of which disasters is a subset, you are thinking about a sudden discontinuation or disruption of service and the underlying unevenness of the distribution of resources. Stigma in the center is a social cause of disease.

With respect to the distribution of life chances, for conditions such as mental illness, leprosy, HIV, or a disability that the world can see, money may not be spent as quickly as it might be on problems that are more hidden, not so disfiguring or not so obviously labeling. The science may lag behind in providing treatment. This reduces life chances of people with these conditions by affecting the education, jobs, housing and health care environment that they experience. Stigma affects all of these things at once. We tend to focus our research on one issue such as mental illness or HIV. Most people have a compilation of characteristics; they may already be stigmatized and another condition might discriminate them further.

This brings up an issue of terminology. Stigma makes you think about the individual who has the problem, the “other.” The word “discrimination” makes you think more about the person who is labeling. The self view has a great deal to do with the cultural milieu in which you live, your life experiences, and how you view your own characteristics, whether it is the color of your skin, an obvious disfigurement, or a disease that people just do not want to get near within the psychiatric realm. These conditions can lead towards a sense of broken self and lower self-esteem. It questions the whole notion of trying to push resilience because it sets up the capability for people to blame themselves for not being resilient or for organizations to blame their members for not being resilient. It also sets up the idea that if our communities are not resilient,

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there is something wrong with the community because they need outside help. I raise this as an example of creating an intervention for a problem that can also create new barriers and new problems.

Stress and fear contribute to reluctance to seek care because of fears of reprisal, and fears of being labeled because care may lead you to be “outed’ with a problem that people would stigmatize. There are many disincentives in the system for people to access care. If mental health services are not co-located with other services, people can tell what problem you have just by what room you go into. We have also had to try to do collaborative care in which we empower professionals of other disciplines to do some of the basic mental health work. The organizational implications of mental health have to do with job evaluations, someone’s position, and how people with mental illness are viewed.

Since this is also about terrorism it would not be fair to ignore it since it was the source of so much money for so long. We can think of terrorism as a subset of disaster. There is the attacker and what they look like or what group they represent. There is the situation that the attacker caused and the inadvertent fallout from that, both of which interact to form a profiling event. A very simple way of looking at that would be the anthrax and World Trade Center disaster and the Pentagon disaster of 9/11, 2001. Crime statistics, especially near places like convenience stores and gas stations, showed that more people of Middle Eastern descent were being beaten up after these events happened because they were now the face of the enemy, even though these people were part of the communities. When anthrax killed workers at the postal service, people were afraid of their children being exposed to postal workers’ children because they were concerned they would get anthrax, as if it were transmittable person-to-person. Labeling occurs not only for groups associated with the attacker, but also the victim. There is fear of contagion associated with the victim and concern you might be the next target.

**DR. HOBFOLL:** The different talks bring up a number of issues for comparison. The military is a closed system. It is all-controlling. Your records are available as part of your performance. Society is an open system, and I think that makes a big difference for stigma because within the military context, it is possible to change policy rather immediately. For example, you could set up a system to reward going for behavioral treatments that enhance your skills, and society cannot do that in general.

I also want to point out that there is almost nothing in our society that is opposite of stigma, especially American culture. The use of the honorific was made absent by the founding fathers in the United States. Part of our problem should be creating an opposite notion to stigma when there is not even a lexicon for it and it has fallen out of the culture.

**DR. RADKE:** The National Medical Director Council and the American Association for Psychiatrists have tried to use the public health model, but there are significant barriers in doing that. There are clinical barriers where the clinicians are focused on active treatment and rehabilitation. They are not interested in early intervention because they have no time and there is no money for that. There are administrative barriers where there are silos created by policy that do not allow for the application of a model. And there is a political barrier where disenfranchised populations such as people with serious mental illness, or children and adolescents, have no say in the political will for using the public health model. Those are additional concerns beyond the stigma that have come to mind as I was listening to the talk.

**DR. HOLLOWAY:** The military is not a closed system. It is an open system that is

different than the civilian system, and both are very complex. The overall assumption that you can equate the overall reduction of burden of disability in a society with a reduction in caseness is based on two ideas being confused. You can prevent caseness and not change disability at all. The example was offered earlier about fixing cars. That is a good example of a situation where you do not change caseness but you lower disability by making better cars. Another classic example would be that you can treat diarrhea, but it would be better to fix the water by putting chlorine in it. That is the way to lower disability. We ought to distinguish in these response systems between ways of lowering the prevalence and incidence of disability as opposed to lowering the incidence and prevalence of caseness. This is important because they are very different systems and they require very different kinds of interventions, which may or may not be related.

**DR. BRITT:** Something worth highlighting is the difference between the stigma and barriers to care of getting treatment following disasters versus military combat duty in terms of the context of traumatic exposure. A soldier who is exposed to high levels of combat is accruing these experiences as part of his or her job. In terms of encouraging treatment-seeking versus focusing on resiliency and not needing treatment, when you have soldiers who are exposed to the highest levels of combat reporting elevated symptoms, there is really a majority who are reporting symptoms. I wonder whether an emphasis on resiliency might be detrimental to that segment of the population getting treatment.

**DR. URSANO:** I noticed the progression of ideas is appropriate to the collegial sense that we are all in this together to do some tussling. That is the usual progress of such a conference that is headed in the right trajectory. It was said somewhere that this is a military meeting. This is not a military meeting. It has to be funded by DoD funds, but remember our topic is war, disaster, and terrorism.

As many others have pointed out, we are attending to the public health model, not just the treatment model. Think about the different tools and the different targets that are present in those two models. All of that is to say there is a reason why this conference is called stigma and barriers to care—because we really do think stigma is just one of the buckets under barriers to care. We chose care and not health care because the questions of dealing with distressed populations involve issues such as increased motor vehicle accidents or people deciding to not shop, which can impair the economy and become a national security issue. That is why this is the forum on health and national security because it is important to address the entire range of populations from distressed, mild disorder, moderate disorder, to severe disorder. There are people with problems caused by the trauma itself, along with those who have emergent mental health problems and who take the opportunity of the trauma event to come in for care. We need a public health model and a treatment model to address the questions of stigma and barriers to care across the whole population.

We have now begun to reveal the complexity of this problem. We want to inform and keep track of this complexity. If you are still in your bucket of being a disaster person or a military person or a terrorism person, it is time to jump out. This is where it begins to be important to think across those frames, because if we do not, there will be national security, continuity of operations, and continuity of government problems for us in the future. Whether the issue is 9/11, suicides in the military, or Katrina, there are substantial issues of getting people to care. Health care is one aspect of care, not all aspects of care, or of sustained national security.

*As many others have pointed out, we are attending to the public health model, not just the treatment model.*



## 6

## CONCEPTUALIZING STIGMA AND BARRIERS TO CARE

*Bruce Link, Ph.D.*

*Bernice Pescosolido, Ph.D.*

*Arieh Shalev, M.D.*

**DR. URSANO:** The challenge before all of us is how to think together so that we can be creative in our endeavor and not only see what we have always seen before and say what we have always said before. I am pleased to have our next panel on conceptualizing stigma and barriers to care. Bruce Link is a professor at Columbia. Bernice Pescosolido is a professor at Indiana University, and Arieh Shalev is professor and chair at Hadassah University School of Medicine.

**DR. LINK:** It is a great pleasure to be here. I have spent a good part of my career thinking about stigma. I think about its effects being very broad, affecting many different circumstances, not just mental health. The effects of stigma penetrate deeply and influence people's lives in deep ways. Stigma is often very hard to see and if you do not have the concepts for it, you will not build the measures for it, you will not capture the phenomenon, and you will not see how it flows out and affects people.

I want to start with some classic definitions of stigma and then talk about a definition that I developed with my wife, Jo Phelan. The dictionary defines it as a mark of disgrace or infamy. You have already heard Goffman's definitions. Jones and his colleagues defined stigma as a mark that sets a person apart and links the marked person to undesirable characteristics. There are two criticisms leveled at those particular definitions. The first is that the attribute or the mark is something that the stigmatized person has; it is their stigma. It emanates from them rather than being conferred on them. The second criticism is that too much attention has been paid to marks and associated stereotypes and too little to the broad disadvantages that many people experience because of stigma. Those two criticisms came from consumer groups in mental health. I wanted to see if we could use those to leverage a new look at stigma and generate a new definition of it.

Goffman had one insight that I wanted to draw upon in constructing this definition, which was his view of stigma as a relationship between concepts, such as the relationship between a mark and a stereotype. Stigma exists when interrelated con-



cepts converge. First, people distinguish and label human differences. Second, labeled persons are linked to undesirable characteristics, creating unwanted negative stereotypes. For example, the stereotype of someone who has been in a mental hospital is that the person is more likely to be dangerous. Third, labeled persons are viewed as an out-group, as “them” and not “us.” There is some degree of separation between us and them. Fourth, people experience emotional reactions to labeled people, such as fear, repulsion, disgust, or pity. Labeled persons may feel shame, embarrassment, and humiliation or, as Pat Corrigan might point out to us, righteous anger. Fifth, as a result of these emotional reactions, labeled persons experience status loss and discrimination. When all of these things unfold, stigma is present, and this definition gives the stigma concept a flow across these interrelated dimensions.

The last thing to point out is that stigma is dependent on power. For example, you can have negative stereotypes about lawyers. But we do not use the term stigma for lawyers because they do not face huge societal discrimination. We are not fighting to keep them out of our neighborhood. I do not mind if my daughter marries one. Stigma is dependent on power and who has the power to exercise the discrimination that follows from their beliefs about a stigmatized person.

Now I want to talk about the kinds of discrimination that can follow in this paradigm of stigma. First is direct discriminatory behavior towards other people. You know about the labeled person and you do something unpleasant towards them. The second one is structural discrimination. Here stigmas exist around some problem or circumstance. For example, in a military context there might be a strong and effective response to wounded soldiers but much less effort put into wounds of a psychic nature. If less has been developed, they face a kind of discrimination by getting less when they have a psychic injury than when they have a physical injury. The third type is discrimination that operates through the stigmatized person. This brings up modified labeling theory. Growing up in our society we learn what it might be like to develop any set of statuses. We also learn what it would mean to develop a mental illness.

Imagine two people, one who never develops a mental illness, never goes into a psychiatric hospital. Beliefs about how other people might treat him if he were to develop a mental illness have no relevance to him. He might think that people would look down on someone with mental illness, might not want to date them, marry them, or hire them, but it does not matter to him personally because he has not developed a mental illness and gone into a psychiatric hospital. In contrast, another person does develop a mental illness, and as a consequence everything learned suddenly becomes potentially personally relevant. That can affect a person in multiple ways. One way is that they feel badly for having entered a status that others view negatively. They might cope by trying to protect themselves from rejection, and, therefore, might withdraw to a smaller group of friends and not venture out. He or she might not look for a date or ask for a job, might eschew going to treatment, or might disengage from treatment to avoid these possibilities feared associated with being mentally ill. Studies have shown that social performance can be harmed if participants think another person knows they have been in a psychiatric hospital.

I developed a measure for this theory that asks what the respondent thinks most people think about someone with mental illness. Items include, “Most women would not marry men who have been in a mental hospital” and “Most people think less of a person who has been hospitalized for a mental illness.” All of us can

answer those questions and then form a scale that works pretty well in measuring the perceived devaluation and discrimination against people with mental illness.

The main idea is that for people who never develop a mental illness, their function is not related to their score on the perceived devaluation-discrimination scale. But for people who develop a mental illness, the stronger their belief that people reject others with mental illness, the worse they are likely to feel, to perform, to withdraw and to have a constricted social network. This theory has been tested with longitudinal data, and we have looked at effects on unemployment, income loss, constricted social networks, quality of life, depressive symptoms, delayed help seeking and self esteem.

As far as implications for help-seeking in military situations, it is possible to ask these questions framed in terms of what soldiers or most military personnel think about someone with mental illness. From the theory, we would expect that the stronger the belief that others would look down or discriminate on someone with mental illness, the less likely someone with a psychiatric problem would be to seek help. What would we do if that theory were true? Do you really want to tell people that other people will not reject them? One response is that the extreme fear is probably excessive, and we could bring that down some. People do not have to fear at the far end of this scale that everyone is going to vilify them. That is probably not in accord with reality. We could change that belief some to good effect. The second response is to change the ambient culture of beliefs, and if we can find ways to do that, then we would be able to move forward and do some good.

The last major topic I want to talk about is motivations for stigma. We often think about stigma as stemming from ignorance. There is a great deal of truth to that perhaps, but people can get things they want from stigmatizing. One motivation is exploitation. For example, racism was a way of justifying slavery. That is an example of stigma in the service of exploitation. Another motivation is norm enforcement, or keeping people in. Stigma can be useful for telling ourselves when we step out of bounds, and we stigmatize people who step out of bounds to bring them back in. The final motivation is disease avoidance, or keeping people away.

I think norm enforcement is particularly important for this forum. In military settings, we need people to be strong. We need them to be brave. We need them to self deny. To reinforce such norms, perceived weakness is stigmatized as a way of keeping people in. From the vantage point that stigma serves a purpose, the question becomes how do we serve that purpose without stigmatizing mental health help-seeking? Can we exempt psychiatric and psychological problems from being perceived as weakness in these cultures? A solution may be to convince people who need these norms to be reinforced to keep those norms strong but to exempt psychiatric problems from them.

To summarize, stigma is a multi-faceted concept. Many concepts have to be integrated to understand all the ways in which stigma expresses itself. Stigma-based barriers involve multiple mechanisms of discrimination, not just person-to-person discrimination, but also structural discrimination that operates through the individual. Modified labeling theory suggests mechanisms that could produce barriers to treatment seeking in military and other situations. Norm enforcement—keeping people in—may be a motivation for stigma that is particularly strong in the military context.

**DR. PESCOLIDO:** I start with a confession. I am not a psychiatric epidemiologist. In fact, I am not an epidemiologist of any sort. I belong to that group which is much less revered, the group of health services researchers. I entered this area of

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research because I had gained knowledge on two of the dominant theories of help-seeking that existed when I started my research agenda: the health belief model and the socio-behavioral model. Unfortunately, after looking at those models for a while, I could not figure out how they matched reality. They were cleaner, more elegant, and had a nicer match with research methods than what I knew from looking around me.

Therefore, I embarked on an agenda to develop a different way of thinking about the ways people enter into services. It is a messier and more complex way of thinking, but it is based in the notion of social networks. Social networks may or may not get people into care, depending upon culture. I started looking at networks and saw, for example, that on the upper west side of Manhattan, having social networks got people into care, while in Puerto Rico social networks were keeping people out of care. That points to a large cultural difference.

I looked at the literature on what people think, believe, and feel about the use of health services. Due to the lack of research on the topic I realized that it was not a popular area to study. When I came upon a line of research pertaining to stigma, I called one of the premiere stigma researchers in the country, Bruce Link, and said, “I think this is something we need to think about.” At that time I was sitting on the overseers’ board of the General Social Survey, which has existed since 1972 and is the longest running monitor of American public opinion, beliefs, attitudes, and behaviors. I thought this would be the place to replicate the three national studies on stigma existing in the United States.

The first national study was done in 1950 by Shirley Starr under the auspices of the National Opinion Resource Center (NORC). The study was never published, but NORC saved every one out of three of the original surveys. The second and third studies were the Americans View Their Mental Health studies done at the University of Michigan in 1956, 1957 and 1976. We drove up to Michigan and found all of the original surveys. In looking at these studies, not only could we get a sense of what stigma looked like in the United States now (1996), but in a rigorous way we could get a sense of how it had changed.

At that point Bruce Link and I went begging for money. Neither the National Institutes of Health (NIH) nor the National Science Foundation (NSF) were interested so we turned to the private foundations. Under the imprimatur of Dr. Ron Kessler, we were able to secure money to do the first national study of stigma in 40 years. And that started a 15 year process.

I would like to give you the eight most important findings we have from that line of research, but first I would like to present the four key points that guided our research. First, stigma disqualifies individuals from citizenship, so stigma is not just centered solely on treatment. It is about acceptance in the family sphere and in the work place. Second, stigma is an attribute known to others, only occurring in social interaction. Thus, as a basis for understanding, we wanted to either observe social interactions or ask people about their social interactions. Third, stigma has different forms. Fourth, stigma is dynamic, not static, and it creates careers. Whether we are talking about careers in the workplace, in the military, or in domestic life, we get a real sense of dynamics from looking at this aspect of stigma.

There are different types of stigma. Today I will mainly focus on public stigma. I think this is important because it sets the cultural context in which people experience the onset of mental health problems, in which others respond to them, and in which they either go on to live a full life, what we now call recovery, or they live a life that is damaged by others’ responses to that illness. A second type of stigma, self

stigma, occurs when people internalize the negative beliefs and responses of others. Another type is courtesy stigma. Ron Kessler discussed how much money goes into mental health research. Institutional stigma is enacted in organizations, including treatment sites. We have conducted studies of both long-term care facilities and acute psychiatric hospitals and find dramatically different attitudes toward people with mental illness in those two sectors of the mental health system. Finally, there is provider-based stigma. Here we are talking about whether or not people who come in for care are given a sense of hope or a sense of discouragement.

Here are some of the findings from the national stigma studies we conducted. The first important finding is that the public has become more sophisticated over time. When we asked individuals, “What is mental illness?” they were able to give us a much broader spectrum of problems that might be considered mental health problems than they could in 1950. The second finding is that there have been changes in formal and informal treatment responses to the onset of mental health problems. There were no dramatic changes in the use of the formal treatment sector; the people who were using avoidance as a strategy continue to use avoidance. In contrast, there has been a dramatic change in how proactive people are in response to mental health problems, and further, the American public has opened up to talk about mental health problems with their informal supports.

Psychiatrists do not use the term nervous breakdown, but the question was whether or not the American public did. We set up a two-stage question. To have comparability with the earlier studies, the first part asked about the term ‘nervous breakdown.’ The second part asked about mental health problems, and we found that most people did respond to nervous breakdown. I would argue that if you watch one episode of Judge Judy you will see that it is still in the common parlance.

The third finding from the national stigma studies shows that stigma is alive and well, that there are clear gradients, and that both the behavior and the label matter. What does this mean? Approximately 50% of the American population indicates some form of prejudice towards people with a variety of mental health problems. I should mention that we did not ask, “Do you want to sit on the bus next to somebody with a mental illness?” We did not even ask the second generation question, “Would you like to sit next to someone on the bus who has depression?” We provided a vignette which is exactly what people confront in the community. We wanted to know one of the most important questions that other approaches did not provide: Do people recognize problems that would meet DSM (Diagnostic and Statistical Manual of Mental Disorders) criteria for mental health? That turned out to be very important in understanding whether or not people want to respond to mental health problems.

There are two clear gradients. First, the type of mental health problem matters. It turns out that schizophrenia is not at the end of the negative spectrum; drug dependence is, followed by alcohol abuse, schizophrenia, and then depression. The second gradient is the venue in which we are asking people to have contact matters. The more intimate the contact, the greater the levels of rejection. In America, and this turns out to be a particularly American phenomenon, the highest levels are in work and marriage. We see the marriage phenomenon everywhere, but the work phenomenon appears to be specific to the United States.

In the 1970s there was a debate in the social science literature about whether it was the behaviors that people were rejecting or the label of mental illness. This debate went on for a number of years, and what we find in our studies is that both

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matter. People respond differently to the behaviors, but those people who went on to label the scenario as involving mental illness also had an elevation in their responses regarding stigma.

The fourth finding from the national stigma studies shows that in some ways stigma has increased, and this is a uniquely American message. There are two findings that support this idea. The first is the work that Jo Phelan did, in which she showed that there has been a doubling of the spontaneous mention of violence and dangerousness in response to the question, “What is a mental illness?” This is a direction that we had neither hoped for nor expected. The second finding comes from recent work by a young scholar who did an analysis of the major newspapers in the United States, Germany, and Iceland. She analyzed the content tone of all articles on mental illness in one year in those countries. She found that the dominant themes regarding mental illness vary across society, so culture matters both in the micro and the macro sense. In the United States, 46% of the articles had a dominant theme of fear and danger. That was not the case in Iceland where the dominant themes were inclusion and integration. In Germany the major theme centered on fear of repeating the past in terms of dealing with difference, particularly people with mental illness.

We are currently analyzing data from samples of individuals in 15 countries looking at stigma and we find there is tremendous global variation. But unlike the World Health Organization (WHO) international study of schizophrenia, these findings do not have to do with societies that are more simple and open. There had been a notion from the Insurance Services Office’s studies that individuals in developing societies recovered faster and better from schizophrenia than individuals in developed societies. They suggested that perhaps this was due to differences in stigma. We find just the opposite. In our sample the three most stigmatizing countries are Bangladesh, Bulgaria and Cyprus. The United States does not anchor the bottom, Iceland does again. However, we do find that competence and public health spending matter for lower levels of tolerance at the societal level.

The fifth finding from the national stigma studies is that sociodemographics are unrealistic, inconsistent, or impotent predictors of public health literacy, treatment predispositions, and stigma. However, we do find occasional correlates. For example, women experience more prejudice, yet they are more tolerant. But that does not exist in all societies or for all kinds of stigma that we might measure. Although there has been a great deal of assumption about how African Americans feel in this country, our research indicates that African Americans are actually more positive about the potential of the treatment system than are Caucasians. This is not the case for all kinds of services, but it does indicate that we need to understand culture rather than make assumptions about culture based on sociodemographic characteristics.

Can we change stigma? We did an evaluation of the Public Service Announcement (PSA) campaign that the Substance Abuse and Mental Health Services Administration (SAMHSA) put out called *What a Difference a Friend Makes*. This campaign was a result of the 1999 Surgeon General’s report, which itself is an indication of stigma. There were Surgeon General Reports on cancer in the 1960s, but it was not until 1999 that there was a Surgeon General report on mental health.

Following the Surgeon General’s report was the 2003 President’s New Freedom Commission whose first recommendation was a national anti-stigma campaign. SAMSHA took that recommendation and ran with it, developing three PSAs with the Ad Council. The first PSA was, *The Door*, in which the person approaches a door,

knocks, and when no one answers, they go through the house. The second, which I call the Friendster video, is a short PSA that shows all the people you are friends with on Facebook. Then it shows all the people you go clubbing with, a smaller group. That is followed by all the people you see on Friday nights and watch DVDs with, an even smaller group. Finally, it asks, “Are you going to be the one who stands by a person with mental health problems?” The third PSA involves two guys on a couch playing video games. One discloses to the other that they have a mental illness, and the question is, “Are you going to be the one who stays, or are you going to be the one who runs?”

