

Insights and Innovations in Community Mental Health

The Erich Lindemann Memorial Lectures

**organized and edited by
The Erich Lindemann Memorial Lecture Committee**

hosted by William James College



**WILLIAM JAMES
COLLEGE**

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Foreward

The Erich Lindemann Memorial Lecture is a forum in which to address issues of community mental health, public health, and social policy. It is also a place to give a hearing to those working in these fields, and to encourage students and workers to pursue this perspective, even in times that do not emphasize the social and humane perspective. It's important that social and community psychiatry continue to be presented and encouraged to an audience increasingly unfamiliar with its origins and with Dr. Lindemann as a person. The lecturers and discussants have presented a wide range of clinical, policy, and historical topics that continue to have much to teach.

Here we make available lectures that were presented since 1988. They are still live issues that have not been solved or become less important. This teaches us the historical lesson that societal needs and problems are an existential part of the ongoing life of people, communities, and society. We adapt ways of coping with them that are more effective and more appropriate to changed circumstances—values, technology, and populations. The insights and suggested approaches are still appropriate and inspiring.

Another value of the Lectures is the process of addressing problems that they exemplify: A group agrees on the importance of an issue, seeks out those with experience, enthusiasm, and creativity, and brings them together to share their approaches and open themselves to cross-fertilization. This results in new ideas, approaches, and collaborations. It might be argued that this approach, characteristic of social psychiatry and community mental health, is more important for societal benefit than are specific new techniques.

We hope that readers will become interested, excited, and broadly educated. For a listing of all the Erich Lindemann Memorial Lectures, please visit www.williamjames.edu/lindemann.

The Erich Lindemann Memorial Lecture Committee presents

THE THIRTY-EIGHTH ANNUAL
ERICH LINDEMANN MEMORIAL LECTURE

Collaboration Between Peers and Professionals: How Lived and Learned Experience Contribute to Recovery

Knowledge, skills, and perspectives in mental health work come from both those who have learned it through professional preparation and those who have lived it themselves and through family and community. This calls for collaboration between these (sometimes overlapping) groups. And both should involve those receiving mental health services in the care process as participants rather than passive recipients, as they can bring inspiring stories of recovery. This Lindemann Lecture brings together mental health peer and professional practitioners to explore and illustrate these principles.

Speakers

Jackie K. Moore, PhD, Chief Executive Officer, North Suffolk Mental Health Association

Katherine D. (Kitty) and Michael Dukakis

Zohreh R. King, BA, CPS, Director of Recovery, North Suffolk Mental Health Association

Derri Shtasel, MD, MPH, Executive Director, Kraft Family National Center for Leadership and Training in Community Health, Partners HealthCare; Michele and Howard J. Kessler Chair in Public and Community Psychiatry, Massachusetts General Hospital; Associate Professor of Psychiatry, Harvard Medical School

Moderator

David G. Satin, MD, DLFAPA, Assistant Clinical Professor of Psychiatry, Harvard Medical School, Chairman, Erich Lindemann Memorial Lecture Committee

Friday, April 24, 2015, 2:30 – 5:00 pm

*Massachusetts School of Professional Psychology
1 Wells Avenue, Newton, MA 02459*

Introduction

Stanley Berman

I wanted to just welcome you, say that I am absolutely thrilled to be able to welcome you to our now 38th Annual Erich Lindemann Memorial Lecture. Dr. Satin, Dean Abby, and the planning committee, Dr. Mervin and others, have honored this remarkable man's contribution year after year. It is always an engaging and important conference. We are also very honored to have such a distinguished teaching faculty, and we want to welcome all of our speakers and thank the Dukakis both as well for joining us. Thank you very much, and I would now like to pass the talking stick back to Dr. Satin.

David Satin

Thank you, Stan. The other sponsor is the North Suffolk Mental Health Association. It was an early partner with Dr. Lindemann in developing a community mental health program in collaboration with the Massachusetts General Hospital. The Chief Executive Officer, Jackie Moore, has been very supportive and very interested, and an active participant, when she could with the many other duties that she has, and now she will help us by presenting at this lecture. I remind you that continuing education credits are available for those who register for them with Dean Abby and complete the evaluation form after the lecture.

The title, as I said, is "Collaboration Between Peers and Professionals: How Lived and Learned Experiences Contribute to Recovery." The presenters will be Jackie Moore first, Kitty Dukakis supported by her husband Michael, Zoreh King, and Derri Shtasel. That will be followed by a panel discussion among the presenters and then open to the audience to contribute and continue the discussion with not only questions, but your own ideas and your own experiences.

By way of introduction, let me say that Erich Lindemann clearly identified himself as a traditional mental health professional; a psychologist first, a psychiatrist, and a psychoanalyst. For prevention and treatment of mental health issues and for theory and research in this field, he looked to the traditional mental health professions: psychiatry, psychology, social work, and psychiatric nursing. He broadened his view of this field to include the social sciences, to understand the social context of health and illness, and worked closely and tried to incorporate social psychology, sociology, anthropology, and also epidemiology to lend public health skills in tracing sources and distribution of pathogenic agents in vulnerable populations.

His hallmark expansion of the view of participants in mental health work was partnership with key community leaders and community based professionals as sources

of understanding of the community and naturally placed resources that mental health professionals can strengthen. He knew of advocates for populations in need, such as the National Association for Mental Health and the Association for Retarded Children, but I have not found any evidence that he looked to professional collaboration with peer groups. During the latter part of the community mental health era and the movements for civil rights and minority rights, the concept of new professionals grew, advocating for non-traditional preparation for traditional mental health professional roles and for new professional roles. This raised the question of the equivalents to traditional mental health preparation and practice, their working relationships with traditional professionals, their scope of practice and licensing, and the places of these two groups in mental health programs and mental health institutions.

Today we look into yet another iteration of mental health practitioner, the peer practitioner. Peer support and treatment has grown in number and popularity as an adjunct or alternative to traditional mental health treatment. How do these two groups relate in the effort to prevent, relieve, and rehabilitate mental health problems? Are they necessarily alternative or even rivals? Or can they complement and even enrich one another? We are fortunate to have several speakers who have experience in the contributions of these two groups and their working relationships.

Jackie K. Moore, PhD

Chief Executive Officer, North Suffolk Mental Health Association

Introduction by David G. Satin, MD

To start off with let me introduce Jackie J. Moore, Ph.D., who received her Ph.D. in Clinical Psychology from Florida State University with a focus on Alcoholism. She participated in clinical, teaching, and directed several academic and state mental health programs. She was the Director of the Massachusetts Mental Health Center and was Area Director of the Southeastern Area of the Massachusetts Department of Mental Health. Since 2005, she has been President and Chief Executive Officer of the North Suffolk Mental Health Association.

Jackie K. Moore, PhD

Welcome. Can everybody hear me okay? It's great to see everybody here, this lecture has grown over the years and it's nice to see all of you here. So I'm going to sort of kick us off and talk a little bit about my perspective and why I think this is important and some of the work that we have done at North Suffolk. There are people in this audience that know way more about recovery and collaboration than I do, so I look forward to the discussion that we have afterwards. But I want to say first sort of where my interests came from. I was trained back in the 70's a long time ago, and it was sort of traditional clinical training so I was trained to assess and write treatment plans and tell people what to do to make their lives better. And I did that, and I thought I was pretty good at it. I actually worked and did my dissertation on aftercare with people with alcoholism, but I was trained as a child psychologist so I worked in a pediatric setting and told people what to do with their kids...and then I had children of my own. You've heard that I'm sure, but one of the things that struck me was when I had one of my children who was colicky and cried every night from 7:00 to 10:00. And I held him the entire time, rocked him, sang to him, and cried myself. My husband would say, "Just put him in bed and let him cry." Well that's what I would have told someone to do if they had come to my office and wanted to know what to do with a crying child. And then I realized I am not a mother who can put a crying child down and leave them. I'm just not, and that doesn't mean that it is wrong for someone who can, it just became very clear to me that I am not one of those.

So I learned that it was an important lesson for me because from then on, in my practice when I was a practicing psychologist, I tried always to talk about, "Ok, these are the things that I'm going to tell you that you need to do. Now let's talk about whether you

can. And if they don't fit with who you are, let's find what will work and what you can do because the same answer doesn't work for everybody. So that was my sort of lesson and no body was talking about any of this stuff. There wasn't a name for it, it was just my lived experience as a mother. But what I did learn from that I think is how important collaboration is when you are working with somebody it is not for me to tell somebody how to live their life. I can help figure that out, but it wasn't for me to prescribe it in that way. So that was a lesson that I had. I want to start by reading you a quote and it's a fairly long quote and it's actually paraphrased because it would be even longer, but to sort of set the stage. Some of you may recognize these words. So here is the quote, because I cannot say it as eloquently as this, 'There's a difference between knowledge and wisdom. Students in the various mental health related disciplines are required to recognize and to master a specific field of knowledge. However students are not required to seek wisdom. Most students emerge from their studies full of knowledge or the abilities to recognize things, but they lack wisdom or the ability to see the form or essence of that which is. For example, when we teach our students about the heart, we teach them that the heart is a pump.

A type of organic machine with valves and chambers, and indeed in time they come to recognize the anatomical heart in all of its detail. After successfully passing their final anatomy exam, we say that this student knows about the heart. But in wisdom we would have to doubt this statement. Wisdom would seek the form or essence of the heart. In wisdom we would see that the anatomical heart, which we have given our students to study, is nobody's heart. It is a heart that could belong to anybody and, therefore, belongs to nobody. Wisdom would have us understand that there is another heart. There is a heart that we know about long before we are taught that the heart is a pump. I am speaking here of the heart that can break, the heart that grows weary, the hardened heart, the heartless one, the cold heart, the heart that aches, the heart that stands still, the heart that leaps with joy, and the one who has lost heart. Wisdom demands that we teach students that human science is about the essence of *this* heart, the human heart. Not the pump that beats in anybody but the one that lives in my body and in your body.'

That's the end of one quote, I'm going to read another quote now. 'At the age of 17, I experienced the on slot of distressing voices. Following two weeks of such torment, I was locked in a psychiatric institution and diagnosed with schizophrenia. After a brief interview with a psychiatrist, I was taken to a room and injected with an antipsychotic drug. When I woke up from that drug-induced stupor, I would barely recognize myself. Just weeks before I had been a strong athlete who excelled in sports. Now I was in a chemical straight jacket. It is widely assumed that antipsychotic drugs are helpful because they suppress psychosis and restore one to a more familiar sense of self. In my experience, antipsychotic drugs were not helpful. The antipsychotic drug replaced me

with a drugged me and worst of all the professionals kept telling me how good this drug was for me. They kept telling me that I would have to keep taking this medication for the rest of my life.

