

UCSF

UC San Francisco Electronic Theses and Dissertations

Title

Reframing "Wellness": The Social Construction of Tobacco Use in the Mental Health Community

Permalink

<https://escholarship.org/uc/item/9jj5695z>

Author

Solway, Erica Singer

Publication Date

2009

Peer reviewed|Thesis/dissertation

Reframing “Wellness”:
The Social Construction of Tobacco Use in the Mental Health Community

by

Erica Singer Solway

DISSERTATION

Submitted in partial satisfaction of the requirement for the degree of

DOCTOR OF PHILOSOPHY

in

Sociology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Copyright 2009
by
Erica Singer Solway

My interest in the prevalence of smoking in people with mental illnesses evolved gradually, and was motivated primarily by an initial interest in disabilities, and in particular, “invisible disabilities.” I began with an interest in promoting mental health among older adults, which grew out of my experiences as a volunteer in nursing homes and assisted living facilities since high school. When I entered the doctoral program at the University of California, San Francisco (UCSF), I had the opportunity to assist my advisor, Carroll Estes, on a study of access to mental health services for older adults in California and Florida. As that project was winding down, a classmate, Brian Grossman, called my attention to an opportunity to apply for a mental health fellowship with the Smoking Cessation Leadership Center (SCLC) at UCSF, led by Steven Schroeder. In truth, I had never considered the impact of tobacco use among people with mental illnesses. As I began to read more about the topic, the high rates of smoking among people with mental illness startled me. I had recently discovered that my grandfather, Bernie Brawer, who had been a smoker in his early adulthood but had quit in 1964 when the Surgeon General announced that smoking was deleterious to health, had been diagnosed with lung cancer. I was with my grandfather in December 2006 when he died after a six-week struggle with the disease, and the experience had a profound impact on me.

My involvement with the National Mental Health Partnership for Wellness and Smoking Cessation began before the official start date of my fellowship with the SCLC.

The summit that led to development of the Partnership was held in March 2007.

Although I had applied for the fellowship in January 2007 and I was not scheduled to start until August, Carroll encouraged me to attend the summit. It was a wonderful experience to meet the people who became personally involved with the Partnership and to be present at what turned out to be a momentous event.

All researchers come from a particular perspective based on their class, gender, race, culture, and ethnicity, and thus my own approaches to my dissertation research are based on my personal identities and experiences. I am often asked, and was asked regularly by the research participants, whether I smoke or had smoked, and I admit that I have never smoked. Yet my interest reaches beyond my academic involvement as a sociologist trained in social work and public health. I am passionate about promoting access to wellness for all and advocating for health disparate groups.

A motivation for focusing my work on this area of research is that many people quickly excuse smoking among people with mental illnesses or promote it based on the notion that it is their “only pleasure.” While I agree that much can and should be done to improve the quality of life for people with mental illnesses in the United States, I see this justification for encouraging smoking as unfair and discriminatory. I believe that all people should be offered education regarding their options regarding their health so that they can make informed choices. I also believe that all people deserve support and encouragement to envision a future that is healthy and bright. It is my passion for helping people with mental illnesses and other disabilities to improve the quality of their lives that drives me to engage in this work.

Acknowledgments and Dedication

This dissertation would not have been possible without the support of faculty, friends, and family who helped me progress through school during these past four years. I offer my utmost gratitude to these people for their support and assistance.

The faculty in the Department of Social and Behavioral Sciences at UCSF provided me with a strong graduate education in sociological theory, medical sociology, and research methods. They have taught me how to think critically, supported me in writing grants and applications for funding, and have served as an excellent example of how to approach my work as a social scientist.

Pat Fox and Ruth Malone served on my third area exam committee (qualifying examination) and my dissertation committee. Pat has always been a careful reader of my writing, providing constructive feedback and suggesting questions for further consideration in my work. Ruth has been invaluable as an expert in tobacco control; she gave me invaluable help when I completed my first single-author paper, even meeting with me on a university holiday to provide feedback.

I feel deeply indebted to Steve Schroeder for welcoming me as part of his staff as a mental health fellow at the Smoking Cessation Leadership Center. The opportunity to work and conduct research at the SCLC has been extremely helpful for my career development, and Steve has been a fantastic mentor. I admire the efficiency and brilliance he brings to his work and his willingness to make time for me in his very busy

schedule. Steve's commitment and passion to educating health providers about their role in helping people to quit smoking is extraordinary.

Carroll Estes has been a role model and a supportive advisor throughout my graduate career. She has given me enormous freedom to pursue independent work while guiding me and showing great faith in my ability to rise to the occasion. Carroll has been extremely helpful in encouraging my growth as a sociologist. She has introduced me to people that I had never in my wildest dreams imagined meeting. Indeed, it is hard to believe that she was once one of those people. I never considered pursuing a doctoral degree until I read Carroll's *Social Policy and Aging* shortly before beginning my dual master's degree program in social work and public health at the University of Michigan. I was so enthralled by Carroll's writing, passion, knowledge, and conviction regarding social policy issues facing older adults that I had to meet her. If not for her willingness to meet me -- a young student and an admiring fan -- I would not be where I am today.

I want to thank the staff at the Smoking Cessation Leadership Center, including Reason Reyes, Connie Revell, Christine Cheng, Margaret Meriwether, Catherine Saucedo, and William Rycpinski, who have been wonderful and inviting colleagues. They welcomed me, taught me about their great work and allowed me to contribute in meaningful ways. I want to acknowledge the wonderful support from Michelle Larkin of the Robert Wood Johnson Foundation and Amber Hardy Thornton of the American Legacy Foundation for making my position as a fellow at the SCLC possible. I want to thank Gail Hutchings, Karen Hudmon, and Bob Glover, partners of the Smoking

Cessation Leadership Center, who helped by reviewing my interview questions and by encouraging this work. I also offer my thanks to Beth Lillard and Karen Balsamico, whom I had the pleasure of meeting at the SCLC and who are true inspirations.

I also want to thank the members of the National Mental Health Partnership for Wellness and Smoking Cessation for their commitment to the health and well-being of people with mental illness and for participating in and encouraging this research. I am in awe of the work these organizations provide in support of mental health services and smoking cessation, which creates a healthier world for all. I am also indebted to my focus group participants who took the time to talk with me about their smoking. Additionally, I am very grateful for the support of Cathy Spensley and her colleagues who supported and encouraged this work.

During my time at UCSF, I have been extremely fortunate to receive funding and awards from various sources. During my first two years in the doctoral program, the UCSF Dean's Health Sciences Award provided me with invaluable support. The UCSF Dean's Health Sciences Award, UCSF Graduate Student Research Award, UCSF School of Nursing Century Club Funds, and Anselm L. Strauss Award were extremely helpful as I was completing my dissertation. Finally, I feel very grateful to have received the Centers for Disease Control and Prevention (CDC) Public Health Dissertation Award (R36), which allowed me to devote full-time attention and effort to completing my dissertation in my final year of the program. If it were not for this funding, my graduation could have easily come in 2019 rather than 2009.