The sixth finding involves our laboratory study using a physiological marker and a national survey. The two methods produced the same finding, which is that overall PSA campaigns showed a reduction in stigma. But each PSA worked very differently. The Friendster video is the clear winner. This one showed the greatest and most consistent reduction in stigmatizing attitudes among the target audience, 18 to 25 year olds. Older respondents found the video game PSA insulting, but the younger ones liked it. *The Door* PSA had either no effect or actually increased stigma. It does have some semblance of a horror movie trailer so I can see why that one did not work. I think we have to consider the plus and minus of focus groups in this kind of evaluation research. People who come to focus groups want to help us make things better so they do not tell us if something is bad. They just try to help us make it better.

The seventh finding from the national stigma studies was that there have been modest changes over the last decade with regard to the adoption of neuroscientific beliefs underlying mental illness. We found that significantly more Americans attribute depression and schizophrenia to chemical imbalance, as well as to genetics, than was the case in the past. There are also fewer people associating mental illness with God’s will. However, there has been some negative change. More Americans are associating alcohol dependence with bad character. Finally, the disappointing finding from this study is that if we look across the different venues in which people can interact with or reject individuals with mental illness, there has been absolutely no change in the United States along these lines.

In terms of general take-away points from this research agenda, the science base is much stronger now than it was a decade ago. The fact that we have been working in trained disciplinary groups, like this meeting, is very important. Treatment-based stigma has decreased but community-based rejection has not. We need to rethink our models. Since World War II, the National Alliance on Mental Illness and other groups have taken the disease model to try to reduce stigma. I do not know if that model has failed because there are no good data on which to make that claim but I think the model has taken us as far as it can go. In fact, Jo Phelan’s research suggests that there is some backlash to the genetic attribution of mental illness.

Even if PSA campaigns are effective, and this is one of the first studies of their effectiveness, the traditional logistics with regard to younger age cohorts and the development of new media suggest that this may not be the way to go in terms of stigma reduction. While beliefs and attitudes are powerful markers, because of the LaPierre study that Ron Kessler mentioned earlier, in terms of changing the hearts and minds of Americans that may not be the way to go. We need to think more strongly about institutional regulations that prohibit people from acting upon whatever prejudicial beliefs and attitudes they might have. We have conducted an analysis of 1,640 hours of television showing that at least one time during each unit

of children's programming a slang term for mental illness is mentioned. Therefore, we also need to think about different kinds of vehicles for anti-stigma campaigns.

We need a new strapline in terms of how we think about stigma reduction in order to get past the inoculation model one panel at a time, one group at a time, one meeting at a time. When reconsidering stigma reduction efforts, awareness and knowledge are important. I think education is important, but it is not going to have a direct result in lowering stigma. One of the things we found in both our laboratory studies and our survey studies is that the ability to attend to television programs that have a character with mental illness depends on whether or not a person has individuals in their social network that have mental health problems. Contact is very potent. Americans respond more kindly to children and children are more kind in responding to people with mental health problems. We need to think about attitudes as a litmus test rather than as the marker that we want to change.

One of my favorite advertisements, which indicates the continued stigma of people with mental health problems, shows world class Olympic athletes, including Jackie Joyner-Kersey, Bob Bearman, Greg Louganis, Bruce Jenner, Peggy Fleming, and Mark Spitz. They all have a range of problems, some of which we think about as stigmatized, such as HIV, but what is missing? There is no person with mental illness in this advertisement. There is no one with depression. There is no one with bipolar disorder. There are two potential explanations for this. First, it could be that mental illness is more stigmatized than any of those other conditions and has not moved as far along on the change dimension. Second, it is possible that the particular drug company that did this advertisement does not have a drug for mental health problems to advertise.

The focus of what we should be looking at from our local, regional, national, and international studies is the idea of similar competence. When individuals see people with mental illness as competent, they are less likely to reject them.

**DR. SHALEV:** I would like to thank the organizers for having me here. I have changed my attitude and my position, but I could not change my presentation so it will remain empirically based. I am going to present barriers to care and I wanted to start with a definition. The Goldberg and Huxley definition uses the term 'filters' to access to mental health care. First, the individual must identify his own issues as being problematic. Second, the provider must identify the presence of an illness. Third is the process of referral to mental health care. These are the three filters to obtaining mental health care. In the Goldberg and Huxley study in 1980 there was a 50% detection error by the primary providers and an 80% referral error. The filters, in 1980, were within the referral identification system.

What we were challenged to do in the Jerusalem Trauma Outreach and Prevention Study (J-TOPS) was to bypass these filters by providing detection regardless of illness behavior. We contacted every trauma survivor admitted to our emergency room over a four-year period to alleviate the need for them to seek help. Once we found that an individual had qualifying symptoms we invited them to clinical assessment. If they met criteria in the clinical assessment they were invited for treatment. We referred every symptomatic survivor to readily available treatment. There was no service delivery constraint. It was almost the ideal setting to observe individual attitudes towards treatment because it reflected their own treatment decisions, not some external constraint.

We offered people to enter a randomized control trial in one of the following treatment groups: prolonged exposure (PE), cognitive therapy (CT), selective sero-

tonin reuptake inhibitors (SSRI) and placebo, or a wait list control. The members of the wait list control received late PE treatment provided five months later. The equipoise stratified randomization allowed our subjects to choose among four treatment options and they could refuse up to two of them. Participants were still randomized to the other two treatment options so we kept almost everyone in the study. There were two layers of longitudinal survey, both blinded and nested. The two layers were telephone interviews and clinical interviews. The telephone interviewers did not know whether the person came for a clinical assessment or not, and the clinical interviewers were blinded as to whether the person went to the recommended treatment, avoided it, or dropped out.

The ecologic sensitive approach, which gives me the opportunity to speak about the threshold issue, is that we were all inclusive. If a person told us, "I need to see someone," he went to clinical evaluation regardless of meeting the threshold of symptoms. If the assessor found that the particular person deserved a treatment for Posttraumatic Stress Disorder (PTSD) symptoms, the individual went into treatment regardless of meeting a DSM-IV structured clinical interview derived diagnosis of PTSD.

Here is the basic structure of the study. Telephone interviews occurred within nine days of trauma, seven months later, and 14 months later. There was a layer of clinical assessment before treatment, between treatment, and after treatment. Only 6% of those approached by telephone within nine days of the trauma declined to speak with the telephone interviewers. These interviews could be up to 40 minutes long, detailing the exposure and what the reactions were. This is a very low refusal rate.

We invited 1,470 people to treatment, clinical assessment, and a face-to-face interview, and about half declined. This is the barrier. People do not accept face-to-face contact with a clinician at that early stage of traumatic event. The bias here is that those who accept treatment have more symptoms than those who decline treatment. If there is any bias, those who need care are more likely to opt for care. In terms of declining treatment, after participating in the telephone interview and a clinical assessment, 27% still said, "I am not going to start treatment." All in all, the majority of those who may require treatment declined treatment at the early stages in this almost ideal condition. There was no difference in symptom intensity or severity between those who declined treatment and those who did not.

Within those who accepted treatment there was an equipoise stratified randomization and the patient could refuse a condition. The single condition that was declined by almost a third was pharmacological treatment, SSRIs. Those who did accept the pharmacological treatment had more severe illness. Those who are less distressed are pickier about what treatment to accept. In terms of treatment adherence, prolonged exposure had a lower rate than all the others. The results indicate that five months after trauma, PE and CT appear the most effective in preventing PTSD. Even those who had to wait four months for PE treatment had low rates of PTSD. This shows that it does not matter if treatment is delayed.

We all think about stigma in terms of preventing care, but we ventured into measuring what happens with those who decline care. At the end of seven months the decline in symptoms in those who accepted treatment was significantly higher than in those who declined treatment or declined clinical interview. Declining a clinical interview within 19 days of a traumatic event affects your symptom trajectory. You are less likely to recover. I think this is one of the first studies to look at the long-term



affect of just avoiding treatment. Only 3% of those who the clinician decided did not need treatment had PTSD at eight months. The false/negative error is negligent.

Now we turn to the threshold issue, unnecessary treatment. I told you that we also took into treatment survivors whom the interviewer believed could benefit from cognitive behavioral therapy, or any therapy, regardless of meeting the threshold criteria for PTSD. Of the 55 individuals with partial PTSD, 17 received active treatment, PE or CT, and 23 were on the wait list receiving no treatment. What happens when we compare them? They get to exactly the same place. Partial PTSD patients, in our study, do not need treatment. For me, that is the illustration of the threshold. Now I will discuss the burden of services. We all think that we will have the resources to accomplish our dream. We had 7.4 new treatment episodes each month for four years. This is feasible if you have a good CBT clinic in a receiving hospital that receives hundreds of injured patients. Even if these numbers doubled to 14 per month it can still be handled in a CBT clinic. It is not beyond our capacity to provide the necessary treatment so why are we not doing that?

One reason is the cost of screening. It took almost seven hours of telephone interviews and five hours of clinical interviews to bring just one patient to treatment. The cost of screening and evaluation is enormous. There is almost more time spent on screening and evaluation than on treatment itself. A prevention program has a difficult choice between allocating resources to earlier assessment or providing expensive treatment to survivors who may not need it. The source of this is that early-on after trauma you evaluate a large number of patients who are going to recover spontaneously. This is the barrier built into the situation of acute trauma.

Despite outreach, most eligible survivors avoid early care. In our study people were not going to be on record. They were not going to be ostracized by their friends. They were almost in an ideal condition, yet even if they did not decline a telephone interview, half declined treatment. Even when you provide almost ideal conditions this barrier is there, and the numbers are quite similar to the ones that you eventually find in military populations. The avoidance of care affects the recovery. This study was the first time we could show that.

The cost of screening and evaluation is significant, and the main source of that cost is the unavoidable inclusion of a survivor who subsequently recovered on their own. My recommendation is that the systematic outreach should be reserved for extreme events where the high probability of developing a disorder justifies the allocation of significant resources to treatment.

**DR. KILPATRICK:** Those are very interesting data, Dr. Shalev. You mentioned that the cost of screening was one of the large barriers to feasibility. What would you think about some type of online screening which could be done in a cost-effective fashion? I still think that if somebody says, “Hey, congratulations. You have a problem that could benefit from treatment,” not all of those people will come forward. But, at least if we considered other ways to screen, there might be a way of reaching out to more people.

**DR. SHALEV:** In terms of treatment, we recently started a telephone-based CBT study on the assumption that people more readily accept telephone contact than clinical contact. The jury is still out, but we are getting quite a number of people who decline even a telephone based intervention.

**DR. KESSLER:** Dean Kilpatrick’s question reminds me of an interesting study Rick Price at the University of Michigan did a number of years ago. He had a job

skills club during plant closings in the Detroit area. The program was for people at risk of family violence, alcohol abuse, and depression after losing their job. Price evaluated their skills and did some behavioral workshops to help them get jobs. As part of this program he did a recruitment experiment. First, he pinned three by five inch cards to the union wall that said, "The program is available. Call this number." Second, he gave a speech at the union to talk about the program. Third, he went to unemployment lines and twisted arms to get people to attend the program. Price conducted three separate experiments with the three groups of recruits.

The first experiment was a complete failure because anybody who responded to the three by five cards was going to do really great whether or not he had his program. They were the aggressive people. The people who he had to drag in failed because they were going to fail no matter what. It was the people in the middle who he had the effect on. It is the idea that there is some gradient across which screening and intervention is going to work and you can maximize that program.

**DR. ESTROFF:** I have a question for Bruce Link and Bernice Pescosolido about the overall state of discrimination, or stigma. How do we parse in the monumental shift to guilty and mentally ill from guilty but mentally ill, and the increased deployment of both outpatient treatment and forced treatment in terms of public attitudes and stigma?

**DR. PESCOSOLIDO:** There has not been a dramatic change. There may have been a small decline in terms of Americans' willingness to support coerced medication, but not other forms of coerced treatment. Even in 1996 when we asked about four different forms of coercion and we had people who did not meet criteria, 10% of Americans were still willing to use legal means to coerce those individuals into treatment. The fear/danger coercion issue is a particularly American thing. I think it is dangerous, and I worry about some of the messages that are put out by the Treatment Advocacy Center. One of the things they argue is that if we show Americans that some of these people are dangerous the public will be willing to put more money into services. Well, we were able to do some analysis in 1996 that shows that there is absolutely no relationship between associating danger and increased funds or treatment resources for people.

**DR. ESTROFF:** My question was more about if the effects of stigma are effecting the institutional change in how we view the deservedness, or lack thereof, of people who have psychiatric disorders in terms of the switch to guilty and mentally ill.

**DR. LINK:** This may not directly answer the question, but the thing about the increase in spontaneous mentions of dangerousness from 1950 to 1996 was that it was all written down and we could see exactly what people said. I thought maybe Sue Estroff's idea was that the coercion of treatment would stimulate the stigma. The most common phrasing in 1996 was 'dangerous to self or others.' When we put forward the idea about coercion people understand it and they parrot it back when they talk about what they think mental illness is.

**DR. PESCOSOLIDO:** I think Sue Estroff's question is too sophisticated for the American public. The American public is smart, I do not want to be misinterpreted. But the notion is that anybody who does anything really bad is sick and people do not make the distinction with legal issues. I ask people all the time about Jeffrey Dahmer and the woman who drowned her kids and people see no distinction whatsoever.

**DR. ESTROFF:** But these statutes do not say that. They say you are bad and sick but your sickness does not mitigate your badness the way it did under guilty but mentally ill.

**DR. PESCOSOLIDO:** I do not think Americans have moved along with that legislation. I do not think they watch these issues at that level of detail.

**DR. BATTEN:** Dr. Pescosolido, I am so glad you are not a psychiatric epidemiologist because your perspective was really important. The data that you presented have a feature that I hope can be discussed tomorrow, this issue of targeting public education campaigns. I also find it interesting that helping people understand the true neuroscience that underlies different forms of mental illness has no effect on stigma and, in fact, may have a negative effect. These potentially well intended ways of trying to de-stigmatize mental illness by saying, “it is a brain disease just like any other disease” could have negative consequences, so what should the next wave of public education be focused on?

**DR. PESCOSOLIDO:** This notion of moving from bad to mad, which is what Sue Estroff is saying, may have had an effect earlier in the history of the U.S., but I think now we have got to find another way. Jo Phelan has been doing extraordinary work on genetic backlash because now people are saying, “This is in their genes and, therefore, it would be in my grandson.” I think the human genome project has had really interesting unexpected latent consequences for science and society.

**DR. URSANO:** The bad news is that the population is beginning to believe in genes.

**DR. THOMPSON:** I am from the Center for Mental Health Services (CMHS) in SAMHSA. I have two questions that I want to ask Bernice Pescosolido. First, did you get any sense, or is anybody at all talking about, this idea that people can recover? That there is a process by which it is possible for people to take advantage of opportunities and become participants in society in some way that they previously were not able to do because of the lack of opportunities?

My second question is related to the research on which a PSA story may have salience with the people. You indicated that there were some differences in age groups. I am wondering if there are any differences by urbanicity, rurality, ethnicity, and gender both by the people receiving the message and the people who are described as being psychiatrically ill. I often wonder whether or not much of what actually ends up being about mental illness is a condensation of a number of other stigmas that get focused in a particular population and projected onto them. Do you have any sense about corresponding prejudices that may also affect how people understand mental illness.

**DR. PESCOSOLIDO:** In our study we varied the gender, the education, and the race of the people in the vignette. We found that the results were not consistent. That is why I said the sociodemographic factors, of either the potential stigmatizer or the person who would potentially be stigmatized, were not very effective. I thought it was genius to target 18 to 25 year olds, and I think the Friendster video really hit a nerve of something that we should be following. You would not be surprised to hear that the video game had a gendered effect with women not responding to it at all. I think we should have different messages for people who have different experiences with mental illness because what we are finding is this very strong social network effect. Telecom has a theory called The Limited Capacity Processing Theory of media effects, or something to that effect. They argue that people filter through their own experiences, and what we are finding is a very dramatic difference between individuals who have people with mental illness in their social networks and those who do not.

When I saw the Friendster video I brought it up to our state government and

they asked me, “What should we do?” I said, “You know what? To me the answer is clear. Put your money on the Friendster video. It is very powerful.” I think we can do these evaluations now pretty simply. Yes, they are not free but they are pretty cost effective compared to the \$250,000 it costs to make a PSA campaign. To show the PSA enough to make it effective would cost about \$10 million, and that is where we do not have the societal support. I am not even sure if we had the support that television is the right median. I am not saying PSA campaigns should not be used. I just think the traditional PSA campaign evaluated through focus groups and put on television has to be rethought.

**DR. BELL:** I am told that the frontal lobes of the brain do not develop until age 26, so in my world children are all gasoline and no brakes. We might want to think about how to influence stigma in young children as opposed to older individuals.

Another issue is that when Dr. Satcher was doing his mental health report and asked people about stigma, most people said, “You know I really do not care whether it is biologic or whatever it is. I am concerned about the unpredictability of people.” We need to figure out how to deal with that because that is what scares people.

**DR. PESCOSOLIDO:** First, I agree that we should target the kids, and target a general idea of ‘difference’ rather than just mental health problems. I take from that a relatively old piece of sociology, which showed that during the Vietnam War it was not that the hawks changed their mind in Congress. We voted them out and we voted the doves in. I think the analogy, although not very kind to American society, is focused on the kids. We need to focus on the children regarding both their own mental health issues, because they are more open at that point, and on stigma towards anyone with mental health problems. I agree that unpredictability is the big issue, but I do not have an answer for that.

**DR. LINK:** That coheres with the most powerful anti-stigma tool: contact. Contact can help with the unpredictability part.



## 7

## MITIGATING STIGMA AND BARRIERS TO CARE

*Patrick Corrigan, Psy.D.*  
*Sue Estroff, Ph.D.*  
*Thomas Bornemann, Ed.D.*

**DR. URSANO:** Patrick Corrigan is a professor from the Illinois Institute of Technology. Sue Estroff is a professor from the University of North Carolina, Chapel Hill, and Tom Bornemann is the Director of Mental Health for the Carter Center, and a retired Rear Admiral in the Public Health System.

**DR. CORRIGAN:** I want to talk more specifically about several issues that people have discussed already today. The issue here is not what the problem is, but more how to fix it. I am not a population person, an epidemiologist, or sociologist. I am a psychologist and the models I propose are mostly focused on psychological constructs. Much of our work comes from the National Consortium on Stigma and Empowerment. We were recently funded by NIMH as a collaboration of Yale, the University of Pennsylvania, Rutgers, and the Illinois Institute of Technology.

There are three goals I want to discuss. First is getting a sense of what it means to change stigma and what stigma is, because defining the phenomena has a big influence on the way we decide to change it. Second is understanding stigma change. Third is discussing implications for evaluation and some of the interesting challenges in trying to study these topics.

I think it is easy to feel like you have been hit in the face with this idea of stigma. The headline “Freed Mental Patient Kills Mom” is from the *New York Post*. That headline is about 30 years old so we hope that things have gotten better. In July of 2002 Trenton State Hospital had a bad fire. The next day headline in the local Trentonian was “Roasted Nuts.” Many people say it was just a media issue and if the media behaves the stigma will go away. I think the impact of stigma far exceeds anything the media is doing.

I wanted to get some sense of what it means to try to change stigma. First we had to get a better handle on what the constructs and types of stigma are. The first construct is stereotypes, which are unavoidable attitudes about groups of people. Everybody in the room today knows stereotypes about people with serious mental illness. Growing up in our society, as Bruce Link suggested, stereotypes are just inevitable. The second construct, prejudice, is agreeing with stereotypes, for example, “Yes, all people with

mental illness are weak or dangerous.” Prejudice brings in an affective component. The third construct, discrimination, is a behavioral result.

The other part of our model is types of stigma, which Bernice Pescosolido discussed earlier. Public stigma is what the public does to people with mental illness when we endorse stigma about them. Self stigma is what people with mental illness do to themselves if they internalize the stigma they receive. Structural stigma involves socioeconomic forces that result in laws, statutes, and unclear structures that keep a group down. The group we are interested in and the kind of stigma we are interested in at our center is what we have come to call label avoidance because it does not seem to fit under any other type.

Label avoidance does not necessarily involve a person with mental illness. It is also not the concern of the public. It is the concern of a person who fears there might be mental illness and in order to avoid that fear they avoid the label. The best way to avoid the label is to avoid all mental health professionals because the easiest way to get labeled is to be seen coming out of a psychiatrist’s office or have people learn that you are taking psychiatric drugs. We realize the reason people do not get treatment is to avoid the shame of serious mental illness, therefore avoiding discrimination.

What is of particular concern is adherence. We have come to understand adherence in two separate ways. Both might be a function of label avoidance. One is to not seek care. We looked at NCS and ECA (Epidemiologic Catchment Area) to get a sense of the huge number of people who never seek care when they are in need. The other way we understand adherence is by looking at people who do seek out care, but who do not stay in treatment.

In thinking about developing an anti-stigma program we have to be clear about what we are focusing on, which is people who are trying to avoid the label. We are looking at one small part of stigma. One of the important behaviors we are interested in is getting people to participate in treatment. One way to assess that is website use because all PSAs include websites with the hope that people will use them for significant information and to get direct help for their problems.

Our research group distinguishes between the processes and the vehicles of stigma change, what an individual might do to change mental illness and the vehicles they might employ to do so. There are three different processes for stigma change. Education is the one that readily comes to mind for most people: If we provide more information about mental illness, people are more likely to give up the myth. The second process, protest, is probably the way a Baptist minister would approach stigma change, “Shame on us for thinking that way. We should not pursue this kind of viewpoint anymore.” The third process is something that is still used, especially in school settings, and that is contact. I agree with what was said earlier—if you had to throw all your money at something, contact is the thing to look at.