They said that I should be grateful for modern psychiatry that there was a medicine that could so quickly restore my functioning, and they said my hallucinations and delusions were gone. I was more in control and stabilized. From my perspective, things appeared quite different. I did not feel better. The so-called hallucinations were still there although they were no longer a bother to the people around me. I was not more in control, but rather I felt controlled by the medication. I was becoming a shadow of my former myself, unable to think or feel. I was not beginning to function. As far as I was concerned, this help was not helpful. What I am describing here is a clash of perception between the psychiatrist and myself, and its important to remember that this clash of perceptions went largely unspoken and unacknowledged. We did not sit down and have a thorough discussion of our divergent perspectives, and because of his enormous power in relation to me, his interpretation of me became the only valid story. It was the truth and my story, my experience, and my voice were silenced. I was told that best I could hope for was to take my medications, avoid stress, and cope. I became enraged. I also made up my mind to become a doctor. Imagine what my doctor would have said to me if I had announced at age 18, having virtually flunked out of high school with a combined GRE score of 800 and a diagnosis of Chronic Schizophrenia, that I was planning on getting my PhD in Clinical Psychology- delusions of grandeur.

Now people, some of you know who wrote that. That is just what this remarkable woman did. In 1995, I heard Dr. Patricia Deegan speak these words and that experience changed me as a clinician, as a professional, and most importantly as a person. It crystallized for me what I had been unable to articulate for myself about my dissatisfaction and discomfort with my craft over the previous 20 years. Her wisdom and insight, and if you got what I just read is from something she wrote called *Recovery is a Journey of the Heart*, if you have never read it just Google *Recovery is a Journey of the Heart*, Patricia Deegan. It is just life changing. Her wisdom and insight gave me the gifts of perception and understanding of what had been haunting me as I had been taught during undergraduate and graduate school but that was so inconsistent with my natural optimism and belief in people and conviction that there is always hope for a brighter future. I've been fortunate to meet many inspiring people in the interim. And about 15 years after I heard Pat Deegan, I met this woman Zohreh King. We had written a proposal to implement some services for the Department of Mental Health, and the proposal required that we have a recovery-oriented culture and that it be person-centered. So I did a lot of reading and I learned a lot about recovery from what I could read, and we wrote a proposal and we were awarded a contract. And part of it required

that we hire peers, so we wrote them into the contract and I didn't know what I was going to do with a peer, and I should be ashamed to admit that. And we hired Zohreh, she was our first peer specialist, and I think that initially we sort of put peers on the team and we weren't really sure what they were supposed to do. But Zohreh is a wonderful advocate, and I'm not really sure why we had our first conversation about it, but we did. And she said, "This isn't what peers should be doing." So one thing I give myself a little credit on is that I'm fairly intelligent and I know what I don't know, and I know I didn't know this but she clearly did. So sometimes I just need to get out of people's way and say "Go do what needs to be done, and I'll support you in whatever way I can."

What I did understand was that recovery had to be integrated into the fabric of our organization, it couldn't be our peers talking about it, it couldn't be me talking about it, it couldn't be a few people. We all had to understand recovery, we had to believe, we had to live and breathe recovery. It had to be part of who we were. So we hired peers and peers specialists. We have been working to integrate that goal into our setting. Zohreh was promoted to the Director of Recovery for our agency because it's not just in our CBF, Community Based Flexible Support Programs, that we need to be recovery oriented but we need to understand throughout our clinical programs. And I knew that we weren't there, so we worked to change our organizational culture. Our goal is to be an organization that embodies the definition and principles of recovery. Zohreh is the person who keeps me focused on the things that we need to do to do that. So for some context, let me offer the latest working definition of recovery as articulated by SAMHSA, the Substance Abuse and Mental Health Services of America.

So recovery is defined as a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. And there are four major dimensions that support a life in recovery. Health- overcoming or managing one's disease or symptoms, and for everyone in recovery making informed healthy choices that support physical and emotional well-being. Home- a safe and stable place to live. Purpose- meaningful activities such as a job, school, volunteerism, caretaking, creative endeavors, and the independence, income, and resources to participate in society. And the fourth is Community- relationships and social networks that provide support, friendship, love, and hope. And there are 10 guiding principles that have also been defined by SAMHSA. Recovery emerges from hope, it is person-driven, it occurs via many pathways, it's holistic, its supported by peers and allies, its supported through relationships and social networks, its culturally based and influenced, its supported by addressing trauma, it involves individual family and community strengths and responsibilities, and its based on respect.

From my point of view there have been a number of keys to our ongoing transformation. I would not say we're there yet, but we are working on it. Choice...always

remembering choice options, information, role models, being heard, developing and exercising a voice, opportunities for bettering ones life. Those are the features of a human interactive environment that supports transition from not caring to caring, from surviving to being an active participant in one's own recovery process. Creating such environments are the skills that mental health professionals must master. People with psychiatric illnesses are human beings with human hearts. Hearts as real and as vulnerable as ours are. So we have to understand people as people, we have to understand the experiences as they experience them. And we have to be willing to be in a partnership that allows us to walk down their road, not our road, their road to recovery.

Recovery doesn't refer to an end product or result and it doesn't mean that a person is cured, and it doesn't mean that they are stabilized or that they are maintained in some way. Recovery involves a transformation of a person in which they accept themselves and whatever limitations they may have and they discover new possibilities, and that's our job as partners in that. It's a process, it's a way of life, it's an attitude, it's a way of approaching each day, it's not linear but I see it as progressive. And it's never our role to judge who will and who won't recover, and I think one of the things that has just really struck me over the years in talking with people is how many people have been told how limited their life is going to be because of an illness. And that's not our role, our role is to help people find possibilities.

Our job is to create environments in which opportunities for recovery and empowerment exist. Our job is to establish strong supportive relationships with the people we work with, it's to be bold and brave and daring enough to remain human while working in human services. Some other things that I think we have tried to do in working with people because some of us have been around a long time and you get the way you are, however you are. Some of the things that I think we need to do with our staff, we need to rebuild passion. What ever brought us into doing this work, we need to find that passion again and not be jaded by whatever it is that has.

So I think it requires our staff to find that passion that they had to help and not to be detached or routinized in doing that but to see each person as an individual and figure out how they can actively engage and work with us. I think we need to build inspiration and a true belief in recovery. Those are not just words, we have to believe in our hearts that people do recover. And I've seen it, and if somebody hasn't seen it, then I think that's part of what we try to do. Zohreh and the peers that work with us have luncheons and other times when they share their stories with staff so that people can hear stories of recovery and learn more about that from that perspective. Think we have to change ourselves from treating illnesses to helping people with illnesses have better lives.

We can't see people as a diagnosis, we can't let a diagnosis define people, but rather we have to help people set goals that improve the quality of their lives. We can't be

satisfied with just symptom reduction or even just look to symptom reduction. I think we have to be life-based not diagnosis based, our assessments need to describe a whole life and not just a diagnosis that the person has. The goals need to reflect life-goals, not limited to reducing symptoms or other clinical goals. I think we need to move from caretaking to empowering, to sharing power and sharing control. When I was trained we were caretakers we were the ones in control, we were the ones who knew what was best, we had the power. That's just a lousy way to deliver health care, isn't it? I mean, when I think about my own health care. I just had a physical this morning and my doctor sat with me and asked about the things that were concerning me and we talked about, "Okay, here are the things we might do...here are the things that might help." Well that's the way to deliver health care, and just sit and talk. I appreciate that and I think that it would be good if we were more empowering and we shared our control and we collaborated on whatever we were doing. And I think recovery in practice sort of rejects the role of the caretaker on the person who knows and shares the risks and control.

I think we have to learn to be comfortable to have coworkers who have a mental illness, we have to be comfortable with the multiple roles that we see in our workplace now. It requires us to break down those walls that keep us separate because you're this and I'm this, and that's not easy to do but we have to see each other as collaborators and coworkers. For us in our setting with peers we have to make sure that our staff sees that people are coworkers and not just see people as an illness. I think that working alongside each other is probably one of the ways to reduce stigma, which is also another thing that we could do a whole other thing on stigma if we wanted to. I think that it's a transforming experience, and I hope for all of our staff that we have to learn to value the subjective experience. Most of us, or I should just go with what I was taught. I was taught to observe and code and record objective information and put it all together and then you come up with whatever you come up with in the process with the treatment plan. Recovery plans are collaborative, and you can't just appreciate what is wrong with the person or the diagnosis or the clinical factors. You have to understand that person's experience, what happened to them, and understand their life and where they are from their experience.

We need to try to understand what it is like to be that person to understand what frightens them, what motivates them, what they care about, and what their hopes and dreams are. So we are not focusing on an illness and getting rid of those symptoms, we're focusing on a quality of life...and that's subjective. You have to step out of the objective part and get to know a person. We have to create therapeutic relationships. I think recovery work suggests to me that therapeutic work is more than just symptom reduction or symptom relief. It really relies on the same foundation that you need for a therapeutic relationship. Ongoing, trusting, collaborative working relationship, shared explanatory

story of how the person got to this point, a shared plan of how to achieve their goals. I think that recovery work, true recovery work, involves lowering our emotional walls and becoming partners. I think you would hear from people that we are most helpful when we are personally involved and they feel that we have a personal investment. That may fly in the face of some of the boundaries...so boundary discussions are rich and we need to have them because they're changing.

We can't be detached experts that give people maps and directions, but we have to walk along with people and hear their journey. We have to understand the process of recovery. I think we understand, or I used to understand...the older I get the less I understand...that monitoring progress as a medical process so we know how to diagnosis illnesses and we know how to treat and we know when symptoms are relieved and those kinds of things, and we alter our interventions and plans based on our assessment of that process. But recovery work monitors a very different process I think. First of all there has to be hope, there has to be the belief that something better is possible, there has to be empowerment, so that people believe in themselves. There has to be self-responsibility, its not my job to get someone else better, its their job. And there have to be meaningful roles apart form the illness. I think if we are really practicing recovery, we help people live with dignity and we help them recover with dignity.

We have to be involved in community and that's why this is sort of an appropriate conversation at the Lindemann lecture because Lindemann was an early pioneer in community psychology. We have to be involved in community. Recovery helps people attain meaningful roles in life, and they do that by integrating into a community not by staying outside of the community. It cannot be achieved when people are segregated, when they are put into institutions or segregated out of the community, people need to be part of a community and we need to make sure that happens. Recovery is inclusive of everybody, people who are homeless, people who you might not want to hang with all the time, it's got to be inclusive. We have to live the recovery values to make our organization be truly recovery-oriented, we have to live the values of recovery, we have to understand that they apply to all of us, and we have to be active with growing ourselves if we want to be effective.

Whatever our job title or daily duties, we have a common responsibility to help each other change our lives. Today a belief in recovery and the possibilities and the opportunities it represents are essential. We have to adamant about ensuring access, eliminating disparities, breaking down barriers, focusing on strengths and abilities, and helping people progress in recovery. We know that stigma is a barrier so powerful that some people choose to suffer with illnesses in silence and private rather than seek help, so we have to be relentless in our efforts to educate and inform and support and advocate. Our real job is to instill hope, to believe in peoples capacity to recover, and to

ensure access to treatment and services that work. Our doors should be open, our skills should be honed, and our hearts should be in the right place. Eric Lindemann believed that mental health profession techniques could help individuals, especially children, to cope with life crises; life events as profound as family death or as commonplace as moving to a new home. His work showed that intervention before predictable occurrences, such as starting school, can safeguard against serious emotional problems later on. Equally important, was Dr. Lindemann's belief in the importance of community in establishing and maintaining wellness. He recruited people from throughout the community, clergy, town government, police governments, other institutions, all to outreach and engage. That continues to be a hallmark of community mental health. Every one of us draws strength from our families and friends, we find security in familiar surroundings. If we want to give the people we work with every change of happiness and productivity, they need to be able to draw on those sources of strengths as well. SAMHSA has articulated the messages that we want to get out; behavioral health is essential to health, prevention works, and when the right kind of supports are in place, treatment is effective and people recover. Thank you.