Cynthia Mercado-Scott and Regina Gudelunas are some of the funniest and most animated members of the department. I could never have applied, let alone been accepted, for the award from the CDC if it were not for their help (especially when Cynthia was so patient and willing to re-upload all of my application materials when I received very valuable last-minute feedback from my dissertation committee). Linda Tracy and Brandee Woleslagle Blank provide the whole department with administrative support to keep it running smoothly and efficiently. They have been invaluable to me in explaining UCSF's procedures and ensuring that I complete the paperwork required to graduate.

My doctoral education would not have been the same without the support and friendship of my wonderful classmates. The members of my cohort, including Martine Lappe, Rosamaria Rosen, Elena Portacolone, and Eric Lai, made class fun and even entertaining. I also enjoyed talking with Krista Sigurdson, Beth Mertz, and John Fecondo about many school-related and extracurricular activities.

My classmates in the dissertation writing seminar, Suepattra May, Katherine Thomson, Robin Higashi, Ben Hickler, and Nicole Wolfe, provided invaluable insights and comments regarding my research. It was a pleasure and a great learning experience to read their interesting work. Sharon Kaufman led the seminar and was extremely helpful in reading my work and providing advice and encouragement.

A highlight of my time at UCSF was working with Students for Social Security and Concerned Scientists in Aging, nonprofit organizations that raise awareness about the

importance of Social Security in the lives of all Americans. In particular, my classmates Brian Grossman and Brooke Hollister, co-workers on all of our social insurance-related projects, were excellent friends, collaborators, and colleagues. I feel fortunate to have worked closely with them over the last four years.

I would also like to thank my friends from outside school, particularly my teammates from the Impala Racing Team, for providing me with support and an outlet to release stress about school and my dissertation. My runner partners are such a wonderful source of inspiration.

Last, but certainly not least, I want to thank my family. My bubby Lee Brawer and my papa Paul Solway offered endless encouragement during the early years of my education and helped ensure a love for learning that remains with me today. My papa Bernard Brawer was so loving and supportive. Since his death in the middle of my second year of the doctoral program, I have felt a great void. I still miss his Sunday phone calls. I also thank my bubby Etta Solway and my grandma Joan Brawer for being so wonderful, encouraging, and fun. I also want to thank Sue and Forrest Butterwick who have been great company on their (too infrequent!) visits to California, and have been incredible cheerleaders.

My sister, Alison Solway, is a great friend and always a wonderful source of encouragement and humor (occasionally at my expense). My parents, Nancy and Harvey Solway, have been extremely supportive of me since the day I was born. They even came to hear me talk about my research at the American Society on Aging/National Council on

Aging conference in Chicago in March 2007, and my Mom came to my talk at the SBS/IHA colloquium series later that year. Now that's support! My mom was invaluable in the very difficult final days of writing, serving as a skilled editor, a fantastic running buddy, and a patient friend. I do not know what I would do without her.

Finally, it is with utmost respect and appreciation that I thank my partner, Alex Butterwick, for his support and encouragement. As I was competing my undergraduate honors thesis in the spring of 2003, Alex told me that while he loved me, he would never be able to date me through another thesis. (It was a challenging experience for me). Yet he saw me through my dissertation and served as a design editor, technology consultant, sounding board, counselor, chef, and fantastic parent to our wonderful dog, Murphy, as well as teacher and confidant. And he did it all with a patience and grace that I can only hope to emulate.

Antoine de Saint-Exupéry said, "If you want to build a ship, don't drum up the men to gather wood, divide the work and give orders. Instead, teach them to yearn for the vast and endless sea." Thank you to everyone who made this dissertation possible. And, more important, thank you to all of those acknowledged above who motivated me to yearn for the vast and endless sea of learning and knowledge. It is to you that I dedicate this work.

Reframing “Wellness”: The Social Construction of Tobacco Use in the Mental Health
Community

Erica Singer Solway

While the rates of smoking in the general population have declined substantially over the last several decades, the prevalence of smoking among people with mental illness remains alarmingly high. For example, various estimates suggest that 50-90% of people with serious mental illness smoke, and nearly half of tobacco-related deaths each year occur among people with mental illness. Moreover, 70% or more of people with mental illness want to quit smoking, yet there often exist considerable barriers to access for cessation support. This research project is an attempt to understand the development and emergence of initiatives based on collaborative efforts between the mental health community and the smoking cessation field to raise awareness about and address the high rates of smoking among people with mental illness and the resulting health disparities that exist for this population. Research methods included: (1) individual in-person and telephone interviews with 26 national leaders in smoking cessation and mental health, (2) focus group interviews with 26 mental health consumers of various smoking statuses in California, (3) participant observation and fieldwork, and (4) a frames analysis of articles on this topic published in the last 10 years from six leading U.S. newspapers. Data were collected and analyzed using grounded theory methods. Overall, this research describes how collaborative efforts between the mental health and smoking cessation fields have resulted in the recognition of the high rates of smoking among people with mental illnesses as a social problem. This awareness has come from a shift in the social construction of tobacco use to one in which cessation is considered integral to overall wellness. The effort to address the disproportionate use of tobacco in the mental health community has allowed for the collective mobilization of the mental health and smoking cessation arenas, fields that have long been divided. This dissertation explores the enactment of and the possibilities for messages and actions to effectively and sensitively lower the rates of smoking among people with mental illness to reduce tobacco-related diseases, increase quality of life and life expectancy, and expand possibilities for recovery.

Table of Contents

	<i>Page</i>
Preface	iii
Acknowledgments and Dedication.....	v
Abstract.....	xi
List of Tables	xx
List of Figures and Diagrams.....	xxi
Chapter 1 Health Disparities Among People with Mental Illness: A Background and Introduction	1
1.1 Introduction	1
1.2 People with Mental Illness as a Health Disparate Group.....	2
1.3 Mental Health and Mental Illness.....	5
1.4 Mental Health Movements	10
1.5 Tobacco Use and Smoking Cessation.....	15
1.6 Tobacco Control Movements	20
1.7 Smoking Among People with Mental Illness.....	22
1.7.1 The Startling Statistics.....	22
1.7.2 Quitting Smoking and Mental Illness.....	24
1.7.3 Other Factors Influencing the High Rates of Smoking Among People with Mental Illness.....	26
1.7.4 Schizophrenia, Depression, and Smoking	29
1.7.5 People with Mental Illness and the Tobacco Industry	30
1.7.6 Smoking Policies in Mental Health Facilities.....	30
1.7.7 Prevention and Awareness of Tobacco Use in this Population	32
1.8 Potential Movements on Smoking Cessation/Tobacco Control Among People with Mental Illness.....	33
1.8.1 The National Mental Health Partnership for Wellness and Smoking Cessation.....	33