Education tends to be a comparison between the myths of mental illness and the facts. For example, one of the myths of mental illness is that serious mental illness is rare. This is known as the “leprosy myth,” the idea that leprosy was this evil rare thing for which people were thrown out of the world. In reality we know that, depending on whose numbers and what epidemiologic study you are looking at, schizophrenia is about 0.8% of the population. That is difficult to get a handle on until you realize that Chicago has about 64,000 people with schizophrenia. That is the same number of people who live in Joliet, Illinois. That is just people with schizophrenia. If you throw in bipolar disorder and significant psychotic depression, serious mental illness is common and frequent.

Protest involves reviewing the stigmatizing images of people with mental illness and saying shame on us for that. There are many tabloid examples of this, such as “Get the violent crazies off our streets.” The problem with protest is that it tends to lead to a rebound effect. Many of you may remember this from Introduction to Psychology: “For the next two minutes I do not want you to think about white bears. Keep them out of your head.” Like most people in the audience you probably have the Klondike bear bouncing around in your head right now. The problem with trying not to think about something is that it actually raises its prominence in a group. There is an interesting study in which people were divided into two groups. One group looked at skin-head pictures with a caption that said, “Don’t think bad things about skinheads.” That group had a much worse attitude toward skinheads than the group that were provided no caption.

Contact, as I said before, is a very important way of looking at changing stigma. Bob Lundin is a friend and colleague of mine and a person with schizoaffective disorder, so the contact situations I will talk about today involve Bob. The way contact works is, Bob will get up and tell his story. He will say, “My name is Bob and I have a serious mental illness. I have schizoaffective disorder. We are not talking about test anxiety. This is a major thing that affects my life. It did not happen as a kid.” There are still frequent attitudes that serious mental illness started in childhood. If it comes later in life it is just because you are weak. One interesting thing that comes out of this is the ‘for real’ effect. “For real? You look too good. There is no way somebody like you could have a mental illness.” Bob has to qualify, and the way he qualifies in groups is to ask what it means to be seriously mentally ill. “I have been hospitalized and I have taken drugs for years.”

Now I want to give you a sense of what some of our research looks like. We did a randomized control trial with a sample of 152 people. The participants took a pretest on mental and physical illness stigma. Then they were randomized into four conditions: education, protest, contact, or a control group. The significant finding here is that education and contact improved in terms of their ability to respond to treatment. Social psychiatrists call this stability, the idea that you are not stuck in your mental illness but you can get out of it. The control condition produced an interesting finding pertaining to social desirability. If I come around and ask you what you think of enkephalins—an actual study was conducted on this made-up word—your attitude is going to get better when I ask you twice because you are thinking, “Well, he’s trying to show if I am a bigot.”

Another study we did involved randomizing people into four groups; two were education groups and two were contact groups, each containing a responsibility group and a dangerousness group. The results are clear: contact has a huge effect over education. What is interesting about this data is not just that contact shows a big effect but that follow up to any education diminished over time while changes due to contact were sustained. Perhaps one of the best ways to challenge stigma is to have people with mental illness come and tell their stories.

I also want to look at the vehicles of changing stigma, the way we get protest, education, or contact out there. We divided the vehicles into media-based, with PSAs being the best example of that, and in vivo, which involves inviting an outside expert to educate people about mental illness.

The media is a population-based vehicle and its strength is that it is likely to hit huge numbers. In vivo is a face-to-face approach and, therefore, localized to individual groups.



A media-based example of a vehicle to changing stigma comes from a Glenn Close public service announcement that came out in October of 2009. Her sister, Jessie, has bipolar disorder. It is a very moving and compelling 30-second PSA. You see pairs of people coming up wearing different shirts. One shirt says “schizophrenia” and the other says “mother.” One shirt says “bipolar disorder” and the other one says “spouse.” This program is called *Change A Mind*. When I am sitting around with friends I ask how many people ever saw that video. When you ask this at the population level no one has ever seen the video. Why not? Well, as you may know, broadcasting networks are required to show public service announcements as part of their national mandate. But when they do this, the PSAs are frequently relegated to timeslots very early in the morning so that the audience seeing it is greatly reduced. Then there is the issue of the Screen Actors Guild. When they produce these public service announcements, they are only good for a limited amount of time, usually one year. If you go beyond that amount of time you have to pay the actors again so these PSAs disappear quickly.

Bernice Pescosolido talked about the issue of impact, that is, do these PSAs change anything? First, I want to look at the issue of penetration. Do people in the world see the PSAs? In response to the video game PSA with two guys on the couch, which was aired nationally, 31% of the population reported seeing it. The good news is that about a year later that sample was still pretty high, about 28%. A quarter of the population seeing something surely shows its wealth and value in terms of affecting a public agenda.

Our other question was whether websites have any value in terms of tracking actual changes in behaviors. There is a set of PSAs that was done several years ago showing different people. Betty is black, Frank is European and Harry is Chinese. There are different ethnic groups and they are all able to work. What do they have in common? They are all mentally ill. This is important because it challenges the underlying stigma, which is the idea that people with mental illness are different than me. Researchers went out and counted how many people went to the website as a result of seeing the PSA. Between time one and time two, when the PSA hit the market and about three months later, they found a pretty significant increase of hits on the website, almost threefold.

That PSA was shown in eight states in the union, to 127 million people. Of those 127 million people, you have a few thousand at the bottom that saw it. The first question is whether that is a cost-effective way to continue to use that PSA. What is even more compelling to me is that, of everybody who went to the websites, 88% left in less than one minute. That phenomenon is probably typical for any type of PSA. Nevertheless, we need to realize that only about 10% of people going to these websites are actually using them.

One of the things discussed today was direct-to-consumer advertising, and people opined that perhaps it has improved attitudes about people with serious mental illness. We did a study about three years ago randomizing people into two groups. One group was a direct-to-consumer advertising for Cymbalta and the other group was a direct-to-consumer advertising for a heart ailment. In both cases, the PSAs were embedded in the clutter of four other commercials. The only thing that differed between the groups was that the PSA pertained to physical versus mental illness. People in the mental illness group showed no change in their attitudes about mental illness or their endorsement of stigma.

I want to address an issue that came up earlier concerning self-help. It seems like

self-help is a great way to go in terms of trying to decrease stigma. I mostly agree with that but I am struck by some perplexing data we found. We were part of an eight state multisite study that SAMHSA-CMHS just put out on consumer operated services. People in the study were randomized to a consumer operated service, self-help, or control group. The mean number of people going to a session was one. People would not go. What is really germane to stigma change in self-help groups is the decision to go in there and make an attempt to change.

The last thing I want to discuss is that I think the best kind of stigma change is targeted locally. PSAs tend to target the overall population. What I think we need to do is narrow the focus down into landlords and teachers. Local might break down to the same branch of service, people of the same ethnicity or same disorder, or we may get more localized by looking at the base in which somebody lives or the regiment to which they are assigned. We also need to look at the issue of distressed people: the depressed employee, the suicidal adolescent, the panicked drug user, and the soldier with PTSD. These are all populations that NIMH and other organizations recognize as important groups.

I have presented a nice balance of the different research we have been doing in terms of analyzing stigma change. I hope today and tomorrow we have an opportunity to talk more about all of these things.

**DR. ESTROFF:** I would like to acknowledge my research assistant for this talk, my brother who was an Army doctor. He retired as a Colonel last year and is now a civilian doctor at Grafenwoehr. There are two things I would like to do today. First, I want to set some common ground in terms of how we understand and deal with stigma and discrimination in general. Second, I want to take some time to talk about several unique challenges.

I want to start with this idea that mental illness is something that we are and not something that we have. I have a quote from Mark Vonnegut's wonderful book, *The Eden Express*: "Most diseases can be separated from one's self and seen as foreign, intruding bodies. Schizophrenia is very poorly behaved in this respect. Colds, ulcers, flu, and cancer are things we get. Schizophrenic is something we are. It affects the things we most identify with making us what we are." We did a longitudinal study on self-labeling as part of a much larger project. We found that it was remarkably unstable and amenable to change. The participants were early in their careers with serious mental illness. We thought that when they started receiving disability payments they would label themselves. Most of them changed their labels from mentally ill to disabled. The process of labeling is dynamic.

A broad review of the anti-stigma strategies out there include human rights and civil rights, the "We're just like everybody else" education that Pat Corrigan just discussed, proximity, or contact, and legislation. The Americans with Disabilities Act (ADA) and the right to treatment are examples of legislation we have tried. One of the questions I always ask my students is "Why did we even need an ADA?" That should tell us a great deal. We need to shift the focus to something like your inability to see my ability is your disability. We also need to challenge what is already established. Only 5% of people who are disabled are in wheelchairs but there is one universal symbol. Why did we adopt that?

The next set of anti-stigma strategies are medicalization, brain disease, empowerment, recognition, self advocacy, and chemical imbalance, which I am delighted to see has a growing consensus that it was a failed strategy. One of the anthems is that stigma is the real disease, not schizophrenia or any other disorder. "I don't want pity, I want rights." This is politicizing rather than pathologizing.

Then we have the issue of the dangerous individual whose rights could be abridged in the safety of the collective, an idea put forth by Foucault. There is a drawing from a Charlotte, NC newspaper displaying a man whose head is a bomb with ‘mental illness’ written on it. The man is holding a gun with the words ‘easy gun access’ written on it. The caption reads “American Suicide Bomber.” What is interesting about this is that it implicates everybody. In addition to the dangerous individual we have this pervasive sense of anxiety out there. So we have these two things, risk and anxiety and the quick cure is a pill, this idea of medicalizing.

Part of the problem has to do with this nonsystem that we have and the idea that you get lost in it, that it is some kind of a maze. Part of the reason I want to raise this notion is that we have to recognize that even though there is a maze, people have some well-founded concerns about seeking services. I do not think this is confined just to the people who might use our services. I have listened to enough of you and I know enough of my clinical colleagues who have serious reservations about the position they get put into in the middle of formularies, regulations and rules.

We are just completing a study in Pittsburgh of people who went to outpatient therapy at a public mental health clinic, and we asked them to tell us what the barriers to engagement were. I think you will see they look pretty familiar: “I’m going crazy. I’m afraid. I do not need it. I am concerned about having to talk about intensely personal topics. I have social anxiety. I do not want meds. Stigma.” We also asked about their apprehensions toward therapy. Responses included: “Nothing has ever helped, I am scared to open up to a therapist, I have loss of privacy worries, I was forced to have an assessment.”

Now I want to talk about the challenges that are somewhat unique. Context is really important. Ron Kessler brought up the idea earlier that maybe after a disaster you could be more normal and you can go get services without being stigmatized. I am reminded of a wonderful book by Lucy Grealy called, *Autobiography of a Face* in which she talks about being facially disfigured. She has a wonderful chapter on how Halloween was her favorite day because she could wear a mask like everybody else.

What is the context? I took the cultural competence test for military culture on a website, which lists the core values of each branch of the military, including loyalty, duty, respect, selfless service, honor, integrity, courage, and commitment. There are three things in particular I want to highlight. The first one is the word “always.” That means no hitches, no down time; you always have to be this way. If you have a setback or things are not going well, that is a problem. The emphasis is on being courageous and faithful and ready at all times. Second, we talked before about this sense of selflessness, of putting others first, something we do not learn about very much in the civilian world except with our immediate families. Third is a question I want to raise. Are mental illness, military service, and treatment autonomy and privacy compatible? Talkot Parsons states that the American Sick Role is that if you want to be legitimately sick, you have an obligation to try to get well and cooperate with others, and you have an obligation to prevent threatened illness when possible. This moral calculus is one of the potholes on the road to prevention. In the service, given those core values and the limited autonomy and privacy, you get caught between those expectations and the symptoms and distress you feel. How do you get out of it?

One of my concerns was the different kind of citizenship you have when you are in the service and the different sense of self you are supposed to have. There is a bill of rights for behavioral health care in the military. It outlines such items as

“individuals should seek and receive behavioral health support to maintain fitness for duty without fear of stigma and discrimination, be taken seriously to receive dignity and respect from leaders, and receive screening and treatment without automatically affecting security clearance solely on the basis of seeking care.” How many people do you think believe that? I think Captain Hammer said earlier that people have to see that this really works for it to be real. Just because it is in the bill of rights does not mean people will believe it.

The commander of Grafenwoehr released a statement after there were about five suicides last year. The statement read, “We need to say it is OK to discuss mental health, and that OK will not disadvantage one’s career.” However, in an article in the Military Times the recommendation was to, “Protect your confidentiality given that there are limits. Read your rights before you seek care. Use hypotheticals or seek help from a civilian mental health care person.” So where is the safe place? Chaplains. That is the only place that confidentiality can be taken seriously, or is inviolate. In that sense I think we have a great deal to overcome.

I want to return to stigma and discrimination. I want to raise other reasons people might avoid seeking care. If I am in the middle of a divorce and a custody battle, the last thing I want to do is see a shrink or get help. There may be rational reasons people do not seek care that we do not think of if we are not in those people’s shoes.

In an attempt to wrap up, I want to point out that we need to stop this process of disablement and enhance recovery. I am currently working on one of the teams that is doing a huge randomized control trial of early intervention, first-episode treatment for schizophrenia. One of our big concerns is avoiding labeling for these young people. However, labels are not all bad. There is a thing called label attachment that we have seen recently with people who have Asperger’s saying, “Don’t take it away. Don’t put us in there with the autism people.” Sometimes people are attached, sometimes not, but we need to watch that process and try to find alternatives.

In the end I have two questions for people to consider. Maybe we are asking the wrong question. Not “Why don’t you get treatment?” but “Why would you?” We know a great deal about people who drop out of treatment, but what about the ones who stay? Maybe we need some information from them beyond demographics. The last question I want to leave you with is one that is of interest to me. I am wondering if there are any changes in stigma about mental health and mental illness related to warriors and soldiers that would generalize to civilians. The thinking is that people in the military are courageous individuals. This is an opportunity for the public to have exposure to people who they honor and see as courageous. Can some of that generalize to people who have not served?

**DR. BORNEMANN:** I am pleased to be on this panel and in the interest of full disclosure I am working with Sue Estroff, Pat Corrigan, Bernice Pescosolido, and others on some anti-stigma work through our venue at the Carter Center. We have been looking at effectiveness of anti-stigma campaigns and the things that work and those that do not.

We have a major anti-stigma effort of our own as well. There is a journalism fellowship program in which we award a one-year fellowship to mainstream journalists and make very few requirements of them. It is not a residential fellowship. It is modestly paid and is awarded competitively. They have to stay in their own venue, their own media form, and then propose a piece of work. They come in at the beginning of their fellowship year and talk to us about what they want to do,

*In the end I have two questions for people to consider. Maybe we are asking the wrong question. Not “Why don’t you get treatment?” but “Why would you?”*

conduct their work during the year, and then come back at the end and show what they have done. We provide a great deal of assistance along the way, a little bit of training in the beginning and a listserv with access to experts and data that can help them work more effectively. We currently have an external review of that program to look at its effectiveness, but so far we have been pleased with and are proud of it.

Bob Ursano asked us to acknowledge the lenses through which we are making our remarks. I will give you several of mine. One is public policy. The recommendations around mitigation that I will talk about will likely have much more of a policy flavor than a clinical flavor because that is what we do at the Carter Center and that is what I have done for the last portion of my career. The second lens through which I am looking involves disaster work that I did for 12 to 14 years of a very different type. That is through the lens of refugee mental health.

We underwent some major migration events during the 1980s, several of which were unplanned and chaotic and caused a tremendous amount of social disruption in certain parts of the country. Some of those who migrated had preexisting mental disorders. Those people taught me a great deal about the kinds of needs that people of other cultures have. Culture was mentioned earlier. I think Paul Hammer was the first one to bring it up. I think culture is vitally important.

The third lens I am looking through is cultures within cultures. I thought about my remarks more from the military standpoint since I am a veteran. As a member of the military, not only do you have thoughts and ideas from the greater culture that we are all part of, but you have a military culture that is very steeped in norms and values. The military culture, unlike other subcultures in our society, talks a great deal about norms and values and reminds the members of that culture that they are expected to live by those norms and values. That sets an expectation that is fairly high. Those of us who are not involved in those types of organizations are not asked on a routine basis to reexamine our values and our adherence to those values. In some ways there is a higher standard.

I want to return to the larger culture for a moment. In working with refugee populations, I realized that my formal education prepared me in no way for that work. All of a sudden we were faced with people from vastly different countries who think about the world very differently than we do, populations that may not have labels for things like depression. Some cultures do not have a word for depression in their language. We initially thought we could take western principles that are very much couched in our own cultures and our own ways of seeing the world and apply them to people of vastly different backgrounds. It was a learning curve for me and my colleagues. It was a very sharp learning curve because as we went to look for knowledge and information to inform our work, there was none. This work generally involves a new migrating group, applying treatment to 15 or 20 people, and reporting on that treatment, and it gets no further than that.

It is difficult to get mainstream refugee research funded. But it taught me the importance of things like community, tribe, and family. Family was vital. When I was trained, family was the potential perpetrator so you had to hold them suspect. In the refugee world, if you do not legitimize yourself with the family and community they will not come. It was important to understand that the role of family is very different than we think about it in most cultures in the world.

What I came to understand, and this is not a criticism, is that we are much more individually focused than most people in the world. America is the outlier in many of the ways we conceptualize care, and the way in which we provide, organize, and

deliver that care is very foreign to most people. We had to learn how to have respect for spirituality, which was trained out of me 40 years ago. “Do not talk about religion or politics.” Well, religion and politics are an important part of people’s lives. We just have to figure out how to do that and do it in a respectful way. Those are some of the lenses through which I make my remarks today.

I saw the Glenn Close PSA that Pat Corrigan talked about. It was sent to us by the group that produced it. When they sent it to us they also sent some trailers. They were not shown publicly, but they were interviews with the participants. They were the most powerful images that you could ever imagine, showing the compassion and the manner in which these families worked things out in such a natural way. If you want to really go after stigma you have got to make it real for people. Most people know somebody with a mental illness, are living with someone with a mental illness, or have a mental illness. If we could get those natural moments out to people, it would have a substantial effect.

Somebody who entered their professional career as an Army medic at the end of the Vietnam War when we were receiving veterans home can tell you it is vastly different now than it was then, and in a good way. We did not do a good job of receiving those people home and we are still experiencing some of the effects of that. I cannot imagine that this type of meeting would have been held in 1971. I applaud the efforts of those who have tried to make a difference by moving these issues out into the sunlight so that we can understand them better and serve these people better on their arrival home.

People are empowered as a group, not just as individuals, in the military environment, which once again speaks to culture. One of the overarching themes in any form of real, legitimate social change is the vital role of leadership. We have learned some other things in terms of mitigating stigma in the military. Soldiers who rate their leaders more highly and report higher unit cohesion are also reported to have lower scores on both stigma and perceived barriers to care. Positive leadership and unit cohesion can reduce perceptions of stigma and barriers to care even after accounting for the relationship between mental health symptoms and outcomes.

One of the areas that I think has unique challenges to the military, and maybe you could add police and firefighters to that, is the career repercussions of seeking care, which Sue Estroff brought up earlier. Everybody recognizes it but I am not sure we operationalize it. What does it mean? There is this career kiss of death for those who seek help. Is it a one-time opportunity and you can either never get rid of it or you can go on to serve? When I was still working in the government we had a big fight with the Central Intelligence Agency (CIA) over security clearances and people who had sought mental health care, even people who had been successfully treated. We did not win that fight back then.

An area of consideration when addressing stigma in military populations and first responders is the public policy angle. Both of the previous speakers talked about this as well. Recently, after decades of struggle, we have ended one of the most obvious structural forms of stigma, which was the lack of insurance parity for the treatment of mental illnesses. Why did that fight go on for so long when the information showed that not only was it the right thing to do but it was the smart thing to do? It was a cost-effective thing to do.

Another sensitive area is illustrated by the example of a veteran, a former Marine, who had suffered tremendous physical injuries but who had a hard time reconciling the fact that he also had PTSD. That raises a very troubling question. We

*I also like the notion that mental illness is something that has happened to me versus who I am.*

certainly have to respect this man's service and sacrifice, but by not acknowledging a mental illness for what it is, are we allowing for structural stigma to continue?

We just launched a new project on scaling up services in a post-conflict environment in Liberia. We took a look at how they deal with stigmatizing conditions other than mental illness. They have reasonably successfully dealt with HIV/AIDS. We went to a village way out in the bush. The form they were using, and this is used in a number of other African countries that I am familiar with, was dramas to resolve social problems that are common in the villages. This is a village with thatched roofs, no floors, no potable water. They did three dramas when I was there. One of them involved a man and a woman, husband and wife, and it was about a rape trauma where the woman was raped multiple times, her husband forced to watch, and they were having ongoing marital problems. They played out this scene in front of the entire village from small children to older adults. At the end they had a conversation about how it went for the husband and the wife. I thought, "Wow. That is powerful stuff." I would love to see somebody take a look at that and evaluate it for its overall effectiveness.

I will close with this. I took a look at the Department of Defense (DoD) Task Force on Mental Health Final Report and Recommendations. There is a recommendation about the operationalizing of career effect. They recommended such things as integrating mental health providers in primary care settings, embedding psychological health workers throughout the outfits and units, including deployed units. This is a great idea and I think it is already happening.

The task force recommends developing DoD-wide curricula for psychological health as an integral part of all levels of leadership training for family members and all medical staff and mental health personnel. This too is a great idea. Thank you all and I look forward to the discussion.

**DR. HOGE:** I liked Dr. Estroff's comments using the term 'fault.' For combat veterans there exists sensitivity to judgment, guilt about things that happened over which they had absolutely no control. There is in fact, the illusion of choice projected backwards in time. Our brilliant cortex has the capacity to project back in time to see other alternatives that appear to have been there at the time but really were not.

This idea gets into fundamental concepts of how our society perceives blame, fault, accountability, and responsibility. We are a society that is quick to blame and find fault with individuals. I am not talking from a legal perspective but from a societal perspective. "It is your fault" implies that there is something personally wrong with you, and that is the way a soldier who has come back from combat interprets it: "There is something wrong with me, or people are saying there is something wrong with me." I hope at some point in evolution there will be a shift toward the concept of responsibility and accountability and away from fault and blame, recognition that in virtually every situation people find themselves, they do not have the choices that they project back in time. That does not mean they are not accountable and responsible for what happens because they were there. But they do not necessarily have a choice in the way that we project onto them with the concepts of blame and fault.