David Satin:

Thank you. I had two quick associations. One is that the definition of recovery that you mentioned sounds very similar to the definition of mental health. Sorry...the definition of recovery that you mentioned sounds very similar to the World Health Organization's definition of mental health with a broad encompassing of function and of meaning in life and of positive aspects of life. The other is the experience of dealing with mental illness from the patients point of view. One of the most enduring effects on Lindemann's life was an experience he had as a teenager when his grandmother was hospitalized for melancholia, severe depression. He and his grandfather were excluded from the hospital because they made trouble, they complained that she was not being fed. Actually she refused to eat, but they blamed the doctors and the doctors would not let them participate and that led him to a life long effort to make medicine more humane, more encompassing of family and of community. And that he sought a prestigious of position as he could, and finally achieving a professor of psychiatry at Harvard Medical School, Chief of Psychiatric Service at Massachusetts General Hospital, he could change medicine and psychiatry to become more humane and more socially oriented. But always working with professionals to have them have this perspective as you described

Katherine (Kitty) and Michael Dukakis

Introduction by David G. Satin, MD

Our next speaker is Kitty Dukakis. She has Masters degrees in Broadcast and Film and also in Social Work from Boston University. Her concerns are for women's rights, human rights, mental health, and the arts. She's worked on issues of the Holocaust and genocide and finally today with the anniversary of the Armenian genocide, and she is a member of the President's Commission on the Holocaust. She's an author of *Now You Know* about her battle with addiction and depression, and the book *Shock: The Health Power of Electroconvulsive Therapy* about the effectiveness of this treatment modality on which she has lectured extensively. She also participates in a support group which is self-directed, and consults with mental health professionals only as they find it useful. Let me also introduce Michael Dukakis, who is here on Kitty Dukakis order as a back up and as somebody who has traveled this road with her. He's earned degrees at Swarthmore College and the Harvard Law School, he spent eight years in the Massachusetts State Legislature and served three terms as Massachusetts Governor, and was the 1988 candidate for President of the United States. He is now a distinguished professor of political science at Northeastern University, and a visiting professor of public policy at the University of California at Los Angeles. I think it's Kitty who will take it.

Katherine (Kitty) Dukakis

Great, thank you. I'm glad Michael has joined our table. It does make a difference to have at least two men sitting with four other women. I'm going to quote something from my late father that he used to say. He was much older than I am now. I'm close to 80, but he was close to 94 when he passed on and was still conducting at times from a wheelchair. So he was a very extraordinary guy and was very close to my sister and myself as we were growing up. And when I first admitted that I had a problem with alcohol, I made sure that he was one of the first people that I called and his response was, "You couldn't be." And I said, "Why, Dad?" And he said, "Because you are Jewish and you're a woman." And I said I could have used that excuse but I didn't. And so I took him to an open meeting of AA that he was allowed to go to, and we got back in the car and he had tears in his eyes and he said, "How fortunate you are to have loving people around you who understand what you've been going through and what you are going through, and who are going to be your partners for a long, long time."

And I had been in recovery for almost 30 years with two slips when I just couldn't take it anymore and I had a full day of drinking, on two separate occasions. But that

hasn't happened in a long time, and I hold close my relationship with the organization of AA. We're not supposed to talk about it, but that's absolute nonsense as far as I'm concerned. Because this is the organization that holds us together, and it is a very telling...special organization of all kinds of people from all walks of life, and from all ages. The one good thing for me, when we go to California, I go to AA and I don't feel like the oldest person in the group. And there are many, many former actors who are a part of my group who are well into their 90's, many of them will be living I'm sure until 100. So I feel very fortunate that Michael and I did not see one drop of snow this year, nor have we for the last 20 years. We are in Westwood, California where he teaches and he walks from our condo. And we had made a pretty good decision, I think, 20 years ago when we decided to go there. Our first grandchild was born in Los Angeles and I said to Michael, "We are never going to see her unless we make a decision about coming out here." And so we are out in Los Angeles, Ally made a decision when she was 17-years-old that she would come East to go to school, and chose from Los Angeles to come to Bates College in Lewiston, Maine. And I was sure we was not going to last, and she did. She loved that school and she was very much involved in Obama's campaign in Lewiston, who had never allowed students to be involved in the umm...Michael help me....Excuse me? The caucus work, right. And Ally Dukakis made a decision to get involved and there were 11 of them including Ally who were representatives at Bates College at that convention. The other thing is that I've had a little bit of distaste for the press in the past, and fortunately I have two members of my immediate family who are members of the press.

Alexandra Jane Dukakis is one of them and she is a very hard worker for ABC television in Washington D.C., and the other is my daughter in Denver, Colorado. And Andrea is a reporter and has been for 30 years with National Public Radio with Denver NPR and just finished, and of course I'm her mother so I have a very strong bias. Just finished an extraordinary piece which you can click on if you click onto AndreaDukakis@NPR.org about a person who was released from jail as a parole, and she followed him for 7 months and wrote this extraordinary piece, I think, about what it was like to be a returning to society human being without any preparation. And just left off on a side street in a major city, which happens all the time to prisoners around the country. You will, I think, have an emotional reaction to her piece. I'm hoping that they are going to make changes in Denver and in other states when they hear about what happened with this case. The young man in this particular case has been out now for almost a year, and is a worker at a construction site, has his own apartment. And after a very shady beginning, not getting into trouble but a very rocky beginning, he is doing very well. And he is from Rhode Island, he's from Providence, and I think that was one of the things that allowed him to talk to my daughter since she was close to his home. But

he was left with a \$100 voucher, he didn't know what that was after having spent 30 years in jail. So the story goes on, and if you click onto her website you can see what happened.

Michael and I are blessed with, I have to count in my head every once in a while, but 3 of our own children with children of their own, and we have 12 grandchildren. Four of them came to us because our daughter-in-law's sister was killed tragically in a car crash with her four children in the car and they are now residents of Newton, Massachusetts and doing, I think, extremely well. I'm proud of my kids for taking them in, and they have adjusted to life in Newton, Mass. And the Newton school systems have been phenomenal. And we see our kids who are here, there are 7 of them in Newton. And we visit with our kids in California in San Francisco and in Denver. They are now old enough to travel to see us without their parents, which pleases them enormously because they tell us that we don't tell them what to do and their parents do.

One of the important parts of my life today is not only my own recovery from very debilitating depression but my helping others with a product, I'll call it, called ECT or electroconvulsive therapy. And I'm always amazed when I'm in a group when people tell me that they didn't know what ECT meant. From the very beginning I was very fortunate for almost 17 of very difficult depression which medication and talk therapy did not help. And when I had my first treatment, I was on my way to recovery. And I see young people and older people, these are all ages, form different walks of life, who have debilitating depression who have this treatment. And I have been blessed, and others could be, with the most extraordinary ECT psychiatrist and human-being that I know, except for my husband, and that is Dr. Welch who is at McLean Hospital now, he was at the Mass General. He has an understanding of his patients and never, ever lets people go, so to say. He never, ever gives up on anybody and some of his patients are very difficult. And I am so pleased that Michael and I had a chance to meet this man 30 years ago at the Mass General, and he has just been like a guardian angel for me in my recovery. I have ECT after treatment earlier, once every 5 to 6 weeks, and I was to have one yesterday and the anesthesiologist took one look at my neck and my story and said that she could not take me yesterday and had x-rays. I fell a week and a half after we left California because I took a wrong turn walking out of my bedroom and broke my...And we have lived there for 51 years, I mean there should be a knowing of where I'm going but I didn't. And I was going to the bathroom, it was pitch black and 2 o'clock in the morning, and I walked to what I thought was a door but it was a bookcase of about 250 books. And I pulled it, and it fell on me with all of these books surrounding me, and it buried me under the book case and the books. And for a short period of time I thought I was not going to make it. And Michael heard me scream, got up, and could not find me because I was buried underneath this torrential bookcase and books. And I'm alright today, I'm not without

pain, I'm walking slowly and holding onto things as I walk. I have black and blue parts on most parts of my body, but it could have been much, much worse. I have so much gratitude for what I have and that's the things that recovery has taught me.

Certainly the message in AA, but also the message of my support group, Recovery with ECT. I started that group because I met so many people who were still hurting and wanting to have some way out of that hurt. And so we have been meeting now for about 5 years. There are a core of us of about 25 but there are many more who come and go with us. One of the unique things about this group is that we are men and women, we are husbands and wives, we are mothers and fathers, we are mothers and daughters, and we sisters and brothers, who are involved either ourselves or with somebody who has been involved with ECT. And they come with many questions when they first begin to be confronted with their own disease of depression, what it means to have this treatment. So we are a group that works with each other, we meet every month at our house and when we are not here, my Vice Chair who is in Lexington takes the group and she is terrific. But all of these members are well into recovery and call on each other when they are having any kind of difficulty. I'm going to stay involved with this group for as long as I can. I told Michael that one of the things I was going to talk to this group about was the other thing that I'm involved with.

And I've just met with the head of the Longy School of Music in Cambridge, Massachusetts, and there is a program that I've been reading about for two years in Los Angeles called El Sistema. I don't know if anybody in this room knows about this group. Any of you ever heard of it? Okay, one...two. This was a group started by an extraordinary man from Venezuela and when he was 9-years-old, he started the violin with the El Sistema group in Venezuela and decided when he was 14 or 15 that he was going to be a conductor rather than a violinist. And of course, I adore that story because it reminds me a bit of my dad and some wonderful, lovely stories. My dad was a wonderful joke-teller and tells a story about one day going to the violin section at the Boston Symphony where he played the violin and one of the wonderful members who just passed away last week, said to him...and he was feeling in his glory because he had had a good night of conducting the night before...said to him, "Where were you last night?" And my dad had been conducting the orchestra, and he wasn't in the violin section. And dad was a bit deflated, but he knew he was teasing him. This group has been working with kids mostly from minority communities, North African, North American, Black Americans, Latinos, and Asian. And it has been going on in L.A. for a good 8 years now, I think a little longer, where families adopt kids from these communities and help buy instruments for them. These are kids who choose, who have never heard a classical musical symphony, and they are now playing these instruments that are provided for them and the lessons. But the wonderful story about Boston, and we're doing this here

and I'm going to be involved, with raising money for these instruments. But one of the wonderful things that we are tutoring these youngsters while they are having their lessons for their instruments. It is a wonderful community that is brought together in very special ways, and so exciting. And also their future audiences for places like the Boston Symphony Orchestra. And so something that I'm going to look forward to working on.