1.9 Language and Definitions	40
1.9.1 Definitions of Mental Illness	41
1.9.2 People Who Experience Mental Illness.....	44
1.9.3 Tobacco	48
1.9.4 Stigma.....	48
1.9.5 Recovery	49
1.9.6 The Mental Health Community and the Smoking Cessation Field	50
1.10 Concluding Remarks.....	51
Chapter 2 The Theoretical Frameworks of Social Problems and Social Movements and Study Research Methods	54
2.1 Introduction	54
2.2 Theoretical Frameworks.....	54
2.2.1 Theories of Social Problems	55
2.2.1.1 Functionalist Approach.....	57
2.2.1.2 Social Constructionist Perspective	58
2.2.1.3 Political Economy	60
2.2.1.4 Framing of Social Problems.....	61
2.2.1.5 The Process of Defining a Situation as a Social Problem and Taking Action	62
2.2.2 Social Movements	63
2.2.2.1 Classical Theories.....	66
2.2.2.2 Resource Mobilization Theory.....	67
2.2.2.3 Political Process and Political Economy	69
2.2.2.4 Collective Identity and Culture	71
2.2.2.5 New Social Movements	73
2.2.2.6 Social Movement Organizations	75
2.2.2.7 Framing Processes	77
2.2.2.8 Collective Action Frames	79
2.2.2.9 Countermovements	80
2.3 Dissertation Research Methods	81

2.3.1	Grounded Theory and Situational Analysis.....	83
2.4	Sources of Data and Data Collection Processes	86
2.4.1	Individual Interviews with Leaders in Mental Health and Smoking Cessation.....	87
2.4.2	Focus Group Interviews with Mental Health Consumers	91
2.4.3	Fieldwork/Participant Observation	98
2.4.4	Frames Analysis	101
2.5	Study Strengths and Limitations.....	104
2.6	Conclusions	109
Chapter 3 The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation.....		
3.1	Introduction	111
3.2	Never Smoking, Smoking, and the Process of Quitting	117
3.2.1	Never Starting to Smoke.....	118
3.2.2	Smoker Perspectives and Attitudes About Tobacco	121
3.2.2.1	Thinking About Quitting.....	122
3.2.2.2	Motivating “Thinking About Quitting” for Those Not Yet Ready to Quit.....	123
3.2.3	Motivating Contemplation for Those Who Are Thinking About or Who Have Quit	124
3.2.3.1	Overcoming Obstacles to Staying Quit	127
3.2.4	Listening to Providers.....	129
3.2.5	Garnering Will Power and Inner Strength.....	131
3.2.6	Succeeding in Quitting	132
3.2.7	“Seeing What It’s Like” and Relapsing.....	133
3.2.8	Accomplishing After Quitting	134
3.3	The Role of Tobacco Use for Mental Health Consumers	134
3.3.1	Managing Stress: Feeling Like a Prisoner.....	135
3.3.2	Being “a Part Of”	137
3.3.3	Creating Comfort	140

3.3.4	Doing More.....	141
3.3.5	Meeting the Needs of an Addiction.....	142
3.4	Forces Influencing Tobacco Use by Mental Health Consumers	143
3.4.1	“Being Brainwashed” by the Tobacco Industry or Mental Health Consumers as Tobacco Consumers.....	144
3.4.2	Changing Norms and the End of “Social Smoking”	146
3.5	Tensions and Complexities in Addressing Smoking Among Mental Health Consumers	150
3.5.1	Recovering as the Exception to the Rule.....	151
3.5.2	“Mixing Up” Medications and Smoking	152
3.5.3	Paying for Tobacco	154
3.5.4	Creatively Maneuvering Through the Health Hierarchy.....	156
3.6	Conclusions	160
Chapter 4 Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses.....		
4.1	Introduction	166
4.2	The Smoking Cessation Field.....	169
4.3	The Mental Health Field	173
4.4	The National Mental Health Partnership for Wellness and Smoking Cessation.....	178
4.5	Framing of Messages Focused on Smoking Among People with Mental Illnesses	182
4.6	Message Frames and Challenges in Developing Messages	183
4.6.1	Making Sense of the Language and Cultural Differences Between the Mental Health and Smoking Cessation Fields.....	185
4.6.2	Acknowledging a History of Acceptance and Endorsement of Tobacco Use in Mental Health Settings	186
4.6.3	Identifying the Varied and Complex Factors Resulting in the High Rates of Smoking.....	187
4.6.4	Understanding and Incorporating Consumer and Peer Perspectives	188

4.6.5	How Providers are Implicated: Addressing the High Rates of Smoking Among Staff and Also Addressing Provider Misconceptions About Smoking and the Importance of Quitting	192
4.6.6	Determining the Role of Quitlines in Helping Mental Health Consumers to Quit	193
4.6.7	Challenging and Reframing Rhetoric that Focuses on Tobacco Use as Legal, Tobacco Use as a Human Right, and Tobacco Use as a Choice.....	197
4.6.8	Recognizing Successes and the Controversial Nature of Smoking Policies or “Bans”	200
4.6.9	Understanding the Realities of Mental Health Consumers’ Challenges in Quitting and Highlighting Stories of Success.....	202
4.6.10	Discovering Ways to Sensitively (Yet Collaboratively) Address Tobacco Use	204
4.6.11	Recognizing Not Addressing Tobacco Use as a Form of Discrimination	204
4.6.12	Finding Alternatives to Smoking	206
4.7	What Do We Make of All These Messages?	208
4.8	The Media	209
4.9	Themes and Messages Presented in the Media	213
4.9.1	Distribution and Use of Tobacco Money	214
4.9.2	Chantix.....	216
4.9.3	Surgeon General’s Report on Mental Health.....	219
4.9.4	Plight or Lived Experience of People with Mental Illnesses.....	220
4.9.5	General Statements about Smoking and Mental Health.....	221
4.9.6	Smoking Policies.....	222
4.9.7	Research Studies	223
4.10	Conclusions	230
	Chapter 5 Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements	233
5.1	Introduction	233