**DR. BELL:** A while ago I decided that I would be responsible for my mistakes. I would not be condemned by them. I struggle with the internet because I think having mental health information there is a good thing, but there is so much misinformation there too. I do not know quite how we send people to the right sources.

I also like the notion that mental illness is something that has happened to me

versus who I am. I remember what a woman who had been raped said to me as I was apologizing to her for manhood. She said, “That which happened to me does not define who I am.” If people can make that subtle distinction it is much easier to do some things.

But I guess I also struggle with people’s level of understanding and how able they are to differentiate these subtle differences. Someone said they were impressed with the American public’s intelligence. I am not one of those people.

**DR. PESCOSOLIDO:** No, I think that sometimes researchers go into research thinking, “These people will not do this because they are stupid” or “These people will not understand what I am saying.” I do not think that is true. People believe what they believe and we may think what they believe is stupid, but I do not think that they are unable to answer the questions that we ask or the things we want to know about.

**DR. HOBFOLL:** I have several thoughts. One, it has been discussed a number of times that, if you had the data, you would do it differently. I think that is in part true. For example, our surgeons ignore psychological stuff entirely except for the transplant surgeons because they get certified. If you fall below a certain level you lose certification so all transplant teams have psychologists on them who they listen to carefully.

**DR. ZATZICK:** Dr. Hobfoll, I have to take issue with that. The American College of Surgeons, for the first time in any general medical setting, has mandated brief motivational interviewing as part of trauma center accreditation. Just like there has to be a trauma surgeon in house 24 hours, you have to have somebody who is available to deliver motivational interviews.

**DR. HOBFOLL:** But every transplant team already has a psychologist involved with them. The second part is that men are generally more resistant to this than are women. I would say that for military commanders, if 20% of people are coming up with PTSD, it is deeply affecting those combatants’ ability to behave in the field. If you look at the data it would have to be obvious and devastating. So, there is something about the resistance to facts that is underlying much of this.

**DR. HAMMER:** I wanted to comment on Dr. Corrigan’s point regarding the effectiveness of contact. There is a program in San Diego called *Kids Included Together*, which encourages kids with disabilities to be included in after school and summer recreation programs. They implemented this in order to help benefit the kids that have the disabilities, but what they found was a concurrent benefit with the kids without disabilities who became much more tolerant, more effective, and more engaged with the kids with disabilities. The benefit was on both sides.

*Kids Included Together* counselors come to the YMCA and summer camp programs, and their mission is to provide the training to the counselors in order to help them know what to do with kids in wheelchairs and children with autism. It is an interesting model that might be useful. They may be further ahead in the anti-stigma campaign for children with disabilities than we are for mental health.

**DR. BATTEN:** *Theater of War* is a project that several of us jointly in the Department of Defense have been spearheading over the past couple of years. Chuck Engel piloted it, but now we have a large contract across the DoD. In *Theater of War* we are presenting two of the works of Sophocles, an ancient Greek general who wrote several of his plays about the experience of warriors and their families. There is a translator from New York, Brian Doerries, who translated the ancient Greek text of two plays, Ajax and Philoctetes, looking at different aspects of the effect of war



on warriors and their families. One deals with suicide. One deals with a warrior who is left behind by his unit and how that affects not just him but also his fellow service members. We have been taking this around the country and we are hoping to take it around the world. We have amazing actors who perform the readings of the plays. They are not staged. There is nothing fancy about it. It is just the words and the performance. It is like the approach of using drama as a method of getting communities to talk and to be able to talk openly about these issues.

Following the play there is typically a panel of individuals up on the stage to get the conversation going. Then we open it up so that the audience, and these are usually service members, family members, sometimes doctors, chaplains, and other professionals, can share how this relates to their experience. It is an innovative and powerful technique. You can learn more about it at Theaterofwar.com or Google Philoctetes project.

**DR. ENGEL:** One fundamental view I have that makes *Theater of War* important is that, although there is a large proportion of people in the military who are not seeking care, many of those people do believe that they have a problem. It leads me to think that we must not be offering the right thing for them to engage. What we currently have to offer is either a pill that affects your brain in some fashion or talking to a stranger about intimate things. That does not appeal to a large portion of people. I like Charles Hoge's view that you wonder who is crazy sometimes.

Perhaps we should reformulate the way we are thinking and try to offer things that work that are outside the box. Sometimes we do not know if these things will work. Certainly *Theater of War* is among those. But, anecdotally, as we go around the United States with *Theater of War* we see communities engaged, we see people respond. It creates a teachable moment where you can provide literature about where they can go for care. Often it is not the people who have issues that are the ones most affected by this. It is the ones who have a loved one at home or in their neighborhood who they know needs some assistance. They are able to learn ways that they can help them. I also think that these are ways that we can reach a larger proportion of people who have needs. When we do not know what the therapeutic effects of these things are, I think we are obligated to study them further. We have to expand our notion of what is therapeutic.

**DR. HOLLOWAY:** Charles Hoge commented on the blame culture. I want to raise the issue that such cognitive activity, along with its overall accompanying emotional consequences, is frequently supported by society as a delusion that we really do have control in these circumstances. One of the large delusions is that when you enter into these deadly quarrels, in which people are actively killing each other in a chaotic and violent environment, certain things can be done and that they will come out in a fixed way. We have seen people plan wars with those assumptions with some disastrous results. The consequence for the individual is to carry the blame and guilt in the psychotherapeutic range. My point is that social structure and cultural assumptions sometimes operate to produce what is in fact undistinguishable from delusional thinking. Nonetheless, it is very hard to get people to give that up because it allows them to avoid the thing that people said made them so anxious: uncertainty about the future.

**DR. URSANO:** This addresses some of the comments Bruce Link and Bernice Pescosolido were making about what motivates stigmatizing and, in this case, what motivates is for the larger society to have a sense of control over a series of events.

## OPTIMIZING ACCESS TO CARE

*C. Hendricks Brown, Ph.D.*

*Wendi Cross, Ph.D.*

*Doug Zatzick, M.D.*

**DR. URSANO:** Our next panel includes the premiere health services and implementation people, Hendricks Brown from the University of Miami, Wendi Cross, the University of Rochester, and Doug Zatzick, University of Washington.

**DR. BROWN:** I really appreciate being invited to join this group. I am going to talk about some of the work that I am doing with my colleague Peter Wyman and other people in the Prevention Science and Methodology Group (PSMG). The PSMG group has been funded by NIMH and NIDA for 22 years to look at the integration of scientific work around prevention science and the methodology that goes with that. Wendi Cross, presenting right after me, is one of the other members of the PSMG group. I do not work with the military or disasters. But I think that some of the work that has been going on in suicide prevention may be relevant here so that is what I would like to share with you.

The first thing I would like to do is ask two questions and have you raise your hand if you agree. How many people have heard the statement that, “The path to Heaven is paved by good intentions?” About a third or so. How many people have heard the statement, “The path to Hell is paved by good intentions?” Which is right? It is definitely a cultural thing.

**DR. ENGEL:** I find “no good deed goes unpunished” is probably more accurate than either of those.

**DR. BROWN:** Right. I think 100% of the people would agree with that. The reason why I raise that question here is because I think the field that we are in—that of delivering effective programs to people in need at the appropriate time—requires more than just good intentions. Most of what we have done so far in this field has been coming up with good ideas, but we do not have a system yet to carefully evaluate whether programs will work and what kinds of policies and programs need to be put together as we move forward. Suicide is an interesting project and test case because a great deal of the research in suicide is behind the times in terms of understanding outcomes, particularly for youth, compared to other outcomes that we deal with such as drug abuse, depression, etc.

As I start to talk about this, I will talk about what kinds of scientific paradigms

might make sense and how we are going to learn anything about this field in very complex settings such as the Army, and in disasters; settings in which we normally would not think of bringing to bear the strongest scientific methods. My suggestion is that we should pause to consider using some of the traditional experimental and non-experimental methods in our adaptation so that we can provide the most useful information on care in wars and disasters.

The goal here is to provide generalized knowledge. I recall going to the World Federation for Mental Health meeting a number of years ago; people were there from Bosnia at the time that the war was going on. We have talked about the same kind of theme. Unfortunately, these disasters are going to be continuing and we need generalizable knowledge about what works and under what conditions. Particularly in the field of suicide prevention, we are facing very important struggles. I think that a number of the programs have at least the potential for doing harm. It is important to recognize that these programs might have negative impact on some individuals, and we should be very, very careful when looking at that.

The most powerful scientific design we have is the randomized trial, so I will discuss ways that we have been able to do this in the suicide field as we move forward with a broader based understanding of what these programs are actually doing. Do studies have the right mechanisms and effective mediators as we expect them to? There are two suicide prevention trials, one called the Georgia Gatekeeper Trial and the other one, the Sources of Strength Trial, both of which Peter Wyman and I have been working on for a number of years.

I am going to talk about issues of optimal care. The first thing that came up earlier today is, “What if there is no optimal care, what if it does not exist?” What do you do? When is any formal care virtually unavailable? I will describe the Sources of Strength Trial. There is data that talk about levels of youth suicide between ages 15 to 19. I do not know if people really are aware of this, but there is certainly a strong relationship between the levels of urban/rural suicide rates for youth, particularly in the west. These are frontier areas, and if you actually go out west, you will see that the environments there are dramatically different from many of the other environments that we ordinarily study in urban settings and other places.

Just as one indication of that, when a principal in some of the plains states gets a notification that a kid is suicidal, they cannot use their own cell phone to talk to the mental health counselors. The reason is because in some rural areas people go to Radio Shack and buy a little device that allows them to listen in on other people’s cell phone calls as entertainment. So what we take for granted here in a different environment may not be the same in other places. Issues of rural and underserved areas are a critically important piece where the mental health systems are virtually unavailable. The question is what we should be able to do under those settings.

There are three general kinds of approaches to handling those exposed to war and natural disasters or terrorism when expert care is not currently available. One strategy is to increase system preparedness. Wendi Cross has been working on an evaluation of a rollout trial for testing the suicide hotline to see whether the new assist program being used in a multilevel training model is going to be effective in identifying those who are suicidal and getting them help. The other two approaches are built on a public health model. To build positive supports of resilience, we need to be close to the time of risk when people might need it most, as opposed to jumping to put people into a care system which might not exist.

The second approach is to intervene early on by looking at targeted antecedent

risk factors for suicide. One name used is developmental epidemiology. Another, used in cardiovascular disease, is called primordial prevention. It is a simple idea: if you want to prevent heart disease, diet and exercise is really good. But you might want to do that early on, when kids are young enough to develop those habits rather than wait until they are 55 years old and settled in their ways.

For multiple levels of intervention, I am going to discuss Sources of Strength, which is one of the interventions that we found in North Dakota that Mark LoMurray has done. We have been in the process of testing through a number of randomized trials. It really has a comprehensive resilience model. Access to mental health and medical systems is one of several components. It also includes spirituality, generosity, etc.—the things that appeal to the broadest number of kids. We have a model and 20 years of research looking at preventive interventions that target issues for kids: depression, drug abuse, family conflict, child abuse, and conduct disorder. We have many interventions that are effective on those kinds of things. So the question is, if we could affect those things in the beginning, can we affect the long-term outcomes of suicide as well? The possibility is there, although being able to evaluate them in a very careful manner is difficult because of the relatively low rates of suicide.

To give you an example of the developmental epidemiology approach to target early risk factors, there are data from an intervention done on first graders. A study did a randomized intervention on first graders called the Good Behavior Game. It looked developmentally at how long effects lasted to age 25. Lifetime rates in the standard setting were over 20%; in the Good Behavior Game, it was down to less than 10%. These can be very powerful approaches, and we have not even scratched the surface of examining what their long-term effects will be.

I will switch now to an intervention that is targeted more directly at the time of the needs that are available, and looking at those who are at risk for suicide. What we are calling a “rollout trial” has a more technical name, Dynamic Wait-Listed Design. There are ways of doing this systematically in community settings with appropriate partnerships. This is an efficient way to provide training, and is what the military does. They efficiently train a large number of communities and get a very high fidelity of that training. Another asset is that it has many nice statistical properties, including an improved statistical power over traditional wait list designs. The Dynamic Wait-Listed Design also improves the modeling and models for causality as well. We have been promoting this as a design strategy that might fit in some kinds of research questions.

The first trial was a gatekeeper training trial that focused on training all adults in schools. The goal of this was to identify and refer those at risk of suicide for treatment. The trial took place in a county that had an active mental health coalition and organization that could be marshaled. The question is, if the schools could identify those at risk for life threatening behavior, could they actually refer those kids more effectively through a training program for gatekeepers? Gatekeeper training is probably the single leading model for youth suicide prevention, as well as the most common one. The target is the intervention. Training is only at the level of the adult gatekeepers.

I will emphasize three things here. One is suicidal youth. We know from other data that almost all suicidal youth tell somebody in their networks that they are suicidal, that they are ready to end their life. They give many suicide warning signs that are just not picked up very often. This model trains gatekeepers to read warn-

ing signs more effectively. It also trains them to directly ask kids whether they are suicidal, and then gives them a way to provide those kids direct links to existing mental health services. That is the model. Does anybody think it is workable? This is the model we are trying to use.

**DR. ZATZICK:** There is a provider level denominator and it might take a very sophisticated provider. I would be interested in what the aptitudes were of the population of providers in training, the providers being the gatekeepers.

**DR. BROWN:** There are some differences at the gatekeeper level. There is an idea that we have been calling a “surveillance model” and it does have the potential of having an effect. In this school district about 8% of kids who reported that they had a suicide attempt this last year were known to the school. If you were able to improve the ability to recognize suicide warning signs and to marshal each person’s ability by a very small amount, you might have a better effect, particularly with a large number of staff in the school. Instead of 8% you could potentially identify 40 % prior to attempt.

We conducted a randomized trial called QPR in a large school district that had already decided they were going to implement the training and we simply stepped in with the support of NIMH and then later with SAMSHA funding to do this randomized trial in all 32 middle and high schools that were available. The school district was extremely well organized. The Mental Health Coalition was also very organized. This is not a disaster model at all. The only two schools that had a suicide occur during the previous year were already trained prior to the trial because the school felt that something needed to be done. If there was a suicide that actually occurred in this school, instead of stopping the study, we were allowed to continue. That was because this school district had an average of four suicides per year. It had 50,000 individuals, not very much above the national average.

When we initially were funded we did not have this technical paper regarding what kind of evaluation opportunities that the dynamic waitlist or rollout design offered, so we came in with a standard waitlist randomized design. Sixteen schools were trained early on; sixteen schools were trained later on. Everybody in the school district was required to get training. What we found was that asking 32 schools to get trained is like herding cats. It took a long time to do. We realized that what we really need to do from a logistics point of view is to focus on smaller numbers of groups at the same time.

We locked on four schools at one time and said, “We want to get you trained this month and then we will evaluate you,” and then we would go to the next set of schools, and then the next set of schools, and so on. We switched to this rollout design so that eventually everybody got trained on the schedule we had intended but in a much more systematic way. That is what the idea of rollout design is. Logistically, the design actually increased the proportion trained in schools. It took much less time to do and it increased the statistical power as well.

We did two-year evaluations from the perspective of those who were trained. We had strong increases over a two-year period of knowledge of warning signs. We also had some very strong effects in shifting attitudes. People were definitely willing to take on gatekeeper roles. Self reported intervention behaviors were examined. When asked, “Did you ask a student about suicide?” they replied, “Yes, a little bit, but not very much.” The training effects and benefits of getting to those students who were suicidal only occurred in about 14% of the staff who were already engaged with students. Wendi Cross has done a great deal of work on identifying

those characteristics of who might benefit and who might not benefit from an intervention like this.

Another thing we did was ask the students, “Did you have a suicide attempt this past year?” and inquired what their likelihood was that if they were overwhelmed by life they would talk to an adult, either counselor or a friend. There were huge differences found. Referrals for life threatening behavior had overall a very small effect, and were significantly positive in middle schools in the direction we wanted, though the effect was nowhere near as large as we had anticipated or thought it might be. Eventually what was happening in the high schools was that the referrals actually decreased.

The referrals also went down immediately upon training, so this is an unworkable model. Particularly in high schools the referrals do not work as an effective method. Effects only increased when most of the adults in the school had completed training. A conclusion from this study is that youth who are at the highest risk for suicide are the least likely to talk to adults. This is an intervention for adults to try to reach out to kids who are not going to reach out on their own, and it just does not seem like a very sensible model. So we did a second trial. We are in the process of doing this with 18 schools. There is a focus now on giving the peer leaders in schools a major role in shifting the norms about suicide and getting kids connected with trusted adults. We also note that the mental health services themselves are not always going to be available in some areas, such as in the plains states.

We also looked at a social network model that involved many adults who are connected to highly connected youth—the peer leaders. The peer leaders are connected to others. We have a systematic way to collect peer leaders from almost every kind of clique we could possibly find, to break down these codes of silence with a training program for the peer leaders. We would then use the peer leaders to give messages of hope and support to those kids who are suicidal. The key pieces are to connect up those peers and use them to connect up the other kids with trusted adults. There are a great deal of other media and new kinds of messages that are also out there.

I will go back to the Sources of Strength. Mark LoMurray, who developed this intervention, has a message that he gives to both the adults and kids. He asks, “Supposing you are a parent and you have a suicidal kid, do you believe if you pray to God that this kid is going to get better?” Spirituality can be extraordinarily important, but it is dangerous if you are only turning to that and leaving other resources out. The same applies to using only mental health services. Activating other methods is important, particularly in areas where we do not have very many formal health systems available.

Our focus is looking at creating youth/adult partnerships to break down the code of silence. These things are measurable. This is looking at the complements that could happen within this social network. Both in Sources of Strength and gatekeeper training, interventions are aimed at making these social links occur. We did this in 18 schools with a randomized design. We identified the peer leaders the same way for all the different schools. Some schools were randomly selected after that point to receive the intervention that first semester. We have baseline and six-month data, and this will be coming out in the *American Journal of Public Health*. The help-seeking norms of the peer leaders dramatically changed. We found effects at the student population level, which is what we really needed to achieve increased help for suicidal peers and help seeking from adults.

It is important to start obtaining generalized knowledge during these unusual experiences where we are not typically using carefully designed randomized trials. What that is going to require is institutional partnerships with advanced directives. Otherwise, we are going to be doing passive studies and making the same mistakes each time. I think there is a good opportunity to design randomized trials in disaster settings. I understand with suicide that a standard control group is next to impossible to do; thus, the rollout design is a useful design. The last point I want to make is that these broad-based interventions have differential impact as a function of social networking. If we do not take that into account when designing and measuring interventions, we probably will not be successful.

**DR. CROSS:** I am going to focus on this pragmatic topic of training and the transfer of training. I hope it has some relevance for what you are all thinking about tonight and tomorrow. Why should we focus on training? This was brought up earlier today. The issue of stigma and disparities in care is a workforce education and development issue. It is an issue in a couple of ways. One is to develop competencies among the providers. Another, which a couple of us were talking about earlier today, is the issue of stigma within our own behavioral network, even in our own workforce.

But what I will focus on today is the first issue, the well documented gap between programs that are shown to be efficacious and how they function in usual care. People are talking a great deal today about evidence-based practices. Those practices, those programs, those procedures, big or small, were developed in one setting and proven to be effective in that setting. Then, when we take them to communities we find them to be not as effective. One of the reasons for that gap is due in part to failures in training practices.

My main point today is that a program cannot be more effective than the person delivering it. Once you choose your program, you need to plan the implementation. The implementation can be measured on at least two levels. One is at the macro program/intervention level and the other is at the implementer/provider level. This is the level that I am most interested in talking about today. It is as if there is a black box. The black box exists between the intervention that you are going to roll out, and the outcomes that you are expecting. There are a number of efforts and activities going on between the choice of the intervention and the outcomes, including training interventionists. They occur in this “black box” of implementation.

Once you have chosen your intervention, you are going to “let your training begin.” Here is a cartoon that shows someone who has just come back from training. He says, “I have this really big binder. The training has already been forgotten, but the binder will last forever. It is a living monument to temporary knowledge.” Not exactly what we want to hear, right? Now, this person who attended the training was probably very satisfied with the training. One thing we know, however, is that satisfaction is not related to learning outcomes. Satisfaction is the one variable that everybody measures though. Whether you are in business or education or mental health, we want to know if people liked the training. Their responses will likely inform our training design. But, satisfaction does not tell us if participants learned from the training or if they will carry that new learning into practice.

I am going to build a model of training and transfer of training that occurs in the black box previously mentioned. One way to think about the model is in terms of phases starting with pre-training characteristics or variables, the training event itself

with its learning outcomes, the transfer of that training — meaning, to the setting it is supposed to be implemented, and then finally the clinical outcomes.

Variables at the pre-training level phase include things like the program components, the curriculum, and manuals. What about the training modality? That is a pre-training variable. Is it conducted face to face? What about the move toward online training? Wouldn't it be interesting to put these modalities head to head in studies of training? Other pre-training variables are the trainer and trainee characteristics. Hendricks Brown mentioned something about this. There are studies that have looked at individual training characteristics, and we have examined some of these characteristics in our studies as well. It turns out that if somebody already had similar training, they show better learning outcomes than those who are new to the training. The question of trainee selection challenges our typical “one-size-fits-all” approach to many of our training programs.

We have conducted studies that have examined training modalities. One study examined a program that Hendricks discussed, the QPR program, which is primarily a “passive learning” approach in the form of lecture. We wanted to do a training study and thought that if we are looking for behavior change as a learning outcome, why do we not put behavior into the training? We randomly assigned people to two conditions, either training as usual — which is a knowledge transfer type of training using a lecture like I am doing right now — or training with a low-tech, behavioral rehearsal condition within small groups. We used standardized patients, actors actually, to test trainee gatekeeper skills. I will present our findings in just a minute. The other training modality that we have examined in two studies is the train-the-trainer model. It is very popular and considered to be very efficient. Here is an example of how a train-the-trainer program can be efficient. First, you have master trainers who deliver the training to people who come to be trained, and here are all those new instructors delivering the training to many other people, who then go on to deliver the intervention in practice to many, many target individuals. Exponential growth!

I said that I would mention two train-the-trainer studies. One was a naturalistic study of a disaster mental health training program. We followed the dissemination process for a year to assess “spread”: Does the train-the-trainer model actually spread the way it is intended? That is, do new instructors go on to train others as intended? The other study is a suicide hotline prevention study. In this case, we are conducting observational coding of the newly trained trainers to look at “quality” to answer the question: If you could get 100% of the people to conduct the training with the next generation in the train-the-trainer model, how well do they deliver it? These are the types of questions you might pose about pre-training characteristics and variables.