But recovery is very important, and I speak often to psychiatrists some of whom in different parts of this country don't know what ECT is. I do grand rounds at hospitals in different parts of the country, and I will continue to do that. It is important for physicians and for budding physicians who are in medical school to know about what is available and that this particular program is available to them. Michael and I lecture every year at USC, at the University of Southern California at the Medical School, that with kids, young people, who didn't know about ECT and never heard about it. And finally, a result of many of our lectures will go into internships with psychiatrists at USC.

It is very important that Michael and I stay in touch with physicians that help us in our support group and we are blessed with physicians who will come and be guidance for those who need help but also for us who are not physicians but have had the experience of ECT. And so it is always a pleasure for me to talk about it, because I see the healing power of ECT with people who have suffered for a long, long time. One of Michael's student's mothers in the South in Mississippi, had been in bed for years and he came to me and asked if I would help. And I talked to her and asked her if she would see the doctor at Duke University who I know. And she has had ECT in the last several months and is in recovery today. I never say that something is not going to work. We have a wonderful story in our family, I have one of my grand-nephews who was diagnosed when he was 4 with Asperger's and he was a very difficult kid. I don't remember that part of his life in part because I was so uncomfortable around him that I stayed away. And I'm ashamed of myself but I knew very little about autism.

Michael has been a part of that group for years, and I think Shane would allow me to talk about him now. Several years ago had an aid that was wonderful, just remarkable, in the Easton School System where my niece lives with her other two children, and this aid gave him the tools to work with. Shane has been on the Deans list at Easton High School for the last two years, and when his teachers from lower grades who had him see him they say, "That's not the child I had in class." And call him the miracle child. His field, he wants it to be animation and he is going to Leslie College in Cambridge, Mass. where I finished up my last year and where his grandmother went to school four years before she taught. And Shane and two of his friends who don't have the disease are going to be triple-mates at Leslie College. And he is an example for me about what we need to learn, what we to not turn off. Because it was so easy with Shane to not to want to be around

him, he was very difficult. And I had to learn some important lessons from him, but I am so proud of him today.

He is not willing yet to talk about his having Asperger's, he does remember those early days. But my niece says that at some point when he realizes that he can reach the lives of other people that he will be willing to do that. And that was one of the reasons that I was public about my depression and about my having ECT, that if I could help others to at least to have another chance at another life. And I remember a quote by one of the people I help saying, "I will try ECT because I want my life back." And that says it all, when someone is able to turn that corner and come around it makes not only a difference in their lives but in the lives of their families. So I applaud all of you here who have worked in this field, it is so rewarding in so many ways. Michael might have some words that he wants to add to this. You want to come up? You want to wait until after we finish this. Okay. Thank you.

Michael Dukakis

The one thing I might add is the new information technology that is available to us has also been extremely helpful in connecting experiences of many people in support groups, as you have shared. We have a website that is ECT- A Light in the Darkness, and you would be astonished at the number of people who somehow find that website or who read Kitty's blog or both and connect with us publically. We hope and expect to bring professionals form the field. But it is not an exaggeration to say that thousands have been helped by this technology and its availability. Kitty speaks with these folks all the time, and occasionally we have had to intervene in states where Medicaid doesn't understand it and won't approve it even though it is one of the most successful treatments for severe depression there is. It's fair to say that Kitty is a living example, one of the best Medicare recipients in America. I don't have to tell you folks that the availability and the breadth of our health insurance has had a lot to do with recovery.

This battle over the Affordable Care Act has weakened...this involves lives of folks and families, its important. The fact that there is this information technology out there and we can connect with people out there easily and inexpensively is an important bridge I think, between people who need help and people who have been trained to provide that help. It makes a difference, there's millions of folks who think that its like *One Flew Over the Cuckoo's Nest*. When they hear that Kitty had this, and it was really a remarkable recovery, after years and years of therapy and every antidepressant, we still have a lot to do to reach out. I'll simply conclude with this, we have come miles folks. I mean, I remember the old state hospitals. Many of you are old and you are also young, but don't kid yourself you have made enormous progress and you are a part of that and you've just

got to continue to do that. But I'm very proud of this wife of mine needless to say, and that she and others like her are willing to stand up and say that, "I have this illness, we've found a way to recovery, and we want other people to know that." And obviously, many of you are a part of the wonderful network of folks who have had a hand in that. So, it's a pleasure to be here and share some of these experiences with you.

David Satin:

Thank you both, I'm glad that you both came and were consented to participate. Just briefly, I think that Mrs. Dukakis has done two things. She talked about mutual respect and the collaborative relationship that she has had with her doctors and that she expects relationships between doctor and patient. And the second is that she and her husband are living examples of people who participate in their care, who set goals for themselves, who support one another, and who help others in the same situation by being public and by explaining what they have been through, and by advocating. So that is a wonderful contribution.

Zohreh R. King, BA, CPS

Director of Recovery, North Suffolk Mental Health Association

Introduction by David G. Satin, MD

Our next speaker is Zohreh King who has already been partly introduced by Jackie Moore so I will add only some of her credentials. She has a B.A. in English and is a certified peer specialist. I didn't know there were such, so that was a bit of education. And she is a Director of Recovery at the North Suffolk Mental Health Association.

Zohreh R. King, BA, CPS

Alright, can you hear me? I want to start off with a little story about fear. Cause we don't talk about it and part of what I have learned in my own career is that the best thing we can do is talk about it. When I was a little girl I was afraid of a lot of things...a lot. But mostly I was afraid of not being with my mother, because she was sort of the one thing that was a constant in my life. From a very young age I had a lot of very tumultuous stuff happen. I was a victim to domestic violence, I moved around a lot. I had some terrible things happen to me, and I knew that if my mother was around at least I had some sense of comfort. So when she would leave, I would cry until I was sick. And she would tell me, "Don't worry." She said we were connected by a heartstring, and if I was in pain it was not because I was missing her, it was because that string was being pulled and we could feel it at the same time. And so I always knew that because we were connected I could feel her whenever I needed to.

So last week I was doing a little bit of research on some different things because we were going to have this wellness walk. And I was going to have people make these light catchers so that they could hang them in their window and have a little light. Something fun. What I found when I was doing the little search for what sun catchers are for and why they have red string. Why does every light catcher always have red string? This is what I found. Chinese proverb, "An invisible red thread connects those who are destined to meet regardless of time, place, or circumstances. The thread may stretch or tangle, but never break." So I thought my mother had lied to me, but maybe she hasn't. So I would just like to acknowledge...from a very young age I felt alone. I always felt like I was keeping secrets, not because I felt like someone had told me that I needed to, but because when terrible things happen in your life you keep them silent. No body else seems to have terrible things.

When I became a certified peer specialist in 2008, what I found was that there were a lot of people who were keeping secrets and I was not the only one. It's not about having

a mental illness, it's about being truthful to yourself and the ones around you. You are here today because you are connected to me by a string...can you just raise your hand? I want to show the world how many people come. That is why I do the work that I do. The people in this room who come for me come because we believe in the work that we do. And I'm so proud to have so many people come because I say, "Hey, we are going to do this. We are going to educate." And it's that string that holds us together that is so very real and is not in fact my mother lying to me.

So that is really nice to know. I hope all of you are connected by a heartstring to those in your life. So if we are going to talk about mental health recovery, what does that mean? I myself consider myself someone in recovery. I was diagnosed when I was in my early twenties with a big one. You know one of those when I say to people, "Can people with a mental illness recover?" And the answer is always, "Yes, but...there is a couple of diagnoses that don't recover." And I have one of those. It's okay for me to listen to that. People tell me that. I don't always tell people my diagnosis. You probably won't hear it today because it's not one of the most important things about the work that I do. But people always tell me, "Oh yeah, people with one of those diagnoses do not recover." But I'm here to say that we do and we can.

So mental health recovery is about, yes, we can change. It's about finding connection. It's about developing a community of people that can support you so that you don't have to be alone, you don't have to be fearful, and you don't have to live in shame. And what we do at North Suffolk, and what I have learned to do by becoming a peer specialist is we talk about it. It's okay for me to say, "Yes, I have problems. I have some symptoms." I have symptoms daily, their not something that are going to go away for me. It's not something that I am trying to actively stop. I'm trying to live the best that I can, with or without symptoms, and that is the work that we are doing. There is something called a certified peer specialist. The Transformation Center in Massachusetts is the group that provides that training, although there are trainings in pretty much every state in the country now that provide training to a lot of people like myself, people with diagnosed mental health disorders, to be able to share their experiences to help others. To make sure that the kinds of experiences we had, negative experiences, experiences of being twenty-three and being told, "You are never going to graduate college. You are never going to work full time. You are probably going to need help for the rest of your life."

At twenty-three...that's a pretty significant thing to think about. That there might be sixty years ahead of you where you are going to be dependent not only your family (hopefully you have some), not only your friends, (hopefully you can keep some), the system at large is going to have to pay your bills, make sure you have a home, make sure you have something to do during the day because your friends are in school and working.

And what are you going to do at home while they are doing that? And so that is a pretty devastating thing. And I know for myself, I felt like, “Well....okay...what do I do tomorrow then? Because today I’m in school and working, and if I’m not going to be able to continue to do those things I should stop now. Because I don't want to put my effort into something that is not going to come to fruition.”

And I think that is the reason why it took me so long to actually complete my English degree, which is what was really important to me at the time. Oddly enough I don't use it all that much now, but it was still important to me to have. And it was definitely important to me to work. I wanted to be able to contribute to my community around me, and if I wasn't working then what would I do with myself? How would I make friends? How do you make friends if you don't work? Where do you go? Where do I go? And how do I support myself if I wasn't going to be making money somewhere? So recovery is about all of those things. For me one of the things that happened immediately was that my mother said, “Well you cant stop working.” She said, “Oh no, no, no, no.” She said, “You know, you only have one thing going. Your life is a mess.” And it was, when I was diagnosed my life was a mess. I kept fabric in my stove and didn't have food and somebody else was driving me to and from work. People were really concerned about me, although I don't know why. Who else doesn't keep fabric in your stove? But my mom said, “You know how to work, you are very good at work. Why would you stop doing the one thing you know you can do?” And so I chose not to, even though when ever I would go in and see my nurse practitioner she would say, “This is too much, you can't continue to do this. You are just going to get sicker and sicker and sicker.” And I just thought, “Well...I don't know any different. I don't know what else could happen to me.”

So I just kept working, and now I am so grateful for that advice that I shouldn't become a burden on the system, that I should continue to work. I wish that I had, now that I think about it, I wish that I had fought back and seen somebody different. But I didn't know, and when you are newly diagnosed and you have no other treatment to compare it to that's all you know. And so you figure that the person you are seeing is an expert. Why would you be the expert? I was the one that was keeping fabric in my stove, and people don't do that. I didn't know that until I went to see this person.