5.2 Branching Out, Collaborating, and Fostering Natural Connections	236
5.3 Appreciating and Maximizing Strengths and Resources	239
5.3.1 Strengths of the Mental Health Community	239
5.3.2 Strengths of the Smoking Cessation Field.....	244
5.4 Understanding Weaknesses and Overcoming Challenges	245
5.4.1 Challenges for the Mental Health Community	245
5.4.1.1 The Conviction that the Mental Health Community is Fundamentally “Different”	245
5.4.1.2 Tensions About the Benefits and Risks of Tobacco Use.....	246
5.4.1.3 Continued Apathy Regarding Smoking.....	248
5.4.1.4 Feeling Overburdened and the Challenges of Getting Airtime.....	249
5.4.1.5 Insularity as a Weakness	253
5.4.2 Weaknesses for the Smoking Cessation Field	254
5.4.2.1 Avoiding a Blanket Approach.....	254
5.5 Asymmetries Between the Mental Health and Smoking Cessation Movements/Fields.....	256
5.6 Maintaining Momentum and Motivation	259
5.7 “We’re Doing This, and They’re Doing That”: Delineating the Roles of the Mental Health and Smoking Cessation Fields	261
5.8 Developing and Implementing Strategies for the Partnership.....	264
5.9 Evidence of Changes.....	266
5.10 Recognizing Opportunities for Movement Development	269
5.11 Inadequate Funding as the Key Barrier to Movement Development and “Success”	273
5.11.1 The Partnership as a Social Movement Organization (SMO)?.....	275
5.12 Filling a Unique Space Within Existing Movements.....	277
5.13 Benefiting from Spillover of Other Social Movements	278
5.14 Conclusions	279
Chapter 6 Structural and Policy Considerations and Implications in Addressing Tobacco Use in the Mental Health Community	281

6.1 Introduction	281
6.2 Funding as the Key to Success	282
6.2.1 The Role of the Foundation	282
6.2.2 Funding for Mental Health and Smoking Cessation	285
6.3 Recognizing the Role of the Tobacco Industry and the Pharmaceutical Industry	286
6.3.1 The Role of the Tobacco Industry.....	286
6.3.2 Concerns About Medications and the Pharmaceutical Industry	288
6.4 Structural Issues Influencing the Social Position and Health of People with Mental Illness	291
6.4.1 Social Support, Education, and Income	291
6.4.2 Employment.....	293
6.4.3 Medicaid and Access to Smoking Cessation Resources	294
6.4.4 Addressing Health Care System Issues	295
6.4.5 Mental Illness, Smoking Cessation, and the Role of the State	296
6.5 Policy Change.....	298
6.5.1 Mental Health Parity	298
6.5.2 Integrating Mental and Physical Health Care	300
6.6 Research and Dissemination	301
6.7 A Fundamental Goal is to Institutionalize	303
6.7.1 Normalizing Smoking Cessation as a Critical Component to Mental Health Treatment	303
6.7.2 Accountability and Incentives.....	303
6.7.3 Education	304
6.7.4 Linking Mental and Physical Health Care Systems Across the Continuum of Care.....	304
6.7.5 Institutionalization Processes and the Effects of Institutionalization.....	305
6.8 Conclusions	307
Chapter 7 Promoting Wellness, Creating Change: Conclusions and Future Directions	308

7.1 Introduction	308
7.2 The Socially Unequal Distribution of Smoking and Stigma.....	310
7.3 Collective Efforts to Address the History of Neglect	311
7.4 The Role of the National Mental Health Partnership for Wellness and Smoking Cessation	312
7.5 Addressing Tobacco Use and Smoking Cessation with Sensitivity	312
7.6 Future Research	314
7.7 Possibilities for Change: Policy Developments	316
7.8 Challenges to Mental Health Policy	319
7.9 Concluding Thoughts.....	320
APPENDIX A Interview Protocol for Individual Interviews with National Leaders in Mental Health and Smoking Cessation.....	323
APPENDIX B Interview Protocol for Focus Groups with Mental Health Consumers.....	326
APPENDIX C Ordered Situational Map.....	328
APPENDIX D Positional Maps.....	330
APPENDIX E Relational Map	332
APPENDIX F Social Worlds/Arenas Map	333
APPENDIX G Articles Used in Frames Analysis	334
Bibliography.....	338
UCSF Library Release Form.....	383

List of Tables

<i>Number</i>	<i>Page</i>
Table 1 Smoking Status Based on Mental Illness in Previous Month	24
Table 2 Timeline of Significant Tobacco Control and Mental Health Events	36
Table 3 Numbers of Leaders Interviewed According to Type of Work.....	91
Table 4 Demographics of Focus Group Participants.....	98
Table 5 Number of Articles Published in Six Leading U.S. Newspapers from 1999- 2009 on Mental Health/Mental Illness and Smoking/Tobacco	103
Table 6 Words and Images Conveyed by People with Mental Illnesses Concerning Tobacco, By Smoking Status.....	113
Table 7 Number of Articles from Six Leading U.S. Newspapers Published Each Year from 1999-2009 on Mental Health/Mental Illness and Smoking/Tobacco ...	211
Table 8 Number of Articles Published in Six Leading U.S. Newspapers from 1999- 2009 According to Topic/Theme	214
Table 9 Research Study Findings Related to Mental Health and Smoking Published in Six Leading U.S. Newspapers in 1999-2009.....	224

List of Figures and Diagrams

<i>Number</i>	<i>Page</i>
Figure 1 The Process of Trying to Quit and Feeling a Sense of Failure	132
Figure 2 Creating and Maneuvering Through the Health Hierarchy	159
Figure 3 The Process of Choosing Not to Smoke, Starting to Smoking, Quitting, and Relapsing	162
Figure 4 The Intersection of the Tobacco Control and Mental Health Consumer Movements	278
Figure 5 Processes for Institutionalizing Policies and Practices for Smoking Cessation for People with Mental Illness	306
Figure 6 Ordered Situational Map: Mental Health, Mental Illness, the Mental Health Community, and Smoking, Tobacco Control, and the Smoking Cessation Field.....	328
Figure 7 Positional Map of Desire to Quit Among People with Mental Illness	330
Figure 8 Positional Map of Level of Priority of Smoking Cessation in the Mental Health	331
Figure 9 Relational Map of Smoking Among People with Mental Illness	332
Figure 10 Social Worlds/Arenas Map of the Mental Health Community and Smoking Cessation Field.....	333

Chapter 1 | Health Disparities Among People with Mental Illness: A Background and Introduction

“Everything they’ve done for any other population, they need to do for people with mental illness.”

- Mental Health Advocate and Government Official

1.1 Introduction

In its broadest sense, this dissertation is about the status and social position of people with mental illnesses in U.S. society today. More specifically, this dissertation explores efforts to address the health disparities that exist for people with mental illness by examining initiatives focused on raising awareness and ultimately reducing the high rates of smoking among mental health consumers. This dissertation describes the ways in which people with mental illness, leaders in the fields of mental health and smoking cessation, and the media understand tobacco use in this population, construct it as a problem, and mobilize around it.

The World Health Organization (WHO) defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 2007). Yet mental health, as a component of overall health, has not been prioritized and has long been overlooked within the U.S. health care system. Mental health is seen as categorically different from other health and medical care in the United States, what Frank and Glied (2006) call “mental health exceptionalism” (p. 6).