Moving on in the model to the training event, we can measure learning outcomes such as knowledge, attitude, and skills. Often, people assess confidence or self-efficacy as a measure of attitudes. In terms of popularity, after satisfaction, the most frequently measured learning outcome is pre-post knowledge change. Change in knowledge is considered to be necessary for change in behavior, but the literature shows that improved knowledge is not sufficient for changes in most behaviors. There is a relationship between enhanced attitudes and skill development, therefore it would be good to measure attitude change — it might predict behavior change. We demonstrated the same learning outcomes with the QPR program as Hendricks Brown did in a different school setting. We found that both parents and teachers had the same change in knowledge about suicide and suicide prevention and the change



was maintained at follow-up. As an aside, we were happy to see, and the school district was too, that the mental health professionals demonstrated high levels of knowledge about suicide prior to training.

In terms of confidence, our attitude measure, there was also a positive change from pre-training to post-training for parents and teachers. They maintained their enhanced attitudes about intervening with distressed kids at follow-up, which was nice to see. As I noted, we had a condition where we provided the opportunity for brief behavioral rehearsal to compare to the training as usual. We found that this small group practice resulted in better gatekeeper skills demonstrated during an interaction with “standardized patient” actors. We measured skills using objective, observational coding of the videotaped interaction.

The difference between that group and the group that received the “passive learning” training-as-usual was maintained at follow-up, but both groups showed decay in skills over time. At three months they were both losing their gatekeeper skills. The question becomes, how might you keep those skills at a high level? These parents and teachers were probably not using gatekeeper skills very often, and decay would be expected. But is it possible that there are ways to keep the skills “at the ready?” We think that using technology may a good way to maintain established skills over time.

Another way to keep skills at a high level is through feedback. We did not give any feedback to participants while they were doing the behavioral rehearsal in this study, but studies show that feedback can be important if you want to achieve a complex skill. Some studies look at how much feedback supervisors should be giving on specific skills. If you want to see results in terms of behavior change and skill development, you likely need to monitor and give feedback for maintenance. Sometimes people think that our providers, or parents, first line workers or outreach people are not going to want feedback. Yet it turned out in our study, with teachers and parents, that 100% did want the feedback that we offered them after the final assessment with the “standardized patient” actor. We were surprised. Then, at the one-year or two-year mark, we did a follow-up survey and asked, “Remember that feedback we gave you about your skills with the actor? How did you feel about that?” Eighty-eight percent of participants thought it was important to receive feedback, and many wished we had provided it earlier. They also seemed to feel that it had some influence on how they behaved later.

One way we measure skill as a “learning outcome,” at least in our field, is in terms of adherence to the program and competence in delivery. If you are measuring a program’s outcomes, you want to know that the program being tested is actually what was delivered, and how well it was delivered. We do a great deal of observational measurement work to answer these questions. Some people use self reports, which are very common and pretty easy to do, but have questionable reliability and validity from our perspective. There have been some observational rating scales that have been developed for the treatment literature and we have developed measures for our school-based prevention program, Rochester Resilience Project, as well.

The PI on this randomized control trial is Peter Wyman. Here is another example where we are looking at provider skills in program delivery. The providers in the Resilience Project are school aides trained to deliver a manualized intervention to at-risk elementary children in schools. We trained the providers and videotaped their program delivery with the kids. Then, we objectively scored their behavior with the children in two ways. First, we coded adherence: Did they deliver the content they

were supposed to in accordance with the manual or did they do something else? Second, we coded their competence, which included items about timing, empathy, and use of active learning techniques, which are very important in our program.

Let me show you why we look at both of these aspects of implementer behavior. Here we have two interventionists; we call our implementers “Resilience Mentors.” In this example, we have coded two Mentors delivering the same session to two different children. They had the same amount of experience delivering the program, by the way. So, as you can see, they each score the same in terms of adherence to the manual — they are each delivering a little over 80% of that session as written. But, as you can see, they do not have an equal level of competence. They scored very differently on this measure: One scored very high and the other quite low in terms of objectively measured competencies such as empathy, pacing, and actively engaging children in learning. We think this discrepancy — between adherence and competence — will likely have some implications for outcomes. This is an important way to start thinking about how people are actually delivering the manualized program, because our conclusions might not be valid if the program is not being delivered in the way that we think it should be. It would not be a true test of the intervention.

The transfer of training phase of the model is often where implementation breaks down for many of the reasons that have already been brought up today. Recall our train-the-trainer model in the disaster mental health program. The question was, did these newly trained instructors go out and conduct trainings for others as expected by the model? How many newly trained instructors went on to train others? In the 12 month timeline that we followed dissemination, 60% trained at least one other person. That means, though, that 40% did not. We are not sure how to think about this finding because not many people have done this kind of work. Is this cost-effective? Perhaps. But, let us assume that we could get 100% of the people to carry out the training with others. Wouldn't we want to know about the quality of the training they conducted? We are looking at this quality question with Madelyn Gould at Columbia University in a randomized control trial using the dynamic waitlist design model that Hendricks described earlier. As I mentioned, the targets for this training are crisis hotline counselors. Centers chose individuals to be trained in the program who, in turn, trained hotline counselors. We videotaped the newly trained instructors delivering the training to their counselors, and we are now coding their delivery to assess how closely they follow the manual — adherence. We are also measuring how competent they are at delivering the training. This is a group-based training program which requires certain group facilitation skills, for example. So, we are coding those competencies. The final outcome is how the counselors interact with suicidal callers and if the training program influenced them. The team is measuring this by monitoring calls. We do not have data on this study. We think the findings will be very helpful to our understanding of the cost-effectiveness of train-the-trainer models.

The model shows two other variables that can contribute to breakdown of a program's effectiveness in communities. One is the population. If a program was developed with middle class, white children in a certain community, the evidence base that is cited for that program is based on this population. When you take the program to an inner-city community, such as downtown Rochester for example, where there might be up to 70% African American and 30% Hispanic children living in very different circumstances, program adaptation by providers may occur. Then finally, we have been talking a great deal about this today, the context for the

transfer of the training is also important. When you come back from your training, are you able to apply what was learned? It may depend on support in the workplace, resources, technology, time or other organizational factors.

I would now like to summarize some highlights of this training model that exists in that black box of implementation: Satisfaction is not related to learning outcomes but is a good thing to measure to inform your training design. A lecture is not likely to help with behavior change and individual characteristics but may matter in some programs. Practice is important for skill development. Skills can be operationalized and studied. Expert guidance and feedback must be ongoing for complex skills to be maintained. Train-the-trainer models may spread a program but we need to learn much more about the quality and the quantity of the dissemination process. Consideration of these factors, this model, is all in the service of training interventionists to do a better job with people who need access to effective interventions in the real world.

**DR. ZATZICK:** I would like to start inductively from a case study and look at it historically or developmentally. I will start in the fall of 2001 when Chuck Engel gave me a call. The Pentagon attack had happened and Chuck was setting up Operation Solace, which was placing care managers in the primary care medical clinics that surrounded the Pentagon, one in each of 10 clinics. From Seattle I was providing telephone care management in our acute care setting, in our trauma center. It was a similar sort of acute trauma intervention with care managers that would go into orthopedic clinics or meet people in primary care and check in with them and try and get them into evidence-based PTSD care ultimately after meeting them, accessing them in their primary point of care and engaging them.

We had an individual who had worked his way up the Pentagon and had been deployed multiple times as part of the Special Forces. He had tremendous exposures prior to the Pentagon attack. He suffered a smoke inhalation injury and had pneumonia but had also witnessed a number of colleagues being wounded and a couple actually dying. He was coming into this primary care clinic ostensibly to get antibiotics for his pneumonia.

His primary care doctor quickly noted that this guy was having problems. He could not sleep due to his lung problem, so he was assigned to one of the care managers in the clinic, who did a fantastic job of engaging him around his primary concern. As the weeks went on it turned out that not only could he not sleep, but during the day he was consumed by memories. He was having nightmares and was ashamed of this. He had been a tough guy, Special Forces, and there was stigma around the revelation of his difficulties with the trauma.

So what are the principles in this case? One is access. This individual is being met at the primary point of care. Hendricks and Wendi talked about delivering these interventions in non-specialty settings. Schools, primary care, forward field stations, disaster mental health tents. That is often where these early post-trauma interventions occur. This is about access and being in the field. The first issue that comes up then as we move out of the mental health specialty sector is the development of evidence-based PTSD interventions from special mental health. There is going to be a fundamental question, an extensive complicated CBT protocol that takes 12 sessions in an outpatient clinic. What is that going to look like in a primary care setting or post-disaster field setting?

The modification, the initial kind of issue we have around the table, is that we have services researchers in these funky settings and we have interventions that were

developed in specialty mental health. We need to know how that is going to come together because we want to hold on to our evidence base. We do not want to throw out those years and important efficacy trials.

The second principle, as we are building on access and meeting people where they are coming to care, is engagement. For engagement I am going to try and bring together two intellectual persons. We have had some wonderful talks by Sue Estroff and other sociologists. Once upon a time I aspired to be an anthropologist, but was not smart enough, so I went into medicine. I followed Arthur Kleinman's work. Much of the collaborative care model is founded in the illness perspective and meeting the patient where they are at. Arthur has some fascinating studies of Taiwanese shamans. The shamans have incredible retention rates because you come with any problem and you can lay it out for the shaman and the shaman will deal with it; marital conflict, death of a relative, a trauma. Those are some of the fundamental aspects, actually, of care management. At a population level, if you are going to do population-based medical phenomenology, you are concerned with the needs and concerns of the population.

I will not get too much into Haiti, but I ended up in this mode with a population that has profound religious and spiritual beliefs. I may not be a priest, but someone may come to me and say, "My church is in rubble. My congregation is scattered and I am having trouble praying, which is my primary coping mechanism." I do not know how to deal with that but I certainly can problem solve around, "Can you find your congregation?" I can deal with the general issue; I cannot help with the actual prayer. What we are trying to do is to engage people with whatever needs and concerns they have.

The third principle gets to what Chuck Engel now is doing 10 years later, which is a stepped-care protocol. There is a very strong evidence base for this sort of intervention, in which a care manager engages the patient in primary care and then steps up the care to evidence-based CBT and medication for depression. There is much less of an evidence base in PTSD. It is very hard to field the kind of trial that Art Kleinman did in the Jerusalem trauma study, even in a day-to-day routine trauma center context let alone in the chaos post disaster.

Going back to Kleinman, we have access, we have engagement, and we have stepped care, all basic principles that can be applied across post-disaster settings. Not much of this has been tested and we have STEPS-UP that is leading up to test these principles in a military context. What about stigma? As a frontline hardheaded clinician, the cases we saw post 9/11 made a great deal of sense to me in terms of the stigma of having nightmares, memories, and wanting to be seen in a primary care clinic rather than a mental health specialty clinic. That makes intuitive sense to me. Arthur and Joan Kleinman have written about how suffering can be biomedicalized. If social scientists do not address frontline patient and provider concerns, we can take what is happening in the clinic and make it too much of an abstraction so it is not really relevant and does not get into clinical encounter.

What I think is important is that in these post-disaster contexts, stigma may be important but there may be other concerns or competing demands that come first. Again, we do not have the luxury of doing population-based clinical phenomenological studies with every population. But as front line providers we need to learn to taste what the different issues are and then engage around the key concerns. We are moving inductively from clinical work and case studies, and we are trying to think about theory. I agree with Sue Estroff, who said that theory is really important

within all these domains. We have social epidemiology, we have clinical interventions, and we have sociology and stigma. Where is the meta-theory that helps out in these incredibly challenging contexts? People around the table have talked about context again and again today. Working in a trauma center I can tell you, whichever training mode you have, something is going to come at you that you have not anticipated.

To me, no matter how much I understand stigma as a provider, as an actor, as part of the exposure, I am going to need to be able to think on my feet. This is what I think Charles Hoge is getting at, especially in the military, with regard to training better officers. I am responsible for a group of people at my trauma center. I cannot always anticipate what is going to come up, but I know I am going to have to have a level head. I know also that there will be these intense moral conflicts raised by what I am experiencing and what is in front of me. I think the meta-idea is that, especially in the acute setting, you are going to be faced with these scenarios that you have not anticipated. That is one of the key things to think through and think about. As the provider and in that work unit you have to ensure access.

We debated screening in October 2001, and when Haiti finally turned itself on its head I realized that the whole population was exposed. We ended up with the old Buddhist question, “Who in this room has not suffered loss?” The true answer is no one. We threw the training out after two hours because everybody had lost a close friend or relative. We took the provider self-care portion and put it up front. Simon Wessely and I have debated screening for years, but the reason you would screen in this context is because you are looking for the 5 to 10% of the population that is going to be able to be resilient and carry the organization and the society through really challenging times. It was not screening for disorder, but screening for resilience.

**DR. WESSELY:** That is a completely noble argument that has been never used before and it admittedly defeats all the other ones.

**DR. ZATZICK:** We were doing an organizational training. Many people left, there were aftershocks during the course of the training. But the idea is that the content is so personalized. Everybody there has experienced traumatic grief, everybody is having PTSD symptoms. We are looking for the people who can get through the training and then work within the healthcare organization long-term. That is what we are screening for.

## DAY 1 DISCUSSION

*Robert J. Ursano, M.D.*

**DR. HOBFOLL:** I will discuss Conservation of Resources (COR) theory. In my own theory across all kinds of trauma, a loss of resources, both economic and psychosocial, is the best predictor of outcomes virtually in every test. I know that this is not the only useable theory, but I do think there is a problem going on in academia when we have to reference someone else's theory. There is a great saying that theories are like toothbrushes, no one wants to use someone else's. I would say for stigma, COR theory is not the essential theory by any means. There are other good theories out there.

**DR. ZATZICK:** At ISTSS (International Society for Traumatic Stress Studies) last November Stevan Hobfoll and Sandro Galea and George Bonanno presented some of these theories on resistance and resilience and I raised the question that is still a question to me. Each of these theories has the exposure, and then there are trajectories of resilience or resistance. It seemed like, and George Bonanno even admitted this, when you try to account for recurrent stressful and traumatic life exposures, randomization or cohort definition, the models do not converge. You cannot account for the patterns of psychological resistance and resilience you have not identified. Sandro Galea presented the West Africa study in which people had had on average 11 serious traumatic life events. It could be that the recurrent events are driving the patterns.

**DR. HOBFOLL:** Absolutely. For example, in studies by Moose and Holihan they showed that a resource loss was the full and total mediator of change in depression over a 10-year period in patient populations. Also, even though there are other things going on, it is one of the areas in which you can pick interventions and points to intervene.

**DR. ZATZICK:** We are both interested in malleable factors for intervention but what I am saying is, rather than attribute it to resource loss without addressing recurrent stressors, you can also target interventions towards recurrent stressors.

**DR. RADKE:** There is a critical point here in this discussion. Many of us do not wander too far from our comfort zones. We have agendas and biases that we bring into this room. That is not why I come to these kinds of meetings. I come to these meetings to learn and to be challenged. We get into these battles which do us no good because it does not get us to the gestalt of trying to deal with the stigma and barriers that interfere with whatever theories we have, whatever practice we have.

**DR. URSANO:** You will now have about 30 seconds to think about this. We are going to go around the room and you will be given 10 seconds to say one bullet: something you liked, something you took away, and something you want people to remember for tonight because you are going to talk about it more tomorrow. This is a way to be sure that even those who are silent have an opportunity to educate us.

**DR. DIEBOLD:** I am the psychiatry consultant and I want to complement all the presenters today. What I would encourage the group to do is think about continuity of care with our service members. One of the reasons I bring that up is that I am stationed in Hawaii, where we have a big Guard and Reserve component. Certainly they are faced with many barriers and stigma going from their civilian jobs back into active duty.

We need to keep in mind the family members as well. Again, this was brought up a great deal today but I would hope tomorrow that we talk about, really, what I view as the big picture here, both the continuity of care for service members and not losing contact with the family's needs.

**DR. THOMPSON:** I will say these bullets: recovery, social inclusion, and the health opportunity ladder.

**DR. SANTIAGO:** I am a Navy psychiatrist in the Department of Psychiatry at the Uniformed Services University. In my 10 seconds I would like to throw out there that perhaps society chooses stigma because stigma is cheap, or inexpensive, relative to our other choices.

**DR. BATTEN:** First of all, culture change is hard, and if we are talking about changing stigma, we are talking about changing cultures. I like the idea of focusing resources where we are likely to get more bang for the buck and have longer-term impact with younger generations.

**DR. BORNEMANN:** I would like to do some more thinking about Bernice Pescolido's data. We are doing a great deal of anti-stigma stuff, and I am not confident that much of it is that effective, so I would like to drill down a little deeper on that.

**DR. BELL:** Something we learned from the Institute of Medicine suicide report and Dr. Satcher's youth violence report is that risk factors are not automatically predictive due to protective factors. Also, there is apparently a split in the states about using marijuana to treat PTSD and I think we need to discuss that tomorrow.

**DR. CORRIGAN:** The question I would like to ask is where are the consumers today?

**DR. SHALEV:** I have the perspective of a person responsible for delivery of clinical service. I live in Jerusalem, where for a third of the population, the ultra-Orthodox, just seeing a psychiatrist is a stigma that may affect your family and your reputation. We humbly try to alleviate part of that by making our clinical services effective and known to be effective to that particular community. This is as much as I think that we can do for them.

**DR. RADKE:** Stigma and barriers to care exist because society allows it to exist as an excuse not to do the right thing.

**DR. FLYNN:** I would like us to take what we have heard today and think about making some very specific application recommendations in four domains: clinical, training and education, program design and management, and policy.

**DR. URSANO:** And research.

**DR. HOLLOWAY:** I want to hear one or more definitively named variables, and I want to know what independent variables are likely to influence them.

**DR. BATES:** I am a clinical psychologist with the Resilience and Prevention

Directorate at DCoE. Since I did not speak today, I would like to make two quick points. One is peer-to-peer programs. It seems to me that social support literature is associated with one of the most robust findings for resilience and promise for meaningful effect sizes. Do we know enough about how to leverage them, are we fully leveraging them? The other point comes after hearing Dr. Hoge's remarks. Is there potential in the value of training our younger recruits in dialectical thinking, similar to the serenity prayer, to deal with some of the ambiguities they face later in their development?

**DR. HOWE:** I teach ethics at USUHS. I was struck by the many comments of what does not work in stigma. The challenge is discovering what will work. We have had many suggestions there. There are some that have intrigued me that I would like to pursue. The first one is structural. There were two speakers, one who spoke of the problem of confidentiality being a block, the other one the problem of security clearances. A question, then, is could those be crunched at all and, if so, how?

The second suggestion I would like to pursue is the picture that we saw of Uncle Sam saying, "Your duty is to get mental health care." I would love to see if that picture could be taken further. And finally, Charles Hoge's and Chuck Engel's comments on when the soldier comes in asking what crazy is, which I thought was very profound, provocative, and courageous. It struck to me the importance of validation being a first step toward engaging, and that might be worth pursuing as well.

**DR. BRITT:** I would be interested in further discussing how mental health problems among combat veterans are really seen as occupational hazards that result directly from the work in which they have chosen to participate. Also, what are the implications of this for addressing stigma and reducing stigma through, maybe, novel interventions that take an occupational health approach as opposed to a victim-based approach?

**DR. HOGE:** We are all touched in some way. Mental illness is part of what it means to be human. How we communicate as mental health professionals, implicitly and explicitly, contributes to stigma.

**DR. REISSMAN:** I want to mention a couple things that have not come up yet, and that is the interface between stigma and ethics in public health. There is an area here that has yet to be explored in terms of health protection strategies. In our current national scene the term 'community resiliency' is being used a great deal. Maybe there are ways to look at that in the different work forces you are addressing, whether military or civilian.

**DR. FRIEDMAN:** I just want to remind people that we are having two conversations. We fluctuate back and forth, and they are overlapping. One is at the clinical level where we talk about access to treatment. Then there is the public health discussion, where we are not necessarily talking about symptoms but maybe talking about distress. The outcomes are really very hard to measure for things like prevention or resilience or self-knowledge. To both of those ends, I think we will have to be thinking outside of the box tomorrow because we need to move this forward.

We have technologies available to us; and we have not had much discussion about that. There is the Internet. There is social networking. There is the science of messaging that we do not use very much in mental health. How can we avail ourselves? I know General Sutton has been doing some of that in DCoE and many of the rest of us have been doing that. It seems like the things that really need to be enhanced are social support, whether it is at the unit cohesion level or at the more general public level, and education. So many of the barriers involve lack of knowl-



edge or misunderstandings or stereotypical thinking that is just wrong. There is also leadership and how it manifests itself in the different clinical and public contexts.

**DR. PESCOSOLIDO:** I have two quick points from the micro to the macro. The micro goes to Tom Bornemann: A number of researchers around the room have data; and we would like to know what you would like to see from it that might help you in what you are doing. For the macro, I would like to go to Doug Zatzick's point, what is the model and what is the study that is really going to push our understanding and our ability to change it forward?

**DR. KILPATRICK:** I would like to talk about erectile dysfunction. In a serious way, I think it might be a good metaphor for us because it used to be pretty stigmatizing, but now you cannot watch TV without having people telling you that they have it and are coming forward for treatment. If we can do it for erectile dysfunction, we can do it for mental health problems.

**DR. RUZEK:** One of the things that struck me is the importance of getting to the places and people that individuals do go for help. We know that they do not go to mental health providers. They are seeing and talking with chaplains. They are in primary care. And, for example, in acute trauma they are going through ERs, so there are places where conversations are happening.

Wendi Cross' presentation is a warning sign for that because that means there are huge training needs, and that training is labor intensive. Quite apart from time constraints, there are training and competency factors that are important. The answer to that may be something that Matt Friedman raised, which is technology. I think that web programs and soon to be iPhone apps—those kinds of things—can be put in the hands of those providers. Those technologies will shape what they deliver, perhaps making it easier to accomplish the goal without complex skills-training regimens.