So recovery is really about finding those things, its about finding those things that you can do for yourself. It might not be the same as what everybody else does, and we often work with people who have been debilitated by the system. They have been on social security, they have food stamps, they often have spent years in institutions, they have been homeless. So the idea that we are making them into something else is probably not going to happen, but we have the ability to help them see to make change in their life. That's really what recovery is, it's the hope that you yourself can somehow determine what will happen to you. It doesn't mean that we all have to be married with

children and living with the white picket fence. It just means that we have the ability to make some type of determination for ourselves, that somebody else doesn't make choices and we go along for the ride and hope that maybe it's something we might enjoy. When somebody says, "Well tennis is great, you will love tennis." And you think, "Well okay, I'll try it." Or someone says, "You should read, reading is great!" And so you just go out and buy every...bring home every book in the library. If you're not a reader, or if you don't play tennis, or if you are like me and don't see out of your right eye so a small ball on the right hand side is not going to be useful.

It is necessary to find activities to help you keep moving in the direction that you want. For me that was always sewing, I was taught to sew at a very young age which is why I kept fabric in my stove. Because I also like things neat, and it was already in all of my cabinets so I needed the space. And I wasn't cooking, so it was okay. But I also really loved theater, I studied it in college for many years. I designed costumes and I went to every opportunity for live theater that I could. So even when I wasn't well, I had things hopefully that I could participate in that I could go and feel like, "Okay, there is someone up there that understands me." That I, while I loved the dramatic part of the theater because I have a dramatic personality, my mother would say, "That's okay, go and emote there and then come home and be calm." But to be a part of that, the greater world, to be sitting next to somebody who loved theater. Not just sitting next to somebody who also has a mental illness, it's not enough.

You know, a lot of the work that we do at North Suffolk, we connect people to other people who have mental illnesses, it's a great start. To say these are experiences, and to meet a peer specialist who has the same experiences as you, it's so important. But it's not enough. I hear voices and you hear voices is not enough to connect us long term, it must be something more. I play basketball and you play basketball. I sew and maybe you like to wear things that I like to sew. You have to be connected beyond and in a greater community sense, and so that is what we do. We try to find ways to connect people to people, not mentally ill people to mentally ill people. We were doing this walk last week where we were trying to introduce people to the eight dimensions of wellness from SAMHSA, and we had people playing Jenga and making these light catchers and walking down the streets of Chelsea so we could introduce people to as many different things as possible. If you have never done that, if you have never walked that mile, if you have never tried to expand your mind.

Maybe you don't read, so maybe you don't consider yourself an intellectual, but that doesn't mean that you can't do things with your mind, expand your ability to remember. And so we try to do all of these different things. That has come for me, that part of my job, which might sound strange. So far you, you know that I share my own story. How many of you have a job where your whole job is to talk about yourself? That's my job!

That's my job! My job is to share my experiences, to talk about what others might be experiencing and from my own perspective to be able to influence the work that we do at North Suffolk. Part of the reason why I am able to do that is because I have freedom.

When we first hired peer specialists, we said, "Well just get them on board and we will see what happens." But we didn't know what we were doing, and peers were doing what everyone else was doing but they were doing it under the name of peer. And what we found was that that was not right, that wasn't what we wanted to do. We wanted to do peer work, we wanted to run groups, we wanted to meet one on one and not have an agenda. You know, you have twenty minutes and you have to fill out these three forms and get signatures and you have to go because you have to be somewhere else really quick. That's not how you develop a relationship. So the peers decided that they wanted more freedom. They needed someone outspoken to do that, and so I started to say, "We need more space, we need a smaller case load, we need freedom to try things." When you try things, sometimes that means you fail. And we have done things that have not worked. We had this great idea, this advisory committee, where people would come and tell us how we were doing and they would give us suggestions. And you know who came? Nobody. Not one person came to the first advisory meeting cause they didn't know what to say and they didn't have any questions, and so that was not a good idea. But we did have a recovery lunch, and I held off on dessert so people could tell recovery stories and people were saying, "Wait, recovery? I didn't know we could. Could I talk to you more about that? That happened to me too."

And so it was just the opening we needed to tell people that there were people who worked for us who had just the same experiences and that would listen if they wanted to bring their voice to us. And then all of the sudden I had people saying, "Well if you had a chili cook-off, I would win." Well we could do that! That's recovery actually! And so we had a chili cook-off and it was a lot of work, and we have done it a lot of times now. And more than 100 people come, and it is recovery-oriented because you have tons of people competing to see who is healthiest, who can bring out the best apron, people who are coming to see who is going to win, but also people who come and say, "Didn't I see you last time and I want to see you again." And they're making friends. And so we have gone outside of that and we have had an enormous amount of creativity to be able to do that. I hope that other organizations have that kind of creativity, but I know for us that has been the biggest thing is being able to try things. And if it hasn't worked, it has been okay. So we have done all kinds of things, simply under the name of we want people communicating, we want to get people talking, we want people to know that there is no shame or fear attached to having a mental health diagnosis. Because until we have that place, until we have an entire community of people saying, "Oh yeah, that happened to me too but I'm in treatment or I do what I need to do or I take meds or I don't need meds

because I run and I keep myself healthy with food and exercise.” Until we have people that do that on a real level, we are always going to have fear and shame and stigma.

And so what we are doing at North Suffolk is being vocal and saying, “It’s okay.” It’s not just okay for the peer specialists, there has been this idea that, “Oh these are peers so it’s okay.” It has sort of a light duty, but our peers do not have light duty. Our peers are professionals who work hard, I like to say they work harder than a lot of other people because they have me to account to. That’s really something that I take very seriously, that the work they do, they paperwork they provide, they show up on time, we say North Suffolk time is seven minutes before regular time. But our peers show up on time. And so I think that is really important, that it is not just about our peers either, you know. We have other people in our agency who are being more vocal about the fact that they have mental health diagnoses. It doesn't mean that they are using that experience in their jobs directly, but it means that they are feeling more comfortable to come out and say, “Yes, this is something that I have experienced, this is something that has happened.” And I think it has created a culture amongst us that has made all the difference, and that we are more comfortable with it. And if you know that it is something that happens, aren’t you more likely to accept it and experience it the way that it is, which is mental health happens to everyone.

Hopefully we have great mental health, but the reality is that not everyone is going experience something fabulous in their lives. We have grief and depression, and we have a lot of snow that creates a lot of serious feelings for some of us. We have things that happen in our lives, and the way we react to it is something that everyone has to deal with, everyone has to have that experience. And so why not be open about it, why not share these experiences and say this is something that happened, this is something that does happen. And when it does happen, we will deal with it. It’s not something like, “Oh...you have one of those? One of those big mental health diagnoses? That must mean you can’t work, that must mean that you are treatment resistant or that you are going to be a difficult patient.”

You know I was once in a medical office dealing with a medical problem and I was asking for a consult with a specialist. And she said, “Oh, I don’t think MassHealth will pay for that.” And I said, “I don't have MassHealth.” And she said, “I thought you had a mental health diagnosis...” And I said, “I think I need a different doctor...” There’s still this idea that anyone who has a mental health diagnosis is on disability, anyone who has a mental health diagnosis is someone who is not going to be able to control their emotions, that isn’t going to be able to advocate for themselves, or want something that is reasonable. But in reality I have really good insurance because I have a full time job and I don't need MassHealth. Not that I’m imputing those who do, but just the assumption of that was very offensive because my mental health condition does not

mean that I am therefore disabled. I don't consider myself disabled, I never have. I sit across from a nurse practitioner telling me that, "You are never going to finish college and you are never going to work full-time." Then as a result of that I must be disabled. I thought, "Okay, I'm going to have a lot of time on my hands. What am I going to do with that time?" And there was this sense that because it was a mental illness that I should go home and keep it hidden. And I have a large family, my mom is one of nine and I didn't explain the fact that I had a diagnosis to my family that live in the state and could have been supportive.

But that wasn't something that I wanted to talk about. It wasn't until I took this job in 2009 that I started talking to my family beyond my parents that I had a diagnosis, that it was something I needed to talk about because it was in my job description. That was a choice, that was a definite choice and I knew that it was probably going to limit my ability to look for other work. Because how am I going to go to a job interview and say, "Yes, I'd like to back to accounting work and the job that I've had for the last few years was about talking about my illness." That's not necessarily going to fly. So it was a definite choice for me in 2009 when I had a friend who used to work for North Suffolk, who doesn't work there anymore, who told me that it was my responsibility to share my recovery story in order to be able to change the minds of the people who do mental health work, and help people who have mental health diagnoses experience the same kinds of things that I have. Well I made that choice, maybe stupidly, because I do think about how it has limited my choices in the future. But I hope that with the work that we are doing that that will change over time. Not that I'm leaving, because I'm not. I have a really fabulous opportunity at North Suffolk, we do...we have peers who work in our CVFS program, who work in our Emergency Services programs.

Other than that we have peers who are present in every program that we provide. We do presentations, I sit on senior management so that I'm there. We're talking about policy, we are talking about risk, we are talking about how peers can influence the work that we do so that we can be talking to people about taking part in their own lives and make choices for themselves that are going to lead to better quality of life. And that's not a small responsibility, and I am really lucky that I have been given that opportunity and that I am seen as someone with some expertise. Certainly mental health is not my expertise, although my own expertise is myself and I can certainly talk about that. And I am lucky now to supervise and mentor a group of peer specialists who also have mental health diagnoses who have gone through the same kinds of training as I have and are changing our agency as a whole. I am really proud of the work that they are doing, and proud that they show up at things like this to support me. So it's happening, I think that recovery is happening. I don't think it's happening at the degree of the pace that we would like. Often I think, "Oh, this is great. We're doing this." And then I go into the next

room and it's like, "Oh...we haven't done it." I would love for us to be hearing that more schools...I know there is a university in Georgia that is trying their psychiatrists in recovery and they are having an entire semester training in their program to be able to understand what recovery is and how to offer recovery-oriented services. But I don't know that there are very many social work schools that are providing recovery training.

When you hear Darry speak, she is going to speak about the work that she does and she has been kind enough to let us come in and train some of her residents, and so I think that we are starting but it's a small number of residents. A large number of residents are not learning about recovery and it would be great to hear that more and more people are, that we want recovery, that we want every kind of mental health area to have recovery, that social workers are collaborating with us. Because it's not that we want to replace you, that's not my idea anyway it might be some, it's not that we are not looking to have social workers, not looking to have psychiatrists, to not have a collaboration with a professional field, it's that we would like to take part in that programming. As much as you want to be a part of our treatment, we would like to be a part of your training program. And I think that that's where I would hope that we would go next is to be able to introduce the work that we do into other disciplines so that we can collaborate together on what you all know and what we know. So that's what I'm always hoping, and that's a lot of what Darry and I do together is that collaboration of that.

A lot of what Jackie and I do together is the collaboration of that. Is how do we work together on an existing team that has some set ideas about what they want and bring in maybe some new ideas, maybe just a shift in an idea that could be improved upon, or maybe we just want to be a part of it because as Judy Chamberlain said, "Nothing about us without us." So somebody who has a mental health diagnosis is a part of every bit of treatment that we provide, so that we experience recovery. I want to quote Pat Deegan too. She always says, "Recovery is a job and a date on Saturday night." So if the treatment that we're providing isn't encouraging people to get a job and a date on Saturday night, money in your pocket, a place to spend it, somebody who really wants to be with you, then we are not really doing recovery that's sustainable. We are not doing treatment that people are going to want to keep coming back from time and time again. Because isn't that what we all want? A job and a date on Saturday night. Thank you.