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

As a result, the mental health system has historically been fragmented and under funded (Dorwart & Epstein, 1993; Frank & Glied 2006; Mechanic, 2008). In fact, it is often said that the mental health system is so decentralized that referring to it as a “system” is truly a misnomer (Frank & Glied, 2006).

Mental health care costs have remained relatively steady and have not kept pace with growth in health care costs generally (Frank, Goldman, & McGuire, 2009). While the President’s New Freedom Commission on Mental Health states that mental illness is a “serious public health challenge [that] is under-recognized as a public health burden,” major structural and funding issues persist (President’s New Freedom Commission [PNFC], 2003, p. 3).

1.2 People with Mental Illness as a Health Disparate Group

Because of the relative lack of attention to mental health, structural and funding issues, and the insufficient integration of mental health into the broader health care systems, people with mental illnesses have long experienced health disparities including higher than average rates of many illnesses and premature death. Although awareness of these disparities has grown over the last several years, the disparities have increased. In examining death records from 1976 to 1985, Colton and Manderscheid (2006) estimated that people with schizophrenia died about 15 years earlier than the overall population during that period. Yet, by the year 2000, Lutterman et al. (2003) estimated based on data from 16 states and Colton and Manderscheid based on data from public mental health

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

agencies in eight states that people in the United States with severe mental illnesses were dying at twice the rate and approximately 25 years earlier than those without mental illness (Colton & Manderscheid, 2006; Lutterman et al., 2003; Parks, Svendsen, Singer, & Foti, 2006).

Over the last decade, there has been increasing interest in better understanding these disparities in morbidity and mortality for people with mental illnesses. In the past, excessive deaths from mental health conditions, such as bipolar disorder, were attributed primarily to unnatural causes such as suicide, homicide, and accidents (Manderscheid & Delvecchio, 2008). Yet, new evidence from the last several years suggests that people with mental illnesses are at greater risk of premature death from the same conditions that result in mortality in the “general population.” In fact, 50% of people with serious mental illnesses who continue to smoke will die prematurely from smoking-related diseases as compared with a 10% lifetime risk of suicide (Campion, Checinski, Nurse, & McNeill, 2008). These smoking-related conditions, which include cardiovascular disease, lung disease, and diabetes mellitus, are treatable and preventable and are often a result of unhealthy behaviors such as smoking (Colton & Manderscheid, 2006; Everett, Mahler, Biblin, Gangull, & Mauer, 2008; Parks, Svendsen, Singer, & Foti, 2006; Roshannaei-Moghaddam & Katon, 2009). Despite political imperatives to reduce health disparities, this topic has received little attention (Campion et al., 2008).

In essence, this dissertation serves as a case study of the ways in which the physical health needs of people with mental illnesses are understood, examined, and

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

acted upon through the example of tobacco cessation. The reasons for choosing tobacco use and cessation as central to this analysis are threefold. First, the rates of smoking among people with mental illnesses are, depending on the mental health diagnosis, two to three times greater than in the population overall (Ziedonis & Williams, 2003). Second, the issue of tobacco use among people with mental illnesses is complex and sociologically interesting given the long acceptance of tobacco use within the mental health community. Third, the efforts to encourage smoking cessation among people with mental illness allow for the integration of the mental and physical health fields in new ways. Moreover, the collaboration between these two arenas is practical to study because it is newly emerging and follows a distinct historical timeline. The general research questions to be explored in this dissertation are: (1) how did the issue of smoking among mental health consumers become constructed as a social problem within the mental health community; and (2) how have actions and initiatives around this “problem” evolved over time?

This introduction will provide a brief background on mental illness and mental health-related movements, tobacco use and tobacco control movements, smoking among people with mental illness and initiatives focused specifically on addressing use in this population, the terminology that will be used throughout this dissertation, and a summary of what is to be covered in the following chapters.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

1.3 Mental Health and Mental Illness

“How mental illness is defined over time has been the focus of philosophical debates about the nature of rationality, sociological debates about the meaning of deviance, and legal debates about the definition of criminal responsibility” (Frank & Glied, 2006, p. 8). Estimates of the prevalence of mental illness vary considerably depending on the definition of mental illness and the survey instruments at any one period of time. In general, it is commonly stated that between one in four and one in five adults in the United States, a total of around 50 to 60 million people depending on the definition, meet the criteria for a mental health diagnosis in a given year (Kessler, Chu, Demler, & Walters, 2005; U.S. Department of Health and Human Services [USDHHS], 1999). Approximately 5-7% of the U.S. population suffer from what are called serious mental illnesses (SMI), a term “intended to convey a history of serious acute episodes, psychiatric comorbidities, continuing residual disability, and high levels of medical and psychosocial need” (Mechanic, 2008, p. 5). Serious mental illnesses include diagnoses such as schizophrenia and bipolar disorder (President’s New Freedom Commission [PNFC], 2003; USDHHS, 1999).

Within and outside the field of sociology, mental illness has long been considered a social problem given the human and financial costs associated with treatment and care of the condition to families and to the state, the challenges for the management of people deemed deviant due to behavioral, financial, or other reasons, and the possibilities of disruptions that the unpredictable nature of mental illness presents for a well-organized

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

society. Recent estimates suggest that severe mental illnesses cost the United States \$193.2 billion in lost earnings per year, and, of course, this estimate does not account for the cost of human suffering (Kessler et al., 2008). The WHO denotes mental health disorders as the most burdensome health conditions in the United States (WHO, 2004). Mental illness can affect people of any age, race, ethnicity, gender, or sexual orientation, and can create significant barriers to health and quality of life (PNFC, 2003).

The understanding of the causes of mental illness have evolved and shifted over time as a result of changing social, political, and historical forces. For example, the reconceptualization of madness as a mental illness, as described by Foucault in *Madness and Civilization* (1961), “came at a time when interest in alternative realities was waning and when the medical sciences were in the process of being born” (Davidson, 2003, p. 8). Shifts in the meaning of and explanations for mental illness can have a profound impact on public and provider perceptions as well as policy.

For example, between 1980 and 1990 there occurred a shift from a psychological mode of thought that attributed mental illness to experiences such as poor parenting to a medicalized model that conceptualized mental illness as a “brain disease.” In fact, the National Institutes of Mental Health (NIMH) designated this period as “the decade of the brain.” This shift to a more medical approach occurred as part of an effort to alleviate the stigma associated with mental illness and led to advancements in mental health parity legislation and the first ever Surgeon General’s Report on Mental Health (U.S. Department of Health and Human Services [USDHHS], 1999). Through the lens of the

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

medical model of mental illness, mental health and mental illness are seen as dichotomous as opposed to points along a continuum (Hannigan & Cutcliffe, 2002). In this model, a diagnosis of a mental illness can be seen as an attempt to define and label deviance (conduct that violates social norms) as a medical condition. Conrad (1980) notes that as a result of its medicalization, what was once considered “badness” becomes conceived of as “sickness,” medical professionals gain jurisdiction over the issue, and medication become an integral part of treatment (Mechanic, 2008). Overall, a plethora of evidence demonstrates that mental illness must be treated as a serious public health issue.