**DR. ARNOLD:** I am from the Graduate School of Nursing at USUHS, Psych/Mental Health Nurse Practitioner Program. I like the contact concept. One of the most impressive things that I saw recently was a one- or two-star general who came to our campus and spoke about the personal impact that mental health had had on him in regards to having a son who committed suicide and having another son who had a traumatic brain injury.

Being able to hear that from somebody at that level is impressive for change. I know the DoD made an announcement two years ago that they want people coming in to get treatment for mental health. It is their duty. But when you think of the number of years prior to then when that was not the case, we are not going to change that overnight. Unless it comes from the top down, we are not going to see that kind of change.

**DR. CREEL:** I am in the Department of Preventive Medicine at USUHS. I want to think tomorrow about identity and social roles and how those play a role, and how we can use them for intervention. Also, efficacy beliefs, both in terms of whether we believe that there is something that can be done for us or for others, and how that plays a role in terms of stigma.

**DR. SCHOR:** I am the Acting Director of the presidentially mandated National Center for Disaster Medicine and Public Health, the purpose of which is to address education and training and competencies in disaster medicine and public health at the domestic level.

I am disliking the word stigma more and liking stigmatizing or stigmatization better because I am thinking that in a couple of interesting ways they are very disparate. There was mention of social networks. We have talked about them as

tools to address this in a good way. I would suggest that social networks are also increasing tools for the bad guys to use stigma against us. I think we have seen some Congressional use of this recently with the stigmatization of voting on National Health Care. I think that was a stigmatization in action. I am sure that folks who live in other countries or are sitting amongst us definitely know that. I see that as a huge national security threat.

Let me take it on a different level. How do you de-medicalize stigma? My experience brings in musculoskeletal injuries and working with the Marine Corps. We do not medicalize injuries. It is for the generals to figure out what the pain needs to be. We were able to de-medicalize injuries in the Marine Corps by using athletic trainers. Those of you that know what athletic trainers do, they do not take people out of the game. They get them back into the game.

From a military, a continuity of operations, a national security or health security standpoint, I wonder, how can we use the athletic trainer model to keep us in the game? Whether it is Haiti or wherever the next disaster or terrorist event might happen, there are two very different bookends that are sort of vibrating around with me.

**DR. HOBFOLL:** To quote Pogo, from whom I learned everything I know, “We have met the enemy and he is us.” We have to look at how as leaders we have not changed training to make a difference. Really the things that we have talked about have been well known for 30, 40 years. The real question is why are we stuck short of implementation and change on these things?

**DR. LINK:** I come here with this interest in stigma and I get to look at it through different lenses and from different angles. One way is thinking about the military culture and also about what is done after disasters or terrorist attacks. One of the things I like about studying this area is that every time you take a different lens, you learn something new. I will say a few of the things that I have learned in listening to the rest of you.

A specific thing I would like somebody to talk about tomorrow, which would have theoretical significance to me, is how stigma lines up with ranks in the military? I have a specific prediction about that from where I sit and I would like to see what others think.

**DR. WESSELY:** What is your prediction?

**DR. LINK:** My prediction in the military would be that the stigma would be strongest higher up.

**DR. ENGEL:** Plus we have more money to go out and buy it ourselves somewhere else.

**DR. WESSELY:** I am the Brit. If I had my time again I would be a historian because historians know that most people have coped with adversity for long before us and without us. There are only a few who do not. Even then I think we have to recognize that at the moment either our products, or perhaps ourselves, still are not that attractive to a large number of people. If only they would come and see us, we can help them, though that really does not seem to be enough.

**DR. ESTROFF:** I am going to fall back on a couple of my favorite old sayings. One is, “not everything that counts can be counted and not everything that we count counts.” That is from Einstein. The other one is, I think, from Will Rogers. I am paraphrasing here that, “It is not what we do not know that is the problem. It is what we think we know that is not so that is the problem.”

Given that, I would like to return to this broader concern of what, if any, collateral repair or damage the entry and openness about stigmatized conditions in

America's heroes will have across the board or not—which way it is going to flow in the broader social sphere.

**DR. ENGEL:** I think this whole notion of stigma is very important. I will establish that right up front. We have to think a great deal about unintended effects. The military, where I lived most of my life, is fundamentally a culture built around collectivism, if you will. It is about small group function to accomplish dangerous tasks. Bruce Link said something about the functions of stigma in some fashion, the idea that stigma reinforces norms, that stigma extrudes, if you will, disease. There are potential ramifications of the idea that we could completely de-stigmatize some of these things. You could have these problems and continue on and make them irrelevant to your ability to stay on in the military.

While we could become more open-minded about our policies, it is going to be awfully tough to completely take that out of the mix. If we do, we may find ourselves in a place that we did not want to be as far as the military goes. By the same token, I think we should be looking for ways to better deliver care. Along the lines of what Simon Wessely said a moment ago, we have to rethink how we consider therapy. We have to think along the lines of what is acceptable to our population. We have to think about choices and we have to think about preferences which, again, we are not accustomed to in the military. We do what we are told.

If we are ever going to reach out to the large fraction of people who do not seek mental health care, I think we have to address the nature of the problem, which is that right now we are pretty limited on what we can offer in terms of acceptability to many of the people we are seeing.

**DR. SLONE:** I work with Matt Friedman at the National Center for PTSD. My role here is a bit different. I am the Associate Director for Information and Communication so I do a great deal of work trying to actually take what we learn from research and get it out to the general public so that it does do some good on the education level.

I want to remind everyone to think outside the box and to remember that this is not just a public health model or a clinical model; there might even be another level in between because the problems are very different. Our thinking about treatment really needs to cover a wide range of areas, not only the public health policy issues or clinical issues, but different things that we do not normally think about such as social media and contacts, and advertising. We cannot just think that one solution is going to fit everything. We need the variety because there are a variety of problems. With policy you need to look at what good you can do for the average person, for the greater sum of people. But interventions for the smaller groups are just as important, and we need to continue to test on those levels as well.

**DR. CROW:** I am the clinical psychology consultant to the Army Surgeon General. I am also Director of the Warrior Resiliency Program which is an Army Medical Command program. Today I heard several references to mental illness in the course of presentations. Sometimes it concerns me when I hear that, particularly if the parameters of the term are not real clear.

I do have a real interest in how we might be able to use concepts and perspectives of resilience and life skills as a way to address problems of living. I get concerned when we talk about de-stigmatizing mental illness or imply that is what we are talking about. It almost seems to require that our beneficiaries by definition have to be sick in order to access our services. I would rather see that we look at ways to make what we have to offer available in a less illness-based kind of a model.

**DR. SUTTON:** It means so much to me and members of my team that each of you would spend this kind of time and this kind of energy to figure this out. Because, as the Secretary of Defense has said, we are truly in uncharted territory going into year number nine of this conflict. What has been said here about needing to look for novel ways to look for paradigms, ways of communicating with this generation, is critical. Some wag once said, “Culture eats strategy for lunch any day.” I would welcome anybody’s thoughts on how we can accelerate relevant cultural change that fits this generation. Keep in mind, our troops today knew our country was at war when they raised their hands and said, “Here I am. Send me.”

That was well before the economic downturn happened. They are a group who do not think of themselves as sick. They prefer to think of themselves as injured. They have been raised and trained to be part of a team. Perhaps that is why the Army slogan “Army of One” was relatively short lived and has now been replaced with “Army Strong.” They develop bonds of trust with their coaches. When that trust is fractured, no good comes out of that. It is a wound that has to be dressed. We have a bit of that going on right now in the three years following the wound that was exposed and endures at Walter Reed.

So I need help from each of you here. How can we help dress that wound of mistrust that still exists, not just between our providers and our public, our leaders and our providers, but within each of us as citizens of this great nation and as global citizens of this very small planet? Someone once said that a wound inflicted is a wound endured. We as a nation have sent our sons and daughters into harm’s way. We have inflicted this wound and together, to heal, we must endure it together. That is going to take time. That is going to take thinking. It is going to take bringing together novel thoughts and novel ideas. It is going to take humility because, I can assure you, not only do we not have all the right answers at this point, I am not sure we have even asked all of the right questions. I would just ask us all to keep asking the right questions, and above all, let us measure whatever success we achieve on this journey through the eyes of our warriors and their loved ones, whom we are so privileged to serve.

**DR. BROWN:** I returned with Wendi Cross and Doug Zatzick and perhaps some others from a conference last week on dissemination and implementation. The thing I would be interested in looking at is how we move from an information production system, which includes things like clinical knowledge as well as some research studies, to a knowledge implementation system where we can actually move practice and policy.

**DR. CROSS:** I would be interested in having people talk a little bit about the difference between the confluences of factors around help-seeking. We talk a great deal about getting people to seek help but I guess I am wondering about the flip side. If you ask somebody if you could help them, would they accept the help? What is the difference between being on each side of that relationship? I am also interested in credible messaging and how that might be helpful.

**DR. ZATZICK:** Disaster and terrorism, clear, simple, eloquent models, ideas that will help me out because I do not know what to do. I have been working with Chuck Engel on his STEPS-UP trial, trying to help him think about returning Central Asian veterans. We need clear, simple, and eloquent ideas to lend these hardheaded clinicians and to help other people implement trials.

**DR. URSANO:** The good news is that we have created a marvelous list. The bad news is that we now all own it, and not just within this meeting. We will clearly only

take a small piece of that which we will ever be able to touch. We have created a list that we all own and that we all have said we wish to address and go after.

I look forward to our discussions tomorrow which will be targeted around the concept of recommendations. It is most helpful for you to let your memory processes think around a clear recommendation, to make two or three sentences of justification that fall into the categories of education, training, research, leadership (policy), and then interventions — clinical and population. I look forward to moving to that level of discussion so that we take our ideas, digest them and come forward with what we would like to see changed and formulate that into recommendations in the proper category. Thank you all for an excellent day.

## CONFERENCE RECOMMENDATIONS

*Robert J. Ursano, M.D.*

**DR. URSANO:** We have much work to do thinking about and making recommendations that we want to capture. Our goal is to limit the discussion to recommendations, and we will try to put them into a bullet form. I want us to think about the question, “What constitutes the level of the burden of disease?” The top two items in the burden of disease within the military, number one is injury, and number two is mental disorders. So what are our targets?

Please remember that psychiatric responses to disaster, war, and terrorism occur in different places. We have the question of mental disorders and also the question of resilience. We have the question of distress responses, and we have health risk behaviors, which include things like changes in use of cigarettes, changes in use of alcohol, and issues of driving and road traffic accidents. These are all targets for prevention and intervention in which stigma and barriers to care can impact outcomes.

The issue of distress responses is particularly important; it falls into the category of mild to moderate disorders in some of the studies Ron Kessler has done, which, number one, indicate that they need treatment because of their trajectory of course. Number two, they also impair performance, and in DoD we are in a performance activity. In the nation, if one addresses the question of safety workers, such as police and firefighters, the question of performance in terms of national security is much more important than disease, because people get sacrificed as individuals in order to protect the continuity of the nation.

Please remember there are disorders, there are distress responses, and there is how we intervene for them. How do barriers to care interfere with these factors and with health risk behaviors? Think about driving accidents, motor vehicle accidents, as one example of that. Across the spectrum, of course, there are also all types of psychosocial responses that have an impact, from sleep problems, to demoralization, to scapegoating and blaming, all of which are outcomes in an organization and a population we are concerned about because they affect performance activities.

There was a study that Chris Warner did, in which he asked people, “If we change this, will it matter to you?” And he found differences among those who were deployed and those who were not. In addition, he found that if we tell you that your family is concerned about you, it has the highest impact. The issue of trying to identify what may be most effective for overcoming barriers to care is one target

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for us to think about. But effective for what, with which population, and for which target? One conclusion of this conference could be that barriers to care in the military are pretty much like barriers to care outside of the military. We are leading the nation in trying to address this issue, and we are trying to solve our own problems at the same time.

Similarly, there exists the question of stigma. One of our targets when we think about continuity of care, and the trajectory of illness, which C.J. Diebold brought up yesterday, is the question of whether we can alter the length of time to get into treatment. That is just one target, never mind onset of disease, never mind the disability level. Can you alter length of time to treatment? The average length of time for a PTSD case is about 12 years, as I recall.

One of the topics we did not spend much time talking about is the topic of families and children. Some of you may know that Ed McCarroll was the first to identify increasing rates of child neglect occurring within the Army since the onset of the war. What about barriers to care that have to do with intervention for family conflict, and, in particular, child neglect? How does one reach out to that population? How does one alter the system? What research do we need to do? What training do we need to do that would allow us to better address that particular target?

Similarly, we did not say much about substance use. Substance abuse is always a problem within DoD. Too often we overlook the question of cigarette use. Altering cigarette use alters, in fact, a huge morbidity and mortality of disease. It is unrelated to psychiatric issues but tremendously related to the health of our families and our service members. We know cigarette use changes after exposures to combat, disasters, and terrorism. Our 18-25 year-olds are those who, in fact, have the highest rates of cigarette use.

If you look at perceived need of mental health counseling, 17% of DoD reported a perceived need of counseling, broken down by service. If you ask if they received a prescribed medication, about 4.8% of DoD has received a medication for depression, anxiety, or sleep; 14.6% have received some type of mental health counseling; 7.8% was from a military mental health professional. So, half of the counseling going on is from a military mental health professional. Somewhere around 44% describe probable or definite perceived damage to their career for seeking mental health counseling. This is not so different from the rest of the nation. What we have is the opportunity to address the ways that may lead us forward around this problem.

We have hardly said anything about somatic symptoms and how they present in times of disaster—whether it is somatic symptoms in family members, somatic symptoms in service members, or somatic symptoms from Katrina or in New York City after 2001. When referring to barriers to care, barrier may be the wrong word, but in addition, people come in who may not need care. There is also, of course, post-concussive syndrome, otherwise known as mild TBI, which we have not spoken too much about.

It is important to our discussions to recall that the number one target within DoD is injuries — often a behavioral event related to distress or risk behaviors. Care for injuries, trying to prevent how stigma and barriers to care increase the injury rate, how they decrease access to treatment after an injury has occurred. Each of these issues would require substantive hours; we are talking weeks of work to think through all of the elements. We can think about each of these targets, and how barriers to care may be impacting performance and health of an individual member, as well as the organization.

Several models we have implicitly been using as we move toward making recommendations. We approach problems from certain angles. One approach is our traditional primary, secondary, and tertiary prevention. How do we respond, and how do we prevent disability? Another approach is the IOM suggestions from 1994, which asks things such as, “Is this for the entire population? Is it for those at risk, or is it for those at significantly high risk?” Where does what we are doing fit in that frame?

If we think about war, disaster, and terrorism — as in the Haddon Matrix — there are also a pre-stage that we have to work in; an event stage in which we operate, and a post-event stage. Therefore, thinking from the perspective of preventive interventions, primary, secondary, tertiary, universal, selective, and indicated are all very helpful. If we were really good, we would take everything we say today and put them into those categories.

The Haddon matrix had much of its original importance with the question of motor vehicle accidents. It is essentially a three by three table in which you have the agent, the vector, and the population. You could think of the agent as malaria, the vector as mosquito, and then choose your population: children, workers, et cetera. So, what would be the pre-event intervention to address the agent? One might take anti-malarial drugs as a pre-event, to decrease the malaria load. Each of those boxes should be filled in to disrupt the disease process.

Is there a similar way to apply the three by three models to barriers to care and stigma? This was accomplished in the IOM report that I and others worked on for a number of psychological issues, so it can be done, but it needs to be thought through. How would it work if we said that the agent was stigma, the vector was the sergeant, and we are worried about the squad members? How would we address stigma or barriers to care across those nine squares?

Disease occurs across multiple domains, and stigma and barriers to care are going to be different across different domains. We have the disorder, say PTSD, but we also have symptoms, and symptom presentations, and perhaps partial disorders. We have nightmares separate from PTSD. We also have to address the question of impairment of function, and how will barriers to care address impairment of function, which is not the same as disability. Disability tends to be an attribute that usually accompanies the award of funds. There is also the question of comorbid conditions. If we are thinking of one condition, what else goes with it, and how do the barriers to care interact with those comorbidities? If we are dealing with PTSD and barriers to care, are we really dealing with the issues of depression and the barriers to care? Are we working toward answering the questions of substance abuse and the barriers to care?

There is a system of care, so where in the system are we focused? A particular example addresses PTSD, and we go from the question of screening and surveillance to education around battle mind, to buddy care, to RESPECT-MIL, Chuck Engel’s program, to DESTRESS, down to the issues of complicated disorder, and the question of care for care givers.

Whenever clinicians use the word “manipulating,” it is usually a sign that the clinician is overworked, and has begun to feel the burden of care as more, in fact, than they can do. During that time, there is a new barrier to care that has been created by the clinician within the clinician, and the management of that barrier also needs to be addressed.

Now lets return to our goal, to come up with recommendations. I want us to



address research first. Why? Because, as Harry Holloway commented yesterday, research recommendations will require us to be more specific about what our operational variables are. We cannot talk about any of the others unless we become a bit clearer on our operational variables. What are the operational variables that we need to learn more about? What might need to be reorganized in our system; which are system comments to think about, address, consider? What are training or education needs for providers, for leadership, for soldiers that might further address these issues? What might we advise leadership to assist in their awareness, knowledge, and interventions in these settings? The spot that we might gravitate the most to, but in truth, we know the least about, is to actually propose interventions, either at the clinical patient level, or at the population level. That is the dichotomy to think through with the question of clinical and population interventions.

With those introductory comments, we are going to open the floor for discussion, and begin to capture some of our thoughts and recommendations.

**DR. ESTROFF:** I have a question about the issue you just raised, the career consequences of seeking help, which we have all identified as a barrier. Do you have any empirical data on career trajectories of people who have sought care? Not accounting for the fact that it is a preselected group, but it would seem to me to be really important to be able to address that in some way.

**DR. URSANO:** First of all, I know studies have been done in the Air Force, in particular, to look at fliers who seek and receive psychiatric care, because there is tremendous worry in that community around that topic. The data say that 80% of fliers go back to work, and complete their tour. That means 20% do not. That may or not may not deal with the fear attached.

Second, there is great interest in this issue of career trajectories. There has been some marvelous work on that many years ago by Card and others. We need to replicate that around the questions of health behaviors, and health risks, and their impacts on trajectory. Harry Holloway, you have been around long enough to know if there are some other data specific to that.

**DR. HOLLOWAY:** There are some. One is the SAMHSA study of fliers who enter into alcoholic treatment, a study of matching them career-wise. Those who finished alcohol treatment then had careers that were better than their matched colleagues, they move forward more rapidly, achieved more in terms of rank, etc. A set of operational items were examined. The Navy is very good about this in terms of instituting alcohol treatment, when alcohol went from being a crime, to being a treatment issue. They did a great deal of highlighting of flag rank officers who entered and successfully completed alcohol treatment at some stage during their career.

I think here it is very important to make sure that we speak generally. The paradox is that any injury or any disease must threaten your career. There is frequently an issue of why confidentiality is so breached in this setting. Obviously one thing they would like to improve is privacy. But the truth is, any time I get hepatitis, or any time I sprain my ankle, I threaten my career. And if I seek care, I may solidify my capacity to continue my career, or I may end my career. These are the paradoxes of serving.

**DR. URSANO:** Sue Estroff, did you want to formulate something around that into an area about which we need to learn more?

**DR. ESTROFF:** Yes. It is in the area of similarities and differences between the civilian and the military population, which would be interesting to look at in terms of vocational consequences. Because there, I think, we are going to see a huge differ-

ence. Many of the people with the more serious problems do not have a vocational career to begin with.

This would be interesting for two reasons; one is to be able to provide some data for people who may be reluctant. Two, to actually look at how, and why, and where those changes were made. Given that every injury, including an injury to your psyche, is going to have some effect, if I am a reluctant soldier I want to know the ins and outs. I think right now we have a very gross understanding of it, in general, but not a real sensitive specific understanding.

**DR. URSANO:** So to capture it: understand the trajectory of vocational consequences.

**DR. KESSLER:** One thing that was said in passing yesterday was about resilience training, and if it could be packaged. People get badges for these things they go through. If there were a way in which having resilience training was something to check off as you went through it, as if it was a skill that you now have. I can imagine packaging mental disorder training so that there is not a distinction of the people who are trying to maximize the upside, and get back to a baseline. Another thing is that in the civilian world there are many people who do not want to go to mental health care through their employer-sponsored health plan so they pay out-of-pocket. The military has now put in place this new program where you can get telephonic psychotherapy without the therapist knowing who you are. I think both sides are being worked in that regard.

The thing I wanted to say before, which occurred to me in regard to Sue Estroff's comment. There were an enormous number of interesting ideas here yesterday, but the one that I went away with, and I kept mulling over, was the critical comment by Dean Kilpatrick about Viagra. Here we have another thing that is a very embarrassing male-oriented kind of thing. It is feeling as though you are not strong any more. Yet there is a flood of people going in for that kind of treatment, despite it being embarrassing. How come? What is the difference? One difference is this: everybody believes Viagra works. I think this is not true for mental disorders.

There is another kind of stigma that we have not talked about. We talked about the stigma of being mentally ill and the stigma of people knowing you are in treatment. There is also the stigma of the processes of care. There exists this image of what it is to be in treatment. There is some work that needs to be done to market a more positive image of being in treatment. It actually can help you. If people had the sense that psychotherapy works as well as Viagra, we would have a long line of people waiting for psychotherapy. In terms of practical research, there are several things that we need to do.

I think the very first thing that has to be done is research on treatment dropout. Once you get somebody into treatment, why is it that such a high proportion of them say, "You know, on second thought, I would rather be depressed than go back to see this guy." We have to figure out what it is that makes people drop out. Is it something about the kind of patient? Is it something about the kind of processes of care? Is there something we can do to improve the way we are doing things? Why is it that more people are more willing to go to chaplains than go to psychiatrists? Years ago, NIMH had an Indian Mental Health Service Program to train chaplains. It was collaborative care between people who were in the non-medical system and the medical system to make it more palatable. How can we package treatment in a way that people would find more palatable?

The second thing we have to do is figure out how to sell mental health treatment.

I think this should be relatively easy once we have a product that has the kind of value that we could sell. If America is good at anything, it is good at marketing, so once we have a product that has real value and that is recognized by the consumer, it should not be a difficult thing to figure out the things that Madison Avenue would do to sell it. We do not have to talk about it, because there are people who are really good at that. Our job is to figure out how to make the product good enough so the people who know how to sell it, can sell it.