David Satin:

Thank you. That's another treat that we have had two peer advocates, one after the other. With Kitty Dukakis talking about advocacy in a public relations and public education and organizational sense, and Zohreh talking about peer function in a clinical sense with individual people with program development. I can't help remembering, you talked about the stigma that people feel about mental illness and how they handle it. I'm

remembering an experience that I had when I was a psychiatric resident at the Massachusetts General Hospital Emergency Ward, I got to see a family who came in and one member of the family told me anxiously and very positively that, “There’s no mental health in my family!” And wondered whether to argue with him about that or not.

Derri Shtasel, MD, MPH

Executive Director, Kraft Family National Center for Leadership and Training in Community Health, Partners HealthCare; Michele and Howard J. Kessler Chair in Public and Community Psychiatry, Massachusetts General Hospital; Associate Professor of Psychiatry, Harvard Medical School

Introduction by David G. Satin, MD

Our next speaker is Derri Shtasel. Her education was also at Swarthmore College, Temple University School of Medicine, the NYU Bellevue Psychiatric Residency Training Program, and the Harvard School of Public Health. She's dedicating to providing clinical care for underserved and marginalized patients, and creating academic community collaboration for service to public sector patients. Recently, she received the Exemplary Psychiatrist Award from the National Alliance for the Mentally Ill. She's now the Michelle and Howard J. Kessler Chair and Director of the MGH Division of Public and Community Psychiatry, Executive Director of the Kraft Family Center for Leadership and Training in Community Health, and is an Associate Professor of Psychiatry at the Harvard Medical School.

Derri Shtasel, MD, MPH

Thank you very much. It's hard enough to be the last on a panel, but to have to be the last and follow Zohreh King, impossible! So I'm going to do my best, but seeing this extraordinary panel...and let me first just thank my colleagues who were so spectacular. Jackie really framed this for us and gave us the concepts that we really need for the afternoon. And Kitty Dukakis, thank for your candor and your authenticity, and for really raising something that not everyone wants to hear about and talk about but is something that is so important to people. And really no one is more inspirational than Zohreh, so just really it's a privilege to be with this wonderful group of women. So thank you.

I'm going to modify what I was going to talk about because some of this has been covered and on a Friday afternoon, I don't think we need to hear things two or three times. So I'm going to jump around a little bit and I hope you will bear with me. A word of two after all those very nice words and...I don't know, acronyms of introduction, I'll just tell you a few things. Because I was a little bit confused about why I was going to be on this panel, so I'm going to try to make sense of it for myself and for you as well. I'm a psychiatrist and I trained at Bellevue, and you train at Bellevue if you want to learn how to take care of really seriously mentally ill folks and think about some of the challenges that come up in people's lives that are often pretty complicated. And so I've been committed to this for an awfully long time. I've always worked on the interface of

academic medicine and community mental health, often in terms of thinking about systems of care and how do we form collaborations that are viable that make sense for people, that are fair, that are equitable, and what kind of programs do we need to build in order to fill some of the many gaps? And I've also always been involved in training, particularly psychiatry residency training, but also medical students and sometimes post-residency.

The early part of my work was really focused on schizophrenia and I was involved in clinical work, and I was involved in some teaching, and some research. And it became clear to me that that was just so narrow of a conceptualization. It didn't really capture what seemed most important, and increasingly what was happening is that a number of many people that I was involved with...the first line in the clinical record is often, "This is a 42-year-old blah, blah, blah with (this)." And the descriptor was "homelessness." "This is a 42-year-old homeless man/homeless woman." And then you just sort of went on, because what could we do about homelessness? It was outside of our scope.

But I found that difficult, and so I wound up over the last 15 or more years being a bit more involved in homelessness than limiting this kind of work to a particular disorder. And then in 2009, I was recruited to MGH to develop and lead the Division of Public and Community Psychiatry, which was a great honor. It was a broad mandate. It had no job description, which sort of had to be made up. Which is very anxiety provoking, because who knows what that really means and then who knows if your meeting the goals that people imagine you might. So I began the way we do which was basically to take stock of what were we doing, what weren't we doing, what were we teaching. And so although review included thinking about our clinical programs and our other aspects of our mission, I'm going to focus now on teaching and training because that's what the focus of today is about.

So I started by what we were and weren't doing. So residency is four years after medical school. You go to medical school and then you do four years of residency, and then you practice as a psychiatrist or you can go on and do more things. So the period of time I'm mostly talking about is this four year period of residency training. So I looked at what were our residents doing, where were they being taught, what were they being taught in their clinical work and their lectures and so forth. And one thing that I will say honestly that I don't think we were teaching a lot of was recovery. And I certainly am not going to suggest that there was none going on, there was certainly some. But as Zohreh said, this isn't necessarily the centerpiece of what traditional academic medicine has done or thought about. And so you might say, "Why should we be teaching this?" Which in this group may sound like an absurd question, but I would start by saying that we teach it because this is public sector psychiatry. You heard the SAMHSA description, I'm not going to re-read that to you, cause Jackie did that already so I won't do that. But the

people we train, that's our next generation. That's who themselves will go on and they will train people, and take care of lots of patients, and they will do other kinds of work. If this isn't a part of what they learn, then we have done a great disservice.

The content of course is critical, the content. So to not understand this way of thinking, and looking at the world and looking at our own role and the work that we do, would be a great misstep and loss. And the other part that I think is really important to be teaching recovery in a standard, traditional program is because it's a message. And the message is, "We teach this because it is important like everything else is that we are teaching." And it's not something that people who are goodhearted will do in their spare time because they are good people, but this is not an extra curricular activity. This is a curricular activity and something that we hold to be important for everyone to learn. And recently, I will add that the accrediting body for residency has changed the way that residency is to be evaluated. And programs need to do this if they are going to be accredited, which is what everyone wants and needs to do. So they have created what are called milestones and are very complicated, there are a lot of them. But basically they're different domains in which one has to demonstrate increasing degrees of proficiency over a period of time, and recovery is now included in some of those domains. That may not sound like a big step to us, but I think in our field it is a big step forward.

So just to back up only a little bit, the vision statement...the recovery notion has been around in a lot of different ways for a long time. But I think that actually the first President Bush who commissioned a group to look at the mental health system and which was clearly in disarray and fragmented, and not helping nearly the way and numbers of people that I think we all thought it should. And so he created a Freedom Commission on Mental Health in 2002 and the vision statement was, "We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatments and supports essentials for living, working, learning, and participating fully in the community." And then went on to describe what the goal of a transformed system would be and that was recovery. Which was to achieve the promise of community living for everyone, new service delivery patterns and incentives must ensure that every American has easy and continuous access to the most current treatments and best support services, advances in research technology, and our understanding of how to treat mental illness, provide powerful means to transform the system. In a transformed system, consumers and family members will have access to timely and accurate information that promotes learning, self-monitoring, and accountability. Health care providers will rely on up to date knowledge to provide optimum care for the best outcomes.

And in 2005 the American Psychiatric Association, which is the major organization nationally for psychiatrists, came out with a statement, which is the following; “The American Psychiatric Association endorses and strongly affirms the application of the concept of recovery to the comprehensive care of chronically and persistently mentally ill adults, including the concept of resilience in seriously emotionally disturbed children. The concept of recovery emphasizes a persons’ capacity to have hope and lead a meaningful life, and suggests that treatment can be guided by attention to life’s goals and ambitions. It recognizes that patients often feel powerless or disenfranchised, that these feelings interfere with initiation and maintenance of mental health and medical care, and that the best results come when patients feel that treatment decisions are made in ways that suit their cultural, spiritual, and personal ideas. And finally, the concept of recovery is predicated on a partnership between psychiatrist, other practitioners, and patient in the construction and direction of all services aimed at maximizing hope and the quality of life.”

You’ve heard the SAMHSA description and dimensions, I hope they are now sort of familiar in your minds. But the reason that I wanted to read those statements is because recovery notions and medical models are inherently complimentary, not contradictory. And there has been in some camps a distortion of sorts, I would assert, that have made these polar opposites and created some degree to contention rather than seeing these as mutually necessary and ideally somewhat intertwined. To get your head around that what you really have to do is be able to think synthetically, and we have to teach synthetically. So what we really have to say is, “Is there room in a medical model embracing room for recovery and can recovery framework have room for a medical model?” And some of the things that sort of immediately one has to think about are reconciling several things. So first is a framework. In the medical model we think about symptoms, we think about deficits, we think about episodes of illness, we think about what our role is, and their challenges around the balance between autonomy and paternalism. Because we are steeped in a tradition of not just being people with more information, often, and knowledge, or believing that we have that, but feeling a need to protect, feeling a need to not taking care of people, but also means not going home and not doing nothing. But there’s always this balance of...is this going to be too much? And we will come back to that in a moment. And recovery framework is different. It talks about strengths, it talks about health, not illness, and wellness, and really redefining one’s purpose and one’s mission in ways that are not specific to having a mental illness. That is not the specific core of one’s identity. And it also, I think, really asks us all to think about risk and what risks are involved, and when do they happen, and who’s taking them? So that really needs to be figured out in order to blend these and be able to teach them.

So I'll tell you what we are emphasizing in our program, because we obviously all of the women that have described are important and part of the package. But what we are emphasizing is what is really important and foundational, because if we have those then the rest sort of follows. The first is hope, you've heard everyone talk about hope. Someone in the relationship has to carry hope, and the only that that I will add to what my colleagues have already described is what I'm sure many of you know- that particularly when people are depressed- depression it's not just a mood state, it's a thinking state. It's not so illogical to assume that if you feel terrible, you will always feel terrible, and hence there is no hope and so it goes on like that. And so remembering that part of our responsibility, if we're the one in the room, is to hold hope always because it's not always bilaterally there, but someone always needs to have that.

The second thing I talk about is power, because really this work is empowering and we have to think about who really the experts are. Whether we are experts, or actually the folks we are involved with are experts about themselves, which they are. And how decisions get made, because there is a difference between having conversations and presenting options as opposed to making decisions for people. But one of the things that I think is the elephant in the room, and I don't know, it's almost 4:30 on a Friday afternoon. There is a power balance, because we as psychiatry residents have the ability to make decisions that take away people's rights and to deprive people of liberty at particular moments in time for particular reasons. And I'm not here to debate whether that is a good or a bad thing, but it is a reality, and to pretend that that is not in the room too sometimes is disingenuous. And so when and how to have those conversations become part of what we need to think about too, and to simply in a somewhat Pollyanna-ish way say, "Oh, it's always an equal relationship." It's not always an equal relationship. So I think figuring out how to level the playing field and have it be a part of the conversation is at least sort of the beginning of how we can start to address some of that.