Yet despite its significance to overall health and quality of life, mental health and the treatment of people with mental illness have been largely peripheral to understandings of health and the health care system. This lack of attention to mental health and illness can be, at least in part, attributed to stigma or fear.

The public at large holds a variety of negative stereotypes about severe mental illness. “Mental patients are dangerous.” “They can’t live on their own.” “There is no cure for mental illness.”...Stigma and pessimistic expectations lead to discrimination (Corrigan, 1998, p. 202).

Although Americans now have a greater scientific knowledge about these conditions, mental illness is still considered an afterthought, and “illnesses of the mind remain shrouded in fear and misunderstanding” (USDHHS, 2001, p. 5).

On a fiscal and policy level, the mental health system has been constructed separately from the physical health system. In the 1990s, traditional insurance was replaced with managed care as a cost-containment strategy. The design of managed care for mental health was different from health care in general because behavioral health

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

services were “carved out.” In this arrangement, the mental health and substance abuse component of health insurance coverage is managed separately from the general health benefit (Mechanic, 2008). Managed behavioral health care has been associated with greater access to care and lower costs.

Access to care is critical because people with mental illnesses are twice as likely as people without mental illnesses to have multiple medical disorders. For instance, 42% of people with mental illness have at least one chronic physical illness severe enough to limit daily functioning (Colton & Mandersheid, 2006). Beyond the disproportionate rates of smoking, people with mental illness, compared to a community sample, were also found to have a higher prevalence of obesity, a lack of moderate exercise, and harmful levels of alcohol consumption and salt intake (Davidson et al., 2001). Countless factors may play a role in explaining these health disparities, including level of social support, engagement in various health behaviors, access to preventive care, and genetics. A connection also exists between physical and mental health, and evidence suggests that worsening medical problems may exacerbate underlying psychiatric conditions (Dixon et al., 1999). Some individuals in the mental health field have called this high likelihood of comorbidity of physical and mental illness “an epidemic within an epidemic” (Torgovnick, 2008).

It is also likely that this co-morbidity may be at least partially attributable to provider behavior. Providers may be stymied in their efforts to address other medical problems beyond the mental illness or may restrict their focus to the psychiatric condition

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

and fail to make an appropriate somatic diagnosis (Sokal et al., 2004). The Association of American Medical Colleges (AAMC) conducted a nationwide survey of physicians in 2005-2006 in four specialty areas: family medicine, internal medicine, obstetrics/gynecology, and psychiatry and found that the cessation practices and attitudes of psychiatrists were significantly different from those of other physician specialties, with psychiatrists being least likely to participate in cessation activities (AAMC, 2007).

Given these statistics, awareness has grown of the need for action to address the physical health of people with mental illness. There has been a recent “call to action” to integrate mental health and physical health so that providers not only focus on addressing people from the neck up but address other health issues that may be instrumental for achieving wellness and recovery. This concern with physical health needs was prominent in the 2003 President’s New Freedom Commission on Mental Health Report, *Achieving the Promise: Transforming Mental Health Care in America*. Since that report was published, the need to integrate physical and mental health care has been written about extensively by other leading mental health organizations (Bazelon Center for Mental Health Law, 2004; IOM, 2005; National Association of State Mental Health Program Directors [NASMHPD], 2005). In addition, the National Summit on Mental Health and Wellness organized by the Substance Abuse Mental Health Services Administration (SAMHSA) in 2007 resulted in the development of the “10 x 10 initiative.” This initiative is based around the goal of reducing mortality for people with mental illnesses by 10 years within 10 years (Everett et al., 2008).

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

1.4 Mental Health Movements

As a result of stigma, fear, and misunderstanding, people with mental illness have experienced experimental, inhumane, and discriminatory treatment throughout history. Until about forty years ago, people with mental illnesses were regularly locked away in large, crowded, understaffed, and underfinanced institutions against their will (Mechanic, 2008; Whitaker, 2002). As a result of the deinstitutionalization movement (also called the community mental health) in the early 1970s, spurred by President John F. Kennedy's introduction of the Community Mental Health Act of 1963, many people with mental illnesses left psychiatric hospital settings and moved into the community. Between 1972 and 1990, the number of state and county psychiatric hospital beds decreased by 70% (Fisher, Geller, & Pandiani, 2009). Deinstitutionalization was based on the premise that people receiving care in hospitals would be better served in the community and would prefer to live there too (Grob & Goldman, 2006). Deinstitutionalization was based on the rise of an overall ideology that favored community-based solutions to social problems over institutionally-focused ones (Fisher, Geller, & Pandiani, 2009).

Yet people with mental illnesses continue to encounter significant challenges to receiving proper care (Dorwart & Epstein, 1993). The long history of mistreatment of some of our country's most vulnerable citizens poses challenges to improving their health and social status today. There have been some successes in improving access to and quality of care for people with mental illness, and while such successes represent important landmarks, they have thus far resulted in only small improvements in the care

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

of people with mental health problems compared to the rest of the population (Mechanic, 2008).

Since the Alleged Lunatic's Friend Society was established in England in 1845, people with mental illnesses around the world have mobilized around their poor and unjust treatment and have given a voice to the experience of living with mental illness (Foley & Sharfstein, 1983; Frese & Davis, 1997). Movements led by and on behalf of people in the United States began immediately after the Civil War with the establishment of the Anti-Insane Asylum Society in Illinois (Chamberlin, 1990). Clifford Beers' (1908) personal account of living with bipolar disorder, which documented the inhumane conditions in psychiatric hospitals, is regarded as precipitating the start of the "mental hygiene movement," the precursor to today's mental health consumer movement (Hierholzer, 2007). Beers was a leader in founding the National Committee for Mental Hygiene which later became the large advocacy organization National Mental Health Association (recently renamed Mental Health America) (Frese & Davis, 1997).

The anti-psychiatry movement began in the 1960s when many social movements, including the civil rights movement, began. The leaders of the anti-psychiatry movement characterized mental illness as a "sane" response to an "insane" society, argued for the need to understand mental illness rather than explain it, and characterized psychiatry as a key mechanism of social control in an oppressive and unjust society (Crossley, 2002). Initially, psychiatrists, psychologists, and sociologists, including R.D. Cooper, David Lange, Thomas Szasz, Thomas Scheff, Erving Goffman, and Theodore Sarbin, led this

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

fight against “psychiatric hegemony” (Chamberlin, 1977; Crossley, 2002; Grob & Goldman, 2006, p. 54).