**DR. ESTROFF:** I would argue that we know more about why people drop out than why they stay. Perhaps we are asking the wrong question.

**DR. HOLLOWAY:** At the time of the beginning of the large drug epidemic, we were approached by a number of advertisers, in particular, the advertisers for Budweiser, Anheuser-Busch. They presented the way you sell beer to psychiatrically disturbed people. They showed us the ads they developed that showed pictures of psychiatrically disturbed people. The standard one was for anxiety, and you may remember a chap by the name of Knox, who used to shake. The minute he would touch a Budweiser, the shaking would stop. They marketed loneliness. You may remember Yooper, a guy who is isolated. Nobody will associate with him, but the minute he touches a Budweiser he suddenly has friends, and people are talking to him.

There is a systematic approach already existent within the overall advertising community that specifically addresses the selling of cures to the psychiatrically ill. When I asked to whom those ads were directed the answer was, the mentally ill. The advertiser's goal was to create a 1 to 2% shift in the market. Notice that a 1 to 2% shift in the market in terms of numbers of referrals is a trivial item, and probably would not improve care. The idea that there is a marketing system that systematically can move large populations is an image that advertisers sell for hundreds of millions of dollars. They will admit, however, that they only want to move a very small segment of the market.

**DR. KESSLER:** In the early 1990s Prozac, along with some other drugs, began direct-to-consumer advertising. Subsequently there was a 60% increase in the percent of people getting treatment for mental disorders in the United States—not a 2% but a 60% increase over the decade.

One of the unique things about the military is that the military is not just a job. The military is a world, with the possibility of having a multi-pronged approach, where you can control what happens at breakfast, you can control eating, and other variables. Several years ago, the *Annals of Internal Medicine* published a paper that analyzed the cost effectiveness of screening for depression in primary care. They evaluated the effectiveness of getting people to admit they were depressed when they were coming in for a cold or for a broken finger, etc. They analyzed the dollars and hours cost to get a patient into treatment and found that, in terms of cost-effectiveness of improving the mental health of the population, it was completely infeasible. The reason was that the first nine out of the ten steps were incredibly cost-effective, and the tenth step was a disaster. The tenth step was the effectiveness of treatment.

In other words, you can inexpensively get many people into care, but when we put in the numbers about how successful treatment is, it turns out it is \$70,000 per QALY (Quality Adjusted Life Year). But the reason was that only 10% of people were getting treatment effectively. Then they said until we improve the quality of care, it makes no sense to screen for depression in primary care. First we have to get the processes of care right and make that clear to the people who are getting treat-

ment. We have to find out what is successful. Then it makes sense to do a marketing campaign.

**DR. URSANO:** Ron is recommending issues that have to do with education or training. The capability to provide evidence-based, effective care is critical. If we are not providing effective care, it does not matter how many people we bring in the door. We are spending a great deal of money without any outcome.

**DR. KILPATRICK:** I think we need research on how treatment can be made more palatable to people. We need to understand what people's expectations are, and what their understanding is of the treatments that we provide. The pharmaceutical industry has done a great job of convincing people that our problems are not personal or societal. They are problems in our synapses that particular agents can address. I wonder what people think about psychological treatments that have good efficacy. We need to find out what causes people to come to treatment. We are not explaining what treatment is, so it is mystifying to people. Secondly, do we really know why people come in? What would make it more attractive for people to come in?

**DR. URSANO:** Dean has illuminated a multi-step process beginning when someone first thinks they have a problem. Then they must believe that there is effective help, and then they must be able to physically get there. How do they make that last leap to actually going to care?

**DR. KILPATRICK:** I am worried about confidentiality, worried about ruining my career, people will think I am nuts, so what about coming into therapy is pretty attractive to me? In other words, what are my expectations? Do I expect to get any change out of this? Do I expect to get better?

Back to the Viagra thing, I think it is pretty clear why people are willing to come in and take Viagra, because they anticipate a pretty specific positive effect. What kind of effects do people expect to get out of treatment? We focused on the negatives, but what are the positive things about it?

**DR. HOBFOLL:** We have lost Goffman's original idea of stigma, which was the purpose of stigma. It is that a person assigning stigma gains status. That is why stigma occurs. No one looks to be stigmatized. So this is the enemy, and he is us. The mental health establishment gains tremendous status by the ability to diagnose. In fact, they can even override the orders of a Commanding General by their diagnosis. That is an incredible amount of power, and that power rests in the Surgeon General's office, and they do not want to give it up easily.

So, the fight in the military is to move it out of the realm of diagnosis, and into the realm of functioning. Of course, psychiatrists and psychologists still have a tremendous amount to contribute there, but they will lose a great deal of power because functioning puts the power back in the Commander's hands.

The one area of policy that must be changed for this to occur is the well-known picket fence, though not in military parlance. Soldiers get evaluations which ultimately determine their rank. If quality evaluations are not perfect, you do not make rank, so any negative evaluation means really the end of your being on the fast track. That has to end. In great armies in the world, including the American Army during World War II, the picket fence did not exist, because you promoted based on performance. Promotion based on the standard of 12 perfect evaluations from your senior officers produces "yes men and women" and people who are scared to speak up. Obviously, someone in uniform cannot say that, but I can.

I will discuss recommendations. Moving to a coach's model does not mean that

you end diagnosis. Diagnosis has an importance, and those with severe disorders should be treated as having severe disorders. Separating and looking at the functioning is important. If 20% of those coming back from Iraq have PTSD, most of those people actually have walking PTSD, meaning that they are still functioning with their PTSD. In the first relevant study on this, we found that PTSD is almost unrelated and that depression is only slightly related to functioning, so you can still function very well, even though you are suffering. Coach's model could be done immediately. That is already going on, by the way. Pushing resiliency and functioning is really the way to go.

As mental health professionals, we have to be ready to let go of some of the status of being the person who stigmatizes. No one has more to contribute to this interaction of distress, stress, and functioning than mental health professionals working now in a team with Commanders who are really interested in performance.

**DR. LINK:** So the story for me would invoke the military cultural components of courage, bravery, strength, and camaraderie. People are trained in the culture, and then they live in the culture. In the course of their career, they have the opportunity, or the misfortune of encountering different types of injuries. I very much like the idea of talking about this as injury, rather than illness, because I think it works well in this narrative. One injury would be like physical maiming or injury. Another is psychic injury. The culture prescribes what happens when physical injuries and psychic injuries occur. If you have a psychic injury you have the possibility of feeling failure, feeling depressed and worrying about your future job prospects. You might also avoid treatment.

There are analogs for studying this kind of process, and research could reveal them. It also could be deepened by qualitative work if we put this story together in a compelling way. This could be a basis for how we portray at least one part of this problem to the people who have the problems. It would also give them a language for talking about what is happening to them. I think we could do that, and I think it could be helpful.

**DR. URSANO:** We might frame that as a need to examine and further explore the relationship of how the narratives of the military encounter the experience of injury. Highlighting a couple of points, Bruce Link, you are actually saying given the success of Theater of War, which is a narrative about the experience of soldiers meeting injury and damage related to war, we should explore that. We should understand it more in the present context. And, also, to go to Steve's comment, the coaching model is a hot model right now within DoD, both in terms of resilience and in terms of networks. There are working efforts to build virtual coaches that would follow someone around during their entire career. These are right in line with efforts that we need to know more about, that are frequently moved forward faster than we have the opportunity to understand their effective elements.

**DR. BELL:** When we were at the Carter Center right after 9/11, the Medical Director of the Fire Department got up and spoke. She talked about how there was not as much PTSD in her fire folk because she had thoughtfully built the social fabric of that group. In their training, she built-in social emotional tools, affect regulation, self-esteem, connectedness—all of the things we described in that paper we did about the five essential elements of responding. This might be the way to go in terms of a universal approach.

We understand that when some people are exposed to trauma they develop post-traumatic growth. Some people take that helplessness and they transform it into

helpfulness, and that is a protective factor. We sort of understand from this 2009 IOM Prevention Report that we just did, that there are things that you can do to prevent these problems. The difficulty is in the implementation, so some research on implementation and effective ways of doing this would be helpful. There is the Internet-based Depression Prevention intervention we have been doing. It seems to be very helpful in terms of coaching people, building resiliency, and helping people learn how to flourish.

Richard Bryant talked about catastrophizing as a risk factor for developing PTSD and how the notion of self-efficacy was a protective factor. The more of those things that can be cultivated, the better off we could be.

The thing that I struggle with in terms of information is all the garbage that is on the Internet. Apparently people who frequent the internet have much more difficulty understanding truisms that are actually real, authentic, and genuine. Part of the challenge is directing people to the right internet sources. Maybe some sort of Good Housekeeping Seal of Approval might be helpful; because I think the Depression Prevention studies we have been doing show that is a very efficacious way to reach large populations. You do not have to worry about fidelity and you do not have to worry about dissemination. You push a button and you are there. The problem is all the garbage.

**DR. CORRIGAN:** Every English-speaking country in the world has an anti-stigma program. In the United States it is run by SAMHSA. It is called the Center to Address Discrimination Stigma. Ken Thompson would be a wonderful resource on that. The person running it is a gentleman named Chris Marshall. I have the website here. They talk about all sorts of important groups of people. They talk about employers, landlords, politicians and the like. Under employers and under employment is the military. They have had webinars on military issues and stigma. One webinar was done by a series of veterans groups, including a veterans group that represents OEF, OIF, Iraq and Afghanistan Veterans of America. Also, we talked about marketing as having some work based on the research here on marketing to employers.

One of the first priorities is to help them further develop their research agenda and their focus on the military. The Ad Center is one excellent start, keeping in mind whatever sort of stuff you use, the unique culture of the military is going to spin that in a way that is very important to them. For example, we talked about contact. Contact with whom in the military? With the General, the NCO, the soldier? Probably with all three groups. We can look for existing research. One is the Ad Center, the other one is NIMH. There are several people in the room that have received NIMH grants on stigma.

One of the concerns I have is that NIMH may be losing its sense of priority in that regard. It had its own portfolio defined as stigma. I am not sure if it is an explicit or implicit agenda, but Director Insel may be decreasing the concern and interest in stigma research. I think we want to really promote this group, promote and encourage more work in that area, especially with a military flair. I am also aware that the VA is starting to pick up on this concern. I am aware of small projects around the country. Rediscovering research agendas at SAMHSA Ad Center, the NIMH portfolio, and the local VA work coming out of some of the minor places into bigger places are all important.

**DR. SHALEV:** I endorse the idea that we need effective therapy. The product that we package must be effective. There is quite a bit of work to do in that regard.

Treatment can be stigmatizing. Early in my career I studied antipsychotics. The main difference between the newer and the older agents is that with the older ones, you and everyone else knew your patient was on an antipsychotic because they were Parkinsonian. They could not smile or interact socially. It was a stigmatizing type of treatment.

I think that when you take a gun from a soldier or marine who takes SSRIs, treatment in itself becomes stigmatizing. So, we should really think about making treatment itself less stigmatizing. The other point is about treatment decliners. There might be situations in which declining care is effective, and we should not just assume that it is always bad. For some of those who do not want to come, they may have good reason to decline. Research into the efficacy of declining care under different circumstances might be helpful.

**DR. URSANO:** So you are saying that clinicians may have false positives, and that we ought to understand our false positive rate as well as our true rate.

**DR. SHALEV:** Those with partial PTSD who declined care did not waste four months of treatment resources that they really did not need. We are not yet at the level of defining the specific phenotype and circumstances that might benefit most from treatment. The point I am driving is that there is a variety of outcomes. If I just measure their PTSD symptoms, for some it may appear that the treatment did not help. However, some patients with persistent symptoms are very grateful for having had that treatment, which helped them to be able to play with their kids without being so sensitive to the noise. This is a multiple outcome question, and we should think about it as a multiple outcome question.

**DR. ZATZICK:** Recommendation one: We optimize survey methods in randomized trials by looking at entry, retention and dropout from treatment. Recommendation two: We take qualitative methods and we move them very much into a clinical paradox.

We are working with The Disparity Center and Spero Manson. We want to recruit Native American patients from trauma wards, and we want to randomize them. People are saying there is no way you are going to get injured Native American patients to be randomized. Native American patients do not enter randomized trials. What did we do? We learned that the Native American spirituality is a core concept and construct. We have to engage these folks immediately after the trauma in this concept of spirituality. What did we do? We got a Tlingit Shaman. We asked her if she would be a care manager. She says okay, I will do this, but you have to let me do my thing. What is your thing? I have all these different rituals I want to do in the Trauma Center, and I want to intervene with patients. For example, if I wake up in the middle of the night having a dream about a patient, I want to intervene. Then you become a boundary spanner. You say, “We want this match component. We want to go to the bedside. We want a Tlingit Shaman to engage this patient and recruit them into the study and randomize them.” Thirty patients consented to this protocol. It is the application of ethnographic methods. It is clinical ethnography.

We know a great deal so let us apply it. Let us measure outcomes and let us span the boundaries that allow us to use the “out of the box” thinking.

**DR. RADKE:** I have two points to make. Being an action thinker, the first thing I think about is Asics which is a shortcut in Latin for, “Sound mind and sound body.” Health promotion needs to be integrated into this discussion because we need to focus on physical and emotional strength and endurance. Unless we do that, everything else becomes after-the-fact, after the injury, after the event. And I do not think

you want to go there, especially when we are dealing with soldiers, and airmen, and sailors. We want to and do have emotion.

The other point I want to make is why stigma? It could be the individual, but it could be the system. We need to be able to discriminate between individual stigma and system stigma. If it is an individual, then maybe it is a lack of knowledge. Why are they feeling stigmatized, or why do they represent a stigmatic situation? If it is a lack of knowledge, then we have the education issues. If it is a belief, we have a whole different world, because beliefs are not going to be argued. Beliefs are going to be discussed. We need to develop relationships like Doug was talking about to get over the beliefs.

Second point, if it is systemic stigma, then we have to look at what we have created. What are the policy and funding silos that have created a system of stigma? Have we politicized the stigma so that we are now fighting in a political arena because it is cost-effective not to treat and not to promote mental health care?

**DR. BATES:** My recommendations utilize a broad comprehensive integrated resource-type model, shifting the culture towards a strength-based focus. What types of skills could we develop in our service members that would counter stigma? How can we identify standardized outcomes that cover the range of stigma and access to care issues, so that we can look at them more broadly across the services? How can we leverage the tremendous resources available across the services components, including the VA?

We recently put together a model of psychological fitness for the Chairman and the Joint Chiefs of Staff. We also advocated a model based on the conservation of resources model, where it is important to identify all the resources we have and leverage them appropriately. The military has a tremendous range of resources we can bring to bear on this problem. We have potential to integrate across our DoD Health and Service Agencies, like Force Health Protection and Readiness, DCoE, and Military Community and Family Policy. I think synchronizing efforts in DoD alone could go a long way.

**DR. KESSLER:** We need to do treatment retention experiments. There is a book by Don Meichenbaum, called *Facilitating Treatment Adherence*. It was written in the late 1980s, and it was directed at behaviors like getting black men to take their hypertension medication. Meichenbaum saw dramatic effects in keeping people in treatment.

We need to understand why people come into treatment. The reason people come to treatment is not the same reason they stay in treatment. Many people come with one presenting complaint and the next thing you know they are talking about something completely different. We have got to figure out how to get people to stay in treatment to successfully market treatment.

In the U.S., only about 20% of the people who have a serious mental illness in a year get effective treatment. That is because 40% never get any treatment at all. Of the six out of ten who get treatment, four drop out. That means that we lose 40% because we never get them in the door, but we lose another 40% after they are in the door, which is a crime. Which 40% is the easiest one to hold on to? We could triple the effect of the system if we could keep people in treatment. We have got to do systematic studies to define best practices to keep people in treatment.

**DR. PESCOLIDIO:** Recommendation one: I think we need to rethink some of our research questions and, at minimum, supplement the way that we think about some of these processes. First of all, it is not help-seeking. In our studies, 25% of the



people who get into mental health treatment are coerced by the police and by their bosses. A third does not really understand how they got there, so I think we need to move away from the image of help-seeking. We need to understand the process and the key turning points. What are the identity shifts that it takes for people to continue to take their medication or stay in treatment?

All of us can think of 100 reasons why we do not want to take a pill every day. What identity shift and acceptance does it take to become somebody who is dealing with a chronic problem? Let us study patterns and pathways, rather than study a fictional decision to use care or not use care.

Recommendation two: We need to normalize the whole idea of mental health in the fabric of an individual reward system that has a high level of altruism.

**DR. ZATZICK:** I would strongly urge that we follow people at different stages of their careers. Look at some of whom have had treatment, some of whom have exhibited symptomatology, and look at how well they functioned. I think that many officers believe that the stigma is from officers. If you screen positive for a psychiatric illness you are considered not fit for duty, or not trustworthy. We can go beyond the belief systems, because the data is there. We just need to look at it.

Secondly, one of the greatest barriers to care is the concern about confidentiality. Except for military chaplains and Vet Center counselors in the VA, we cannot guarantee confidentiality. How can we find out how often the Command is actually requesting confidential information? If people felt that this was a very, very low probability event, I think that would reduce this kind of a barrier. Internet-based treatments, where one can have privacy, are a good resource. Web-based treatments are getting more sophisticated and more effective.

My final suggestion is to frame PTSD as they do in Canada, where it is considered an operational stress injury. It is not considered a psychiatric disorder. How does the re-framing play out in terms of function, in terms of follow-up, and in terms of future prospects?

**DR. FRIEDMAN:** Military populations do not want to think of themselves as being mentally ill. They are horrified by that thought. We need to find a way to circumvent that.

What people are doing today is talking about function. Many of our leaders use the term PTS, and actually abhor adding the D to it. They are trying to encourage the term PTS without the D in the common parlance of the language. I like what Steven had to say about function, because I think that is the key thing. Can they function? We need to highly encourage and improve the whole concept of embedding mental health providers in the operational forces. It is incredibly effective when you have your doc walking around. You can walk up, hey, doc, let me run this one by you. I am not sleeping very well. When you have access to that you do not have to make a huge leap to drive all the way to the hospital. You do not have to leave the culture that you live in, and enter the medical culture. Once you cross the threshold of the hospital or the clinic, you get into the medical world. You enter another vulnerable place. By embedding providers, like the flight surgeon model, or the division psychiatrist model, or the OSCAR model they are using now, you become more effective.

What they are doing in the Marine Corps now is OSCAR Extender Training. The OSCAR program stands for Operational Stress Control and Readiness. Mental health professionals are the OSCAR professionals, but they also have Extenders modeled on what the TRiM program does with the Royal Marines. Extenders are trained to be peer counselors. Part of that training involves leaders talking about

their own experiences with traumatic stress type symptoms. It is an incredibly powerful experience to have the Major who is the CO of your battalion talking about his own symptoms, and his own struggles with dealing with his symptoms post deployment. To have a Major, a Sergeant Major, a Gunnery Sergeant, and a Master Sergeant talk about their symptoms is incredibly powerful. Encouraging leaders to talk about their experiences is very important.

**DR. SCHOR:** I think that there should be a strategy for identifying the research needs. If you do not influence the decision makers in DoD, and in Health and Human Services to apply resources, and if you cannot sell it, then why should they want to buy it? There should be some sort of a needs assessment approach, perhaps stratified across different areas. Education, training, policy, and clinical versus population health all have different needs assessments.

**DR. ARNOLD:** You must have the leadership buy-in. I am speaking from the perspective of a Combat Stress Control Fitness Team Leader. When we got to Iraq, we made contact with the leadership of the units we were supporting. Soldiers from the units that did not buy into what we did usually came to us fearing that their leadership did not understand, and did not care. Unfortunately, that often panned out to be true. From the leadership perspective, we need public service announcements from all levels of leadership. Leaders need to be able to tell their service members that coming to seek help, whether it is for mental or physical health, is compatible with the core values of the service to which they belong. If they can convey that message by speaking openly of personal experience, it is very moving, because the person seeing that realizes that they can step forward. They also see it has not adversely affected their career. They have been able to go on.

When I was in Iraq, many soldiers came to see me with their battle buddy. They would not come on their own, but they would come with their battle buddy. Sometimes they came in clusters. It was amazing to see how once one person got help, and the other one saw what was going on, then they would come back individually and seek more help. I think we need to take the battle buddy model and incorporate it in basic training in all branches of the military.

**DR. URSANO:** Robert, you are suggesting two battle buddy models. One could actually study the effect. One could study the match in attitudes between battle buddies and see if one's perception of stigma and barriers to care is the same as their buddy's. One could look to see how altering one alters the other. It is an education and an intervention strategy.

**DR. RUZEK:** One priority for research would be to show the impact of psychological programming on war-fighting performance, and other kinds of performance. The strategy that I would like to champion is a series of RCTs comparing basic training with psychologically enhanced basic training. Let us look at the outcomes, based on people's ability to perform in the field. I am quite sure that techniques like anxiety management and buddy systems, disclosure training, and self-taught procedures would enhance ability to perform in stressful situations. If we could implement and demonstrate that, then we could begin to de-stigmatize psychological programming.

The second area of research I think is important is comparative research that looks at different ways of presenting treatment and making referrals. We do not know as much about why people are coming to treatment and what they hope to get out of it. We need to learn more. We also need more research on what role significant others, spouses, partners, and family members play in getting people to treatment.

There is a very important group of potential patients who are going to be recal-

citant to coming to care. They are the ones who are having problems in tyrannizing the family and withdrawing from the world. Probably these people eventually arrive for care through the intervention of family members. In the field of alcohol, there is an evidence-based protocol working with the significant other of an alcoholic who is refusing care. I think we can develop similar protocols based on this model.

This is a technology transfer issue more than a research issue. We know that getting videos of patients talking about treatment and sharing their reluctance to enter treatment are good teaching models. They are more effective than mastering models in reducing anxiety about entering treatment. There are also different ways of making referrals that are more effective, too.

**DR. URSANO:** Recall that our plan is to create a transcript from which we will develop the most important part of the document that will become the Executive Summary. This process will take somewhere between three and six months. Afterwards you will all receive a copy of the document.