The third concept that we emphasize is, of course, quality of life. Symptom reduction is great, but that's not the same as quality of life. And quality of life is really, again, hopefully defined by the person with lived experience who knows and has ideas about what they want. And the only reason I say hopefully and why, again, I don't think it's that straightforward is that when people are demoralized and depressed and feel pretty horrible and have no sense of hope and no goals for themselves, to simply agree and say, "Okay. That's what your plan is." That is a very irresponsible thing to do. So I think that of course someone else's wishes and desires need to be recognized and honored in a way that makes sense for them and what they would wish if they felt better. And the last thing that we teach is this notion of really who's risk is it? Is it our risk or is it someone else's risk? Because we worry a lot about risk and we worry about our trainees and how to

assess risk, because that's often what they are asked to do in Emergency Rooms and other settings. Is it safe for this person to do x, y, and z?

So it's a funny message, because on the one hand the message is that we are the ones who should be making that decision and have some way to know that. But on the other hand, worrying an awful lot that if the other decision is made outcomes can be catastrophic. I don't think honestly we make these decisions because we are worried about covering our backs or lawsuits, I don't think that that's what drives it. I think it's genuine concern to not make a decision that could have very very bad consequences. But that said, that's what we teach in the beginning. But what we also have to do is let go a little bit, because really it's not up to us. People are going to do what they do. It's humbling to realize that there is only so much that we get to do when we are on a journey with someone. And so being mindful about that and recognizing that there are big picture risks that we may or may not have the ability to influence and then there's a whole range otherwise. And I think this notion...like Zohreh mentioned that she was told she will never work again.

But someone comes into a hospital, they're young, they're in school, maybe it's their first time they've been psychiatrically hospitalized, and the message when they leave...I know what that message is. The message is an incredibly protected message, "Don't go right back to school. You know if you just had a heart attack, you wouldn't run the Boston Marathon this year. You would wait, get your strength up, do it a little bit at a time. So maybe you could just...and don't go live independently, go back to live with your parents because they'll take care of you." And all of that is done in a way to be protective and a way to ideally prevent someone from falling back. It's a moment of vulnerability. But that's probably not the message that we need to be giving and we need to be teaching our trainees to give. But it is one that we struggle with because it is done for reasons that I think are benevolent reasons, but may not be the ones that are in our domain to make. So these don't have clear cut answers and that is what I'm really trying to say. And those are the conversations that we try to have with our trainees, so they can struggle with some of these things and frankly talk to their patients and listen and do a lot of listening.

So what we're doing...so I'm involved with the MGH/McLean residents. There are 64 of them, there are 16 each year which is sort of a drop in the bucket each year. Let me just give a gigantic shout out to Zohreh King to Janet Whitman to other people who have helped in this and others. But first we need to think about who is going to teach recovery, and who should teach recovery, and what are we going to cover, and how are we going to do it? Without my colleagues sort of guiding and leading this, I don't think we would know what we are doing. So I really have to start with that. What we've done in the last several years is several things. One is that we have added more clinical opportunities for our residents to take care of pretty sick people at that moment in time and to have places

and more spaces to introduce and then use these concepts as they are going along. And so as an example, in one of our early rotations we start by giving the residents a recovery inventory, it was actually created based on some of the work coming out of the University of Georgia. And they have to answer a series of questions, and they are very politically correct answers, you can see what they are supposed to be if you are sort of savvy and the person is wanting to get the right answer.

They do pretty well in terms of what the recovery answer would be. One thing that people get stuck on, usually without exception, is this notion of in order for recovery to occur symptoms need to be treated. The language is something like that, and they answer “true” to that question. It’s very hard in the field that we are in to separate those issues that one might or might not have symptoms but absolutely has a path to recovery. It’s just been an interesting thing to watch, that of lots of different areas where there might be some sticking point, that’s a hard one. It’s also a hard one because it falls into people need to be back on medicine before anything else can happen, and that’s sort of a believe that we work hard to disabuse our trainees of but it’s also a part of a tradition that they have inherited, I think.

And so in addition to several different kinds of rotations and experiences where they have these opportunities and these complications, we’ve also added some other really peer-lead, driven, and run opportunities for them. So we have a seminar that is peer-directed and run, we have different rotations where they hear people with lived experiences and often tell their own recovery stories, and they have the opportunity to interact with them. We have our residents kind of ask clinical questions to peer specialists with lived experiences who have come to meet with us and they become our supervisors and invariably have much, much better consultation and advice than we have been able to provide internally so that we are trying to normalize this and make this a part of the training experience. So beyond the specific moments in time, we have tried to incorporate this framework across much of our clinical supervision. And I say much because many of the people supervising themselves have never been taught this, it wasn’t even a part of the conversation when your this age.

So we’re trying to make this part of what is applicable to anybody, frankly, it doesn’t matter what the problem is. The notion of dignity, and autonomy, and hope, and self-direction, and self-guided goals, this is applicable to anyone that one might encounter. So those are some of the ways in which we are teaching this. We’re actually starting this year a fifth year fellowship for those who are particularly interested in this area, not limited to recovery, but in continuing public and community psychiatry. And that will add yet another opportunity for us. And that’s how we’ve started this process, but I present it to you as the very beginning. I hope that several years from now, if not sooner,

we will be talking and doing more than we are doing now. We've taken these steps to date.

I'm looking at the time...Let me just mention a couple of challenges that we think about, I hope that it will add to the conversation that we will have a group in a couple of minutes. One is language. The language of recovery and the language of medicine are not always the same, and so it's very comfortable for me to continue to use the word "patient" as an example but I understand what that confers and can mean. I have great respect for other language and I think language has meaning, so I'm not suggesting it doesn't matter. It does matter, but part of this need to merge these ideas is I hope for all of us to have some degree of reasonable tolerance for different languages that are spoken at different points in time, and it doesn't mean that there is a shift in conceptualization. Another challenge that we face is that we believe this stuff has to be taught early in training, because it is so foundational and it sets the stage for the next four years. The challenge is ours, but what our residents are doing during the first two years or so is that they are working in the most acute settings. They're in emergency rooms, they're in inpatient units, and so we're teaching and fostering a sense of being on a journey together and being a collaborator in treatment when they are in settings that pull for the most, clearest imbalance in power and decision making, in settings that can be coercive, in treatments that may not be voluntary. So we have to balance those and it's not been the easiest, and I don't quite know what the right answer in balance is, I don't think the answer is that we just ignore it for two years because it doesn't apply. But we need to sort out for people that they need to learn to do some of the things that are hard and are often some of the least collaborative, and yet at the same time that these people are real and we are not just paying lip service to them.

I have a long list, but I'm not going to do that now. I'll just mention two other things briefly because I think it's better to have more conversation. Another challenge is that psychiatrists have been relegated for lots of reasons, philosophical and economic, probably, I think, are the drivers of these crazy roles of being the med-manager. And I don't know anyone who likes being called that or really sees themselves quite like that, you know, we don't call someone who has diabetes and is going to the endocrinologist, we don't call them a med-manager. And yet, that's how it is and we get these tiny little increments of time to do their work and push them to the next. It's not a simple thing to solve, but when that's the way you are asked to work, that's the structure of time you are given, these are the goals you need to accomplish, it's pretty hard to keep this other hat and other framework in place because that requires a lot of other things to happen, including the time and space to be able to have certain conversations. So that's a challenge and we struggle with it. And another challenge, but a good challenge and an easier challenge, is how we have our trainees extend these principles beyond this

rotation or this population of people, but rather the principles to generalize across anything they do and any clinical encounters they have. That one I think we are getting a lot more traction with and is easier to work with, and so that is a few of them. So in conclusion, what I would like to say is we strongly believe that recovery needs to be taught, it needs to be expanded, it needs to be part of the day to day of what all of our future psychiatrists learn and think about and breath and convey to the clients/patients, people they are involved it, that it is intrinsic to any kind of teaching activity. And in particular, we welcome and need our peer experts, peers, and colleagues to guide me and us as we move forward in this process.

Discussion

David Satin:

Now's the time that we have an opportunity to talk to one another, and with it about whatever is unsaid. Maybe there are burning questions that you need to ask one another. If there aren't, I wanted to ask for another perspective. It seems to me that you are all have been talking about the treatment of mental illness and you are talking about mainly treatments of severe mental illness. How does this perspective on whole lives and positive function and meaningfulness of life, how does that extend to prevention before people get sick? To prevent people from getting sick? Or to enhance people's health and people's lives? Does this perspective apply in this sphere also or only after people have gotten sick? Is that a topic of interest to recovery? Because it was a topic of great interest to Erich Lindemann, he wanted to throw out the whole nosology of mental illness and all the diagnoses. He wanted to talk about people's function and when they got in trouble with their function and how that lead to various degrees of the spectrum of problems, and how to prevent that by maintaining and enhancing people's lives. So I didn't know if you pay attention to that part.

Zohreh King:

Well you know before hand, before someone gets sick, it's really being able to have a conversation. If we don't have stigma, if we don't have this idea of prejudice and fear of being treated for mental health...when you have something medically wrong with you, your neighbor doesn't say, "Oh my God, you have high blood pressure?!" There comes a time when we can say, "You know I went to seek help, I have a mental health concern." And I think there is some prevention in that, if we were able to seek treatment when we needed it...it's the same thing as when you are talking about medication as when you are talking about prevention, if someone says to you, "You have high blood pressure." We should be saying, "Is there something I can do besides medication?" And the doctor may say, "We can try exercise, diet. We can try these things and we can try these things for mental health too. Are you taking care of your diet? Are you taking care of your sleep? Are you making sure you're getting enough exercise? If that doesn't work we can try the next thing." I think that's all a part of prevention, it's not mental health prevention it's health prevention. We are bodies and souls, and we need to take care of those bodies and souls just like anyone does. If you have grief or depression or whatever, you should be able to seek treatment for that without shame or fear or delay because of what people might think and I think that is hopefully a part of what we are doing.

Audience Member:

And I think maybe that one thing that strikes me...I think about young people who have problems that may or may not be diagnosed. And one of the real values of peers is helping people at that point to engage, to not feel so alone, to maybe not be as fearful. So I don't think it's a part of the discussion of preventing, are we ever going to prevent illnesses, but hopefully we are learning to make ways to make the work we do more affective. And hopefully we are able to prevent that horrible trajectory that we used to see into the life that may have been described to people, that they are never going to be able to work or have a date on Saturday night. I would hope that we are on a track that prevents that, that trajectory, and not to a chronic state of dysfunction.

Derri Shtasel:

I want to just throw in one more perspective on this, which is the principles that we throw out today presuppose a premium on health determination and choices and opportunity. And until we think about doing something about a playing field that's really not very level at all, because unless our schools are good and our neighborhoods are safe and people have access to green space, to food that is healthy, and to jobs and opportunities, then this is just another sort of strip of horrible bad luck. But I don't think we can ignore what all the people call social determinants of health in this kind of a conversation about prevention. So I think we have to think about individuals, but I think we also need to go upstream.

Kitty Dukakis:

I think one of the things that I'm learning about is how society works with people who have had a mental illness, how people who are hiring others are handling people who have a mental health diagnosis. And I just changed drug stores when I found that my drug store was not hiring people with disabilities the way that another drug store was, and I feel very strongly that we have to work with these people in order to encourage them. Especially when it comes to mental illness, because the stigma is still there and it's great. And my local drug store is now hiring people with disabilities, many mental health areas. And I feel very good that we have moved over there because of that, and I have let the manager know. And I think we all have to be a part of that kind of action, you don't have to be professional in order to do it we can be consumers and help in a very positive way.