The modern American consumer-led mental health movement, called the psychiatric patients’ liberation or mental health/survivor/psychiatric patient movement, began in the 1970s and developed during the same period as the transition from institutional to community-based care (Chamberlin, 2005). The leaders of this movement were unaware of the long history of such movements in the U.S. and abroad but mobilized around the realization that former psychiatric patients, similar to other marginalized groups, regularly encounter stigma and are denied basic human rights (Frese & Davis, 1997). Groups developed in Oregon, New York, Boston, and other locations across the United States based on the premise “that mental illness was a social and political construct and that people needed basic legal and human rights protections” (Chamberlin, 2005, p. 10). In particular, Chamberlin’s (1977) personal account of her experiences as a patient in a psychiatric hospital shifted the focus of the movement to the embodied and politicized nature of mental illness. Consumers fought for “involvement,” which meant “nothing less than full and complete decision making power over such fundamental questions as whether to be engaged in mental health treatment” in response to the long and painful history of involuntary commitment (Chapman, 2005, p. 11). They took on the broader disability movement’s motto “nothing about us without us.”

This wave of the movement achieved great success. The number of consumer/survivor-controlled organizations has grown dramatically in the last 30 years.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

These radical groups of ex-psychiatric patients include the Mental Patients Union, the Campaign Against Psychiatric Oppression (CAPO), Project Release, Network Against Psychiatric Assault, Mental Patients' Association, Mental Patients' Liberation Front, Survivors Speak Out, United Kingdom Advocacy Network, Reclaim Bedlam, the Hearing Voices Network, and Mad Pride (Chamberlin, 1977; Crossley, 2002). Many of these consumer-led organizations now have local affiliates that work alongside national groups to strengthen their energy, resources, local ties, and political force. As noted by Brown et al. (2004), the mental health consumer/survivor movement has resulted in major shifts in the way mental health care is provided, "including the provision of many civil rights that used to be inferior to those of prisoners," including the right to better, more humane treatment and the right to refuse some treatments (p. 51).

The broader mental health movement also includes active involvement by family members of people with mental illness and mental health providers. For example, the National Alliance for the Mentally Ill (NAMI, now called the National Alliance on Mental Illness) was founded in 1979 by and for family members of people with mental illness who organized around their experiences with their adult children's conditions and the medical establishment's focus on the "schizophrenogenic mother" as the cause (Cadigan & Murray, 2009). In 1985, NAMI formed a subgroup for consumers, now called the NAMI Consumer Council (Frese & Davis, 1997). Mental health practitioners are also actively involved in NAMI and other similar groups.

Based on the activities of the various waves of the mental health consumer

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

movement, several changes have been achieved. For instance, federal law now requires states that receive funds for mental health service to include people with mental illness on all mental health boards. Other advancements such as the development of “consumer report cards” that reflect consumer perspectives on measures and indicators of quality, the development of outcome measures for mental health services based on recovery and empowerment, and the endorsement of research by “consumer researchers,” have given people with mental illness a voice and an opportunity to advocate for their own preferred treatments (Campbell, 1997; Frese & Davis, 1997). Most recently, the consumer movement has focused on self-help as a treatment modality and the goal of recovery. “Self-help is a consumer response to perceived inadequacies in an established care system in areas interstitial between treatment, adaptation, and rehabilitation. Self-help takes over issues that ‘fall between the cracks’ of existing agencies and providers” (Sommer, 1990, p. 206). Moreover, the recovery model argues that recovery is an individual outcome and that mental illness is only one aspect of a person (Corrigan & Penn, 1999). Recovery is seen as a process and does not require full remission of one’s mental illness.

The various organizations that comprise today’s broad mental health social movement are extremely diverse. The groups have differing memberships that may include physicians, other mental health providers, family members of people with mental illness, and people with mental illness who speak and act from their own personal experiences, among others. These groups can also be vastly different in terms of how

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

they define and understand mental health and mental illness. For example, there exist radical groups who call for overhaul and more moderate groups who emphasize the power of “transformation” of the mental health system (PNFC, 2003). For decades, the issue of parity has unified the various movement actors. The lack of parity has been labeled a discriminatory insurance practice for mental health and substance abuse conditions. Parity is considered the standard for excellent mental health coverage and has for several years been seen as the “holy grail” of mental health policy (Goldman et al., 2006, p. 1379). Yet the fragmentation of interests in mental health creates many challenges, especially in the areas of problem definition, agenda setting, policy advocacy, and social movement development, given the various perspectives that must be aligned and the diverse groups and interests to be mobilized.

1.5 Tobacco Use and Smoking Cessation

Cigarette smoking is the leading preventable cause of death and disability in the United States (USDHHS, 1990). The adverse effects of smoking (both active and passive smoking) on the public’s health are well known. Smoking harms virtually every part of the body causing cancer, pulmonary and cardiovascular disease, and reproductive issues, among other diseases and conditions (USDHHS, 2004). Since the 1964 Surgeon General’s report *Smoking and Health*, smoking has been well-recognized as a social problem in light of the health consequences for smokers and those around them and the high demand for health care services that result from tobacco use.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Globally, 1.3 billion people in the world smoke and 5.4 million people die each year from tobacco use (Guindon & Boisclair, 2003; WHO, 2008). Seventy percent of these deaths occur in low and middle-income countries (Campion et al., 2008). It is estimated that this will increase to 10 million deaths per year by 2030 (WHO, 2002). In the United States alone, 43.4 million people smoke, 8.6 million people experience disability as a result of a smoking-related disease, and 443,000 people die prematurely each year as a result of smoking or exposure to secondhand smoke (Centers for Disease Control and Prevention [CDC], 2008). In fact, more people in the United States die from tobacco use than from AIDS, alcohol, motor vehicle accidents, homicide, illicit drugs, and suicides combined (Mokdad, Marks, Stroup, & Gerberding, 2004). The economic burden of tobacco use parallels the enormous health burden. Smoking-related illnesses cost the United States more than \$193 billion yearly (CDC, 2009). Although cigarettes are extremely harmful to health, they remain legal for people in the U.S. age 18 and older. This is due to the long history of tobacco production in the U.S. and the strength and the complex strategies enacted by the multi-billion dollar, multi-national tobacco industry (Brandt, 2007).

Cigarettes, as any smoker will readily attest, are highly addictive. It is the nicotine in the cigarette that is addictive, but it is the nearly 4,800 compounds in tobacco smoke that cause illness, disability, and death (National Cancer Institute [NCI], 2001). Cigarette smoke is composed of 11 chemicals that are known to cause cancer in humans and 49 chemicals that cause cancer in animals and *may* cause cancer in humans (NCI, 2001).

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Smoking commonly begins in adolescence, and about half of those who do not quit eventually die from smoking-related disease (WHO,1997). Approximately one third of smokers attempt to quit each year, but fewer than 10% succeed (Dani & Harris, 2005).