Consider the question of other system issues, or reorganization that you wish to bring up. Consider the questions of leadership, direction to leadership, the question of intervention, clinical or population-based. The truth of the matter is, we do not have much data on what will work, but we may have some thoughts of things that may be worth considering. And perhaps the most important one is to foster required program evaluation, which is very difficult to accomplish. Those of you who work in states know that. It is the same issue within DoD. General Chiarelli says, “I have a thousand programs planted, but which of those are really bearing fruit?”

I want to make sure that we also touch on and talk about the issues of disaster and terrorism, not just DoD. Many of your comments apply in all those areas. We have not said anything about emergent mental health needs that occur after a disaster. We have not said anything about the tireless work Ron has done related to Katrina, which clearly documents the doubling of mental health disorders after Katrina, and what that implies for particular barriers to care. We have not raised anything about the distribution of people after a disaster. I am sure many of you have seen the map that shows how people dispersed post Katrina. It would have done little good to concentrate resources in New Orleans at that time. The distribution of resources and barriers to care that have to be addressed become widely dispersed.

**DR. COZZA:** I think we need to have a better sense of the primary concerns of the population as they describe them. We tend to focus our research on disorders and diagnoses, instead of how to best understand the target population’s concerns. We are dogmatic in thinking that mental disorders are the population’s principal concerns, but they are not. Understanding their concerns serves as a portal of entry for intervention. I think we can better access our target audience when we better understand their concerns, making our interventions more effective. Second, we need to change our language. We may like naming our disorders, but people do not like the complicated words that we use. As we were discussing, I think people accept Viagra because ED is a more like a yes/no diagnosis — you know whether you have it or not and it disturbs you if you do. You may not like accepting it, but you have to accept it if you want to solve the problem. How does a person distinguish between what is normal and abnormal? This stigmatizes people. People do not like to think of themselves as abnormal. Third, I think we need to be targeting interventions to where individuals are most likely to feel the pain, and most likely to engage and want help. Bill Beardsley has done great work with parental depression. You can engage families around parental depression when they realize that they can be

good parents, if they take responsibility for their disorder. It helps parents be able to frame any problem in away that reflects the importance of their parenting, which may allow for more engagement.

Finally, we should look at functioning as an important intervention strategy. Although we get concerned about the treatment and the pain of PTSD, what we get most concerned about are the dysfunctional changes that occur as part of the development of the diagnosis of PTSD. I think if we focus on certain targeted symptoms or behaviors that are far more likely to be self-identified as problematic, we may be more successful.

**DR. CROW:** My recommendation would be to utilize a task force, a Blue Ribbon Panel, that would include stakeholders, perhaps a subset of the group that is here from Uniformed Services University, DCoE, U.S. Army Public Health Command, and civilian experts to provide a strategic vision of how the DoD can develop and implement a Behavioral Public Health capability in the form of a brief White Paper Task Force Report oriented toward senior leadership.

A public health approach would provide a vehicle for addressing issues of resilience, life skills, and performance enhancement. Looking for a vehicle that allows us to provide a behavioral public health orientation to the service is what I am recommending.

**DR. ESTROFF:** Consider the process of how, or if, non-civilians would connect with civilian processes dealing with stigma and discrimination. There is not a whole lot of overlap, and there is a great deal going on. The big elephant in the room is how or if people want to collaborate.

I think it is a mistake to assume that research is equal to listening or knowing people's experiences. I want to harken back to Pat Corrigan's comment yesterday about the absence of consumers. We have to question our own expertise. I am reminded of two anthems from the consumer and mental health groups that I know. The first one is, "Recovery begins with non-compliance." The other one is, "Do not let your treatment interfere with your recovery." I take these as very serious statements. Research is not necessarily listening. I do not think research is the only thing that is going to help. One thing that can be helpful is diarizing and journalizing in a freeform kind of way, which is both therapeutic and also informative.

There is a tremendous amount of literature accumulating on what is called narrative medicine. We have had some good effects with this approach. It preserves privacy, and deals with the third issue. I think that trying to talk with people, and work with people is really the key.

**DR. WESSELY:** I have four points. On research, I think you have an adequate knowledge of precisely what is going on in the figures that have been presented. I just think it is increasingly implausible, that one-third of the Reserves have PTSD, even though they score high on the PCL. You need to look and see what actually is wrong. One of the reasons they may not be coming forward for treatment is because you may be treating them for something that they have not got. I do not think we have a grasp of what is going on. There is a concern that we may not adequately understand what the question or studies are saying. There is a remarkable lack, despite all the research money, of interview studies.

Switching to policy, Ron Kessler has said that marketing is not the answer if people do not like the product, and that is absolutely correct. But there is a second possibility. Perhaps they do not like the people delivering the product. In the film *Hurt Locker*, the stereotype of the psychiatrist was very cringing and embarrassing,

but it was telling us something that we should not ignore. How do you improve the product? That is quite difficult, and many people smarter than I have been working on that for a long time. To echo what is being said across the room, it is time to mobilize the non-mental health sector that has higher credibility.

Point number three: It is pretty clear that targeting people, telling them they have a problem, let alone a mental health problem, or they need to change, or they need to be more resilient, or less vulnerable, is not working. No matter how you phrase it, people feel that you are targeting them. And, in a way, you are. Be clear as to what these Peer Support and TRiM Programs are doing. They are not treating PTSD. What they are doing is enlisting people to identify, support, and help others. It is an appeal to altruism. You are here to support others, but we hope, it actually supports the individual directly to help themselves. It is free of stigma and the intervention has been done without people actually being aware that they might be the target of the intervention. It might help them. It certainly does not do any harm.

All of you will feel much better when you finally admit that screening programs are incredibly expensive, and they do not work. It is flooding your system with people who immediately drop out of treatment, if they go into treatment at all. We know from Charles' papers that the ones you want to target are missing the system. They are missing the system because they are the ones who are most severely ill, who most severely feel the stigma, and, therefore, make the best efforts they can to avoid your system. Resources are being wasted on an ineffective intervention. It is clearly not working, because your rates are still going up and up. All of you will feel so much more relieved when you finally admit that screening is not working.

**DR. BATTEN:** I just realized that we have not mentioned our Real Warriors Campaign. My Bottom Line Up Front (BLUF) is that the Defense Centers of Excellence would welcome anyone's partnership in this room with either the implementation or evaluation of our Real Warriors Campaign. Our Real Warriors Campaign is a national and international public awareness campaign primarily targeted in the Department of Defense to promote help-seeking for those who are having functional concerns that are not resolving on their own. We did focus groups before we launched, in which we talked to service members and their families, and asked them, "What would encourage you to seek treatment?" They said, "We want to see examples. We do not want to have a shrink telling us what to do. We want to see examples of real people who have had struggles like ours, and who have sought treatment. We want to see proof that it has not harmed their careers." That is the foundation on which our campaign has been developed. We find individuals from a variety of ranks, from Sergeant up to Two-Star Major General, who have talked about their experiences after returning from combat. We also have some medical professionals who talk about compassion fatigue from treating trauma patients in theater. They talk about what it was like to come home. What struggles did they have? What was their resistance and hesitancy to enter treatment? How did they finally come to treatment? Usually it is either a family member or a leader who intervenes.

We use video-based clips that you can view in 30-second or five-minute versions, which we have been pushing out around the country in both PSA format as well as a longer format. We have a Facebook page and a Twitter page. We have forums in which people can type to each other. We have a chat function, which they can use to talk to trained health resource consultants 24 hours a day. We are very proud of the program. It has only been up and running for about 10 months. Our primary

mode of evaluation has been market saturation, not effectiveness and outcome. We were recently notified by Nielsen that we have made one billion—with a b—media impressions. I do not really know exactly what that means, but it is a big number. We feel like we are getting the program out there. We would love to tap into the expertise of those of you who can help us with some of the more outcomes-based evaluation. We want see if the program is actually doing what we hope it is doing. We are also evaluating the Theater of War project.

**DR. BROWN:** My recommendation is that it is important to put effort where you are going to make big differences. I suggest that the evaluation component is where you can make a big difference; that is, there needs to be large-scale emphasis on a large group-based randomized trial. The level of the group is something very large like a base. There is a history of this in the military. It should accomplish three goals. Developing and testing implementation. Developing and testing effectiveness and inputting a quality-improvement control system so that you actually are improving over time. What we have been lacking is a knowledge-base to tell us whether big-scale programs are improving.

It seems like there are many brilliant ideas in programs already. Perhaps they are not integrated as well as they should be. That is the component we can test. One of the best examples is the Thai military experiment that David Celentano ran years ago, which demonstrated that you can reduce HIV infections in the Thai military. The study was a randomized trial of probably about 50 to 100 thousand recruits in the Thai military. The technology is there for us to use.

The last comment I want to make is about psychic fitness and resilience issues. We can learn from other cultures outside the military. One example is the culture in Disney World. The Disney Institute is very good about service. That is what they train people to do. They train people to be very effective in a very difficult job in a service setting. They have a concept called “On Stage and Off Stage.” When you are on stage, you have a set of standards to which you are expected to adhere. They also provide a set of standards for off stage. That is not the analogy for the military. However, the culture in Disney is just as strong as it is in the military. I think we need to figure out where these key pieces are, and repeat them systematically over and over again in the interventions.

**DR. SHALEV:** I will raise another construct, which is the anti-stigma. In my country of Israel, we are struggling with some people who seem to be stuck with a deteriorating course of PTSD for years. The more help they get, the more they deteriorate. We should remain aware that some disorders in certain contexts become so rewarding that people maintain them. I would recommend looking at the maintaining factors. Maintaining factors of disorders, symptoms, impairment, disability, reported disability, or perceived disability, are all important because at the end of the day, these individuals perceive themselves as having severe disabilities. We should remember that once you get into the PTSD club, you can get out of it. PTSD and several other disorders are transient. They are not one-way tickets.

**DR. URSANO:** That is an interesting challenge to think about exit strategies. How does one exit the illness role and how does one exit the picture. How does one get in it, and how does one get out of it?

**DR. FLYNN:** I would like to suggest four recommendations based on the idea that these recommendations are how to move the field forward, not necessarily things we ought to be doing. We might want to consider changing the sequence of the title that we are using. I have gone through a transformation preparing for

this group, thinking about stigma being first, and then other barriers being second. Most of what we are talking about is other kinds of barriers, of which stigma is one important one. Maybe we want to shift the sequencing.

The second is that we broaden the perspective domains that we are discussing. This is not a criticism, it is an observation. I think there is a bias of our discussion that is a product of the constellation of people here. There has been a great deal of discussion about research, primarily, because many of the people here live in the world of research. There has also been a bias about medical systems and health care systems, because that is where most of the people here live. However, many of the concerns that we are talking about do not play out in these systems or in research. They play out in the workplace, in schools, in jails, in decisions and choices that leadership make, whether that is politic leadership or organization leadership. A future recommendation is to broaden our scope.

The third recommendation is to expand our discussion of issues of history and culture in the discussion. We have not had much discussion about the role of otherness, shame, blame, power dynamics, and those kinds of things as part of this dynamic. The final recommendation is that we make sure that we include a wide array of expertise as we begin to make recommendations to the field. Many of these issues include our areas of expertise. We should also include faith issues, anthropology, linguistics, social marketing, and communications. There are many very professional fields that have a great deal to contribute.

**DR. HOLLOWAY:** I recommend that we investigate ways of integrating our service delivery toward primary care. It may not be obvious how to do it so we may want to try several different models. My overall statement is that the system that we have now, to go back to Simon Wessely's point, is not working. We will all feel better if we admit that.

The other thing I would like to focus on is that we take care as we develop our expansion into new areas—examine what the real potential is rather than what we believe about the potential. The chaplaincy does not have, by the way, confidentiality. Number two, the chaplaincy right now is badly split between the Fundamentalist Churches and the traditional churches. The Fundamentalist churches are refusing to provide religious care to soldiers who are not of their particular domain. Those battles are part of what it means to contact the chaplain. It is not just a chaplain. It is which kind of chaplain, which place, and it becomes a large bureaucratic struggle.

In each of these cases we need to examine what the real facts are on the ground. For instance, the overall misstating of facts here was striking. The Surgeon General cannot use a diagnosis to overrule anybody. He is a Staff Officer; he is not a Command Officer. Number two, it was stated that people follow orders within the service. Commanders would love it if people commanded and followed orders. But let me tell you, Commanders know that they are giving orders to people, and that people act like people.

**DR. REISSMAN:** Suppose you have a physical injury instead of a psychological illness? There is a whole literature on safety climate, and changing the climate, which is how people talk to each other about what is going on in an organization. How culture gets into climate is not always so straightforward. That relates to what some people were talking about earlier with injury.

I think we also need to think one step beyond those who are in the active component. We need to think about those who are in the reserves, including the Guard who come in and out of this kind of activation. How do we work psychological

fitness into this component? How do we think about reintegration more broadly, so that reintegration is not only to civilian life but also back to military life? All those transitions play a big part in where some of these wounds are coming from.

Finally, vocational rehabilitation is part of the shaft of support. Vocational rehab should be a component of performance enhancement. It does not mean you have to change your job. You need some help getting back to your job. You might need help feeling like you fit the core values of your job.

**DR. TUMA:** My recommendations will be framed as questions. I would like to know how we can help an important point of contact through primary care. Rather than blame, bash, and burden, how can we assist and extend through primary care?

I would like to know how the ideas of psychological maintenance and fitness can become embedded and tested in the military and civilian cultures. This is not something that is going to change in a generation, but I think keeping up the battle is a good idea. We might get to a point where early symptoms and signs of distress, and perhaps functional problems, would be viewed as injuries that have an unknown prognosis. With a physical injury one might wonder for a few days whether they can manage. If they cannot manage it then they would seek some assistance. Framing things in terms of psychological fitness or maintenance is one strategy that has not been studied. There is certainly a great deal of activity now and exciting programs being put in place. I would be very interested to know if we have the ability to monitor what programs actually change beliefs and behaviors.

Third, I would like to know how to get rapid relief for people who do make it into care because I think it helps people continue care. Related to that, I would like to learn how to better mitigate the other reasons people discontinue care. I would like to know what actually happens in therapy. You know, several comments have been made about marketing, and the way people flock or do not flock to certain approaches. I would like to know what happens in psychotherapy to know whether we can tell a better story about why people should participate.

Finally, I would like to know something about the use of technology to scale-up. I would like to know how successful technology is to extend care. If it is successful in the context of a crisis, what are the lessons learned for people in non-crisis situations to access care?

**DR. CROSS:** My BLUF is going to address the research area and also training and education. As programs roll out there is an opportunity to add to the science of training, and maybe bring the science of training to some of the evaluations. We are talking a great deal about mental health and stigma, but there are all kinds of training efforts that could benefit from some of this work. We could learn about training and education, and transfer of these programs, regardless of who the interventionist is. We have heard about the use of coaches, peers, extenders and mental health professionals. We have heard about many program models. Whatever the setting is, we could study implementation at all levels. We could even do hypothesis testing. We could do trials within trials. Some of these training and transfer studies could be rolled into other evaluation and research efforts. That is why it is research, and training, and education, with the effort to improve these processes over time.

Secondly, I really like the idea of building skills. I have never seen the Haddon matrix before. I would like to focus on the left-hand of that matrix which is the life-skill building part.

**DR. RUZEK:** I was struck yesterday about the importance of self-help organizations. That is where many people are actually embedded in mental health



care. Participation in self-help organizations can also help maintain participation in professional care. I think something is being overlooked in research, and it has been relatively overlooked in terms of partnerships, engaging people in services, and changing stigmatization.

One of the benefits of working with self-help organizations is that you then have a cadre of people who model outreach, as well as internal mutual helping. I felt for some years that I ought to be trying to build a self-organization of PTSD sufferers inside the VA, but I think it is far more general than that. We ought to work with existing organizations, as well as create new ones. Many self-help organizations were partnerships between professionals, mental health professionals and the lay public who were suffering. There is a potential for real synergy between them. It makes sense to follow the inherent preferences of our people who are talking to chaplains, talking to primary care docs, and who are going to ERs at the early stage of recovery. But it brings up many issues.

Number one, we have not developed and tested interventions for post trauma and psychological problems in those environments, so there is a research issue. There is a research issue in terms of whether those kinds of ordinary referrals, or ordinary contacts, are helping people, or not. Should we be bringing the evidence-based protocols into those settings or modifying them for use by other folks? I think there is a big hole there.

I wonder if it would be feasible to mount a health education campaign with Hollywood and media moguls directed at how treatment is represented in television shows, films, and other media places. It is fairly clear to me that showing people wrestling with issues about coming to treatment and showing the benefits of treatment opens up the black box of what happens in treatment. My bias is that treatment is the most practical thing in the world. It is sitting down and setting a few goals. It is prioritizing what to do. It is problem-solving issues and learning a few very practical skills. It is not all this crazy stuff that people think it is.

**DR. BROWN:** Many in our group have resonated with the resilience theme of “taking a knee” and being “on stage or off stage.” Sue Estroff noted that “always” is an element of so many military core values and associated expectations. An important target of universal prevention may involve teaching people to recognize when they need a break, how to take a break, and how to shift the cultural expectation to allow rest. Additionally, all of us must continue the struggle toward understanding what works in therapy.

**DR. KILPATRICK:** My colleagues have developed two online training courses about evidence-based treatments for PTSD. Trauma Focus CBTWeb is for child trauma, and the other is CPT, or Cognitive Processing Therapy Web, which has only been online for about a month. Trauma Focus CBTWeb is a nine-hour course and has had more than 60,000 users. There has not been evaluation of these kinds of methods in terms of what is the best way to use them. Could they be used independently? Should they be used before going into more in-depth training? Should they be used as a reinforcer? I would recommend that there be some evaluation of these kinds of approaches. We like them very much. We can give some great testimonials, but I am not sure we have information about how online courses work.

The second thing is if we are talking from a policy point of view, many of us around the table are pointy-headed intellectual researchers; therefore, data and studies are very important to us. I have observed that many policy makers do not

like data. I think there is power in the personal story. How can we appeal to both the researchers and the policy makers?

**DR. GOLDENBERG:** What do primary care physicians think about psychiatric illness? And is it stigmatized there? Is the psychiatry clerkship a place where stigma reduction can happen, or does it happen just by exposure? We talked a great deal about exposing people to patients with psychiatric illness. Is that a place where stigma reduction or promotion happens?

**DR. TYLER:** During the Cold War and first Gulf War, I studied fatal training accidents involving armored track vehicles in deployed organizations in Germany. What struck me the most was the wonderful way that soldiers of all ranks took care of each other in these perfectly horrible situations. I think there needs to be more examination of how that happens, and what makes it work.

**DR. BENEDEK:** I was very much impressed by Dr. Pescosolido. What I learned from her was that we have made some progress regarding stigma in some pieces of mental illness, and we have gone backwards in others, particularly with substance abuse.

I also would echo the importance of figuring out what causes people to drop out of treatment. What is the tipping point that makes people enter treatment? It may be very different for different people. It is supposed to be different for different people.

**DR. NAIFEH:** Are we trying to make it so that every single person who could potentially benefit from treatment is both willing and able to seek treatment, and stay in it for the full course? Is that realistic? Is it even desirable? And if not, what are we willing to tolerate? What is a realistic and desirable goal in terms of getting people to seek services and to stay in services? At what point does the cost outweigh the benefits?

**DR. GUIMMOND:** As a child-focused person, I have been thinking about how children are integrating messages about mental health. There are so many concerns about over-treating or over-labeling kids.

**DR. BIGGS:** What can we do to change the perception of threat that someone with mental illness might have or impose? Ultimately, we are talking about helping the individual man or woman. The perspective I have is that there are three things that need to be kept in mind. How does he or she see the world? How does the world see him or her? And how does that person see himself? That is the ultimate focus.

**MS. DICHTTEL:** From a nursing perspective, I think stories are important, and I think buddies are important.

**DR. SCHOR:** I am not sure that we have emphasized a total workforce development approach. What skills do people need to have at different work force levels? I have not heard risk communication mentioned. That may be primary prevention, but the way in which you discuss this risk may actually mitigate the impact of the injury and how it is perceived. I am not sure that we have emphasized that enough.

**DR. HOWE:** Sonja Batten pointed out that from the focus groups, a reason for a person not getting treatment has to do with security concerns. What we have not addressed at all is the possibility of changing that structure. I may be optimistic but it can be changed. What I am talking about is the military's structural policy of how it handles confidentiality. In the early days of HIV infection, there was a new policy that came out when it was essential for the military to identify the source of HIV. They made some new rules regarding confidentiality for people who would acknowledge, for example, that they were gay. Similarly, there used to be a concern about commanders going on fishing expeditions. That has been changed as a matter

of policy very profoundly, so that it could be that inroads in those areas could make it easier for active duty persons to go for treatment.

**DR. SHALEV:** Stigma is a bit of a heavy word. We are dealing with belief systems, so maybe we should more closely examine what people believe about themselves and others. It might be better if we use other words.

**DR. BATTEN:** We need to work with people on developing more flexible ways of looking at the world, understanding there are lots of possible alternatives and interpretations.

**DR. HOLLOWAY:** I recommend one further conference, primarily focused on barriers to care and forget stigma. Half the attendees of the conference should be officers who have commanding responsibility, NCOs, and at least a quarter of the professionals should be primary care doctors to consider these same issues.

**DR. URSANO:** Great comment, both as an intervention and as an education activity for all at that conference.

**DR. ARNOLD:** I would like to include in that conference people who have actually had these injuries, the consumer.

**DR. ESTROFF:** Two concerns. One is that this is not a randomized controlled drug trial, and it is going to take a long time. Tom has heard me say this over and over at the Carter Center, and this sort of anxiety about measuring and doing is going to take a long, long time. I see the change from when I started teaching medical students 30 years ago to what I see now, and many of the things that we find problematic are no big deal to them. Gender issues, ethnicity, they are in a different place, and who knows why they changed, but it is going to take a long time. We should not expect that we will be able to see an effect like that in the time span of our studies, which are totally arbitrary in duration. Research is not the same thing as knowing and listening. It is not clear to me that there has been enough of that. It is just not a substitute. A survey and symptom scale is not going to tell you what you need to know, with all due respect, at the level that we need to know.

**DR. BROWN:** In closing, we have achieved one of the primary goals of this conference, bringing people from different disciplines and fields together to build relationships and bridges between one another. Thank you so much for coming.

**DR. URSANO:** I would like to thank everyone for your outstanding contributions.

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