David Satin:

Questions?

Audience Member:

I'm wondering Zohreh, when you asked at work and told you supervisors that you wanted more time with people you work with, how much time do you think you needed? And can it be flexible? Tell us about the time that people benefit from.

Zohreh King:

So we work in a community outreach program, primarily our peers do, and that time is flexible. When someone is hired to do outreach, typically they have a caseload of 10 to 15 people, and peers have a maximum of 5 on their caseload to make sure they have as much time as they need. For someone who has been literally debilitated by the system for a number of years, it is not just a simple outreach and you develop a relationship just sitting for half an hour, it can take months, it can take a long time. So visiting someone in the hospital when they're not well, meeting someone in the community, helping them grocery shop, joining a gym with them, and showing them that exercise that they incorporate into their life is not a 1-2 process. And so in the outreach that we do, our peers are allowed that time.

I'm a senior manager, and so I don't have a great...I always talk about with the peers about a degree of separation between themselves and a senior manager because their colleagues in each of their team is not someone who is supervised by a senior manager so they have a little bit more power because they are supervised by a senior manager. My degree of separation from Jackie is very small so being able to reach her and say we want something different was not difficult, and I was never given opposition to the idea that peers need time to do peer work and that involves going to the gym and getting in the pool if that's what someone wants, or going for ice cream, or navigating the T, it might take a long time. So we are allowed the time, I don't think they have as much time as they would like because what happened was that over time their time began to see as so valuable, that people want them. So there is a lot of demand on their time, but when they know that they need it they are given that time.

Audience Member:

So it's not talk time, it's a combination between talk and activities?

Zohreh King:

No we do rehab services but what we do is psych rehab services. And what that is, it was designed by Bill Anthony's Psychiatric Rehab, that what we are doing is person-directed and is really what a person wants. But we are doing rehab services, and so it's not just sitting and talking, it's really someone who wants housing and might have some barriers that they have identified or maybe that we see as risk factors and we're working on that. So the work that the peers do is always very active and very involved and trying

to get people in the community or access therapy if that's what they want, or helping them find a family member if that family member has been lost. It's a lot of rehab.

Audience Member:

Hey, I just wanted to return to the conversation about language that we are having and also the moderators question about prevention. So this isn't so much a question as a thought that I will just wanted to throw out there, because in my perspective I think that a lot of the things that we call illness, these are a part of the human experience and are a part of the spectrum. And as long as there is culture as long as there is globalization, abuse, oppression, things like that, people are going to experience the things that get called symptoms and get diagnosed as illnesses. So if we are talking about language and choice and self-determination and the things that we associate with recovery, we cant ignore the fact that when people enter the mental health system and then come back and become chronic patients, that they are pathologized. Their experiences are pathologize and are not given brain tests or scans or blood tests or anything that can show an imbalance or anything that makes this anything like heart disease. And that very language of illness and sickness is something that limits choice in and of itself, that there are limitations in what you can do.

That no matter what your clinician says to you, you are going to leave the hospital and have symptoms, whereas before you had experiences. And you are going to have an illness whereas before you were having trouble. So I know nobody likes the language police, but when language implies something as so self-defining as who you are and what your problem is and something inherent about you, I think it really is the work that all people who support those in stress and especially certified peer specialist. I myself work with advocates. To you know really give people the option to understand their experience the way they want to, the British Psychological Society is understanding psychosis and schizophrenia complication that came out of this past year is a really good example of how language itself can be a healer. It gives people the space and opportunity to make those choices and not having those ideas coming from at every angle and then back.

Michael Dukakis:

I'm sure there is a great deal of wisdom in that, but you have to understand that with Kitty's experience she was just sick. She was a very...she went through 17 years of recurring cycles of depression this bright, beautiful, and involved person. And when she went into those periods of depression, folks, all of this...it has nothing to do with language. She was just a very, very sick person. She could not drag herself into consciousness. And nobody could explain it, it began when she was early 40's and on. I know that's not what we are talking about in other places. What about these GI's

committing suicide? Some of that has to do with an environment where you cannot admit that you are having problems because it will seriously affect your military career. But these are people who have gone through very tough stuff and they are real, they're real. And we have to understand whether it is Kitty or these GI's or whatever that your treatment is essential and support is essential.

There's no question about that, we're trying to help people understand what is happening with that. There's no explanation for what happened to Kitty, and it would happen every 8 to 9 to 10 months for no apparent reason. I know we are talking about finding ways to treat this illness so that you can begin to see recovery. And unfortunately it took forever, frankly, for the people who were treating. In fact, some of them never even suggested ECT. John Matthews from Mass General was the one who said that, "I want you to sit down with Charlie Walsh." And we did. And the first ECT treatment ended depression like that. Now, the recycling and cycling continues and Kitty now has ECT treatment every 5 to 6 weeks, she is totally off medication, yes she is. We are very fortunate, but I think we have to understand that this is an illness in many cases and its serious. And creating an environment in which somehow Kitty Dukakis is going to spontaneously recover, it never happened, never happened. Fortunately we happened to find this treatment, it works for her and it works for a lot of people. We are very lucky that the medical sciences introduced it."

David Satin:

Somebody over here?

Audience member:

Yeah, it just struck me that in the last...Dr. Shtasel's comments about ways that psychiatrists are push towards med-managers and are identified that way. So much of treatment is shaped by policy and what you can get people to pay for by insurance companies and so, do you sort of have any thoughts about what do we do as professionals to affect policy change, which ultimately provides access to treatment?

Derri Shtasel:

There's a small question...I agree with many of your comments, I guess I would say that there is some hope with new models of care that we will shift out of these transaction events so that, fee for service medicine, so that each event is built towards or seen in that way. And instead people will need to think about the whole picture. And when we have different contracting mechanisms with insurance companies and so forth so the risk is for population and keeping everyone as healthy as we can, then the rules change. There is much more opportunity to do the right thing to do, which is what's best for each particular person rather than to be so pigeon holed in these particular ways. So I

do think that hope is on the horizon, and I think that's part of why all of us need to be involved in making decision and electing people that will think about health care issues. I mean, Massachusetts went forward with health care and access to health care and health insurance before other states did, and even this...I don't want to distort us into a conversation about Medicaid expansion, but each of these pieces is part of the story and part of what influences policy and what ultimately happens. So thank you for raising that.

David Satin:

We have somebody who has experience with political process and including health policy. Do you have any suggestions about what we can do?

Michael Dukakis:

Oh we have a crazy, crazy health care system, folks, when it comes to paying for things. It's so complicated, this insurance system, that 25 cents to every prepaid dollar goes to administrative. With Medicare its about 3%, and one of the reasons these other advanced industrialized countries provide excellent healthcare for about half the cost that we do is because health insurance is health insurance, its not 72 products with 50 billion codes. I mean, hundreds of people in our hospitals do nothing but fight with insurance companies and wrestling with every doctor and 2 or 3 people on staff. It's crazy. We haven't even been able to change that. I don't know, we will see. Right now we are just trying to provide access to people in whatever way, but the amount of waste in this system has nothing to do with healthcare, it's mind blowing.

Lets hope that over time we can start to clean out some of this stuff. Pay for real health care and do so in a way that is as simple and uncomplicated as possible. Tufts New England Medical Center, 400 beds, how many people do you think they have on staff doing nothing but arguing with insurance companies? 500 salaried employees, that's all they do. And when it comes to reimbursing for behavioral health, I suspect you can double that. It's nutty, folks, but at this point we are just trying to make it possible for all Americans to at least have access to this and to do so in a way that frees up this whole process. It really is a wacky system and it's costing us a lot of money.

Audience Member:

So first of all, thank you to the panel for mentioning ECT. I think it is something that is important for people to know and destigmatize and also very sick patients. I want to make a comment and also a question about the lack of knowledge amongst mental health providers on ECT. I think it's something that mentioned by Kitty. So I'm a psychiatrist and I'm a child psychiatrist, but I also do ECT. So I see geriatric patients and offer ECT for them, and I'm a pretty young psychiatrist so residency training was not too long ago

for me. When I was a resident I remember it was very difficult to find a mentor to train me to do ECT, because there's not too many providers who have done many cases of ECT who feel comfortable mentoring others to do ECT. And I think that is one issue. And another issue is after all my training, when I became an attending psychiatrist I needed to get myself credentialed and published at the hospital to do that.

So in other words, I needed to find another mentor who would supervise me to do enough number of cases in order for me to get published to offer ECT in our facility, so there's another barrier. And then after that, so after all the barriers, does it pay off to overcome all of that? Well I would say professionally it pays off, because to see all of my patients get well quickly after ECT is really rewarding, but financially it's a different story. So I can tell you in some cases, for example, if you are the psychiatrist in an inpatient setting and after seeing the patient you feel that they should get ECT and you want to offer ECT for your own patient, you can certainly do that. But at the same time, from the buildings standpoint, in some settings, at least in Massachusetts, you can bill for the service of ECT or you can bill for the service that you provide by being the attending psychiatrist for that patient in the inpatient unit, so you cannot bill for both. So that is your own patient, and you definitely need to see them everyday and write a note, manage the patients care, so on and so forth. And at the same time you offer ECT for a patient, but you cannot bill for that part. So I guess this is my setting for providers to provide ECT, so the cycle repeats so there are not enough providers, not enough training mentors for trainees, and the cycle repeats. So I think that is part of the reason why mental health providers and even psychiatrists don't have enough knowledge about ECT. So I guess my question is whether any one of you has discussed with anything to address this funnel for questioning.

Derri Shtasel:

Just a very, very short answer. I think that many of the things you say are challenges and things that we dissolve, and there are some places where there's a lot of ECT is done. And I think it's like any kind of thing, more and more people get trained in doing it but I don't think that there are easy and quick answers to the challenges that you raise.

Audience Member:

I just wanted to make a comment about the insurance. There is I think available in front of the house about reimbursing certified peer specialists with Medicaid. And we are one of those few states in that we are lagging behind in that we are not reimbursing certified peer specialists. So you can contact your legislators about that, Debra Deblin has more information about this particular activity. The other thing I just wanted to comment about while we are talking about finances, is that there doesn't seem to be in

the programs any pay for the certified peer specialists to do any training. There's no funding...we need to look for funding to integrate certified peer specialists into the training at schools like this and into the training at Mass General about how to bring about change that has to do with resources. That's not my personal stance, but thank for you today.

David Satin:

Any other questions? I think people, as with any good discussion, this is a start and raises questions and raises interests, but doesn't answer all of the questions. So I hope that this has been stimulating and useful for people to pay attention to what is good care and what is ethical care, and what is comprehensive and meaningful care, and how many people from different experiences and different points of view can contribute to that. I want to thank you all for coming and bring your attention and ideas, and hope that you will be back next year for the 39th Annual Erich Lindemann Memorial Lecture, and thanks again to you all.