People of any age and mental health status can benefit from quitting, and helping people quit smoking may be the most important thing a clinician can do (Schroeder, 2005). There are five basic ways to help smokers quit: increase the price of cigarettes by raising federal and state taxes, pass clean indoor air legislation that bans smoking in public places, create and disseminate effective counter-marketing messages about smoking in the media or as graphic package displays, ban tobacco advertising and promotion, and provide aids for cessation (Schroeder, 2005). Current clinical guidelines recommend that clinicians practice the “5 As” when addressing smoking among their patients: asking individuals about tobacco use, advising people to quit, assessing their readiness to make a quit attempt, assisting with the attempt, and arranging follow-up care (Fiore et al., 2000; Schroeder, 2005). A shortened version, “AAR,” is now also recommended for busy clinicians when addressing smoking among patients: asking individuals about tobacco use, advising them to quit, and referring them to a source for information and support (Smoking Cessation Leadership Center [SCLC], 2009).

Currently five types of nicotine-containing medications (nicotine replacement therapy, often referred to as NRT) and two medications that do not contain nicotine have been approved by the Food and Drug Administration (FDA) to help with smoking cessation (Fiore et al., 2008). The NRT aids include gum, patches, lozenges, inhalers, and

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

nasal sprays (the first three are available over the counter). Two prescription medications, bupropion (Zyban) and varenicline (Chantix), are also available. Bupropion (also called Wellbutrin when used for treating depression) was originally developed for use in people with depression, and varenicline is the first oral medication designed specifically to help people to quit smoking (Fiore et al., 2008). Smoking cessation efforts are most likely to be successful if they include a combination of NRT, counseling, and social support (Fiore et al., 2008; Schroeder, 2005). Free telephone quitlines are also available in every state for people who want to quit smoking or who want to find information on quitting. People who call the helpline at 1-800-QUIT-NOW can receive telephone counseling, self-help materials, cessation medications, and referrals for additional support; the specific services available through the “quitline” can vary by state. Over 400,000 U.S. tobacco users contact the quitlines each year (Cummins et al., 2007), and the efficacy of quitlines for the overall population has been rigorously demonstrated (Anderson & Zhu, 2007: North American Quitline Consortium [NAQC], n.d.; Zhu et al., 2002).

One of the most significant advances in public health in the past 30 years has been the continued decline in the prevalence of smoking. In 1965, the year after Surgeon General Luther Terry offered the public the first definitive conclusions about the connection between smoking and lung cancer and other diseases (Menashe & Siegel, 1998; Office of the Surgeon General, 1964), smoking prevalence had reached a high of 42% (with over 50% of men smoking) (Mendez, Warner, & Courant, 1998). With the denormalization of smoking due to increased awareness of the substantial health risks

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

along with policies such as clean indoor air laws, tobacco taxes, and youth prevention strategies, rates of smoking have declined to 21.3% among men and 18.4% among women to a modern day low of 19.8% overall in 2008 (CDC, 2008).

The majority of people who continue to smoke today are those who are “stranded in the periphery” (Schroeder, 2008, p. 2284), including people with mental illness and substance use disorders, people in prisons and jails (Kauffman, Ferketich, and Wewers, 2007), and other populations that are socially disadvantaged and politically disenfranchised. In 1971, smokers were indistinguishable from nonsmokers in terms of their integration in their social networks, but groups of smokers began to quit together over time (Chrisokis & Fowler, 2008). “Three decades later, reflecting major shifts in societal views of smoking, smokers were at the periphery of social networks and aligned with other smokers” (Schroeder, 2008, p. 2285). “There appears to be a ‘hardening of the target,’ in which the remaining tobacco users are concentrated in the lower socioeconomic classes, are more nicotine dependent, and have more medical and psychiatric co-morbidities” (Morris et al, 2009, p. 37). Accordingly, the social context of smoking has recently begun to be explored. “This growing interest in ‘the social’ parallels a broader shift within public health research from a biomedical model of illness and disease towards an understanding of the broader social determinants of health” (Poland et al., 2006, p. 59).

1.6 Tobacco Control Movements

While the tobacco industry's clever and sophisticated marketing led to the normalization of smoking in the first half of the 20th century (Brandt, 2007), the findings regarding the health effects of tobacco from the Surgeon General's report (1964) motivated and mobilized health professionals, advocates, and government officials to reverse the epidemic in the United States and around the world (Schroeder, 2008). In 1965, Congress required that warning labels appear on all cigarette packages and tobacco advertisements; in 1967, tobacco control advocates began meeting every two to three years to share information at the World Conference on Tobacco or Health; and in 1970, Congress prohibited tobacco advertising on television and radio (Brandt, 2007; Houston & Kaufman, 2000; Menashe & Siegel, 1998; USDHHS, 1989). As a result of these regulations, efforts, and other policy initiatives, the tobacco industry "began to counterattack the awakening tobacco control movement" (Menashe & Siegel, 1998, p. 307).

The message that tobacco kills, which placed full responsibility for the tobacco epidemic on the tobacco industry, unified the tobacco control movement. In particular, the realization that exposure to secondhand smoke takes 50,000 lives each year has resulted in enormous efforts by the tobacco control movement to advocate for smoke-free buildings and other public places to protect the health of those who do not smoke. Over approximately the last 15 years, the tobacco control movement has shifted its focus from "confronting tobacco as a deadly product to combating youth smoking and the marketing

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

of tobacco products to youth” (Menashe & Siegel, 1998, p. 309).

Furthermore, the Master Settlement Agreement (MSA), the largest civil settlement in U.S. history, an agreement between U.S. tobacco companies and the attorney generals of 46 states (Mississippi, Texas, Florida, and Minnesota had earlier reached individual settlements), created restrictions on practices by the companies and levied payments by them estimated at \$206 billion to compensate the states for the costs of providing health care to people with smoking-related illnesses (Brandt, 2007; Schroeder, 2004). The tobacco companies also agreed to finance a \$1.5 billion antismoking campaign and disband industry trade groups. Further, more than 50 million pages of internal tobacco industry documents were made publicly available through the MSA and are now housed at the Legacy Tobacco Documents Library at UCSF (American Legacy Foundation [ALF], 2009; Schroeder, 2004). These documents provide evidence that the tobacco industry has historically misrepresented scientific evidence and has targeted specific groups (Apollonio & Bero, 2007). The documents have enabled tobacco control advocates to better understand the industry’s strategies and tactics (Apollonio & Malone, 2005).

On a global scale, the tobacco control movement’s efforts led the WHO to foster the development of the Framework Convention on Tobacco Control (FCTC), which began in February 2005 and was signed by 163 parties (Daynard, 2003; WHO, 2009). The FCTC requires that signing parties adopt a strong framework of tobacco control measures in several areas including protect nonsmokers from secondhand smoke, require

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

manufactures to disclose the contents and emissions of tobacco products, place large health warnings on packages, and restrict or banning all tobacco advertising, impede smuggling, ban sales of tobacco product to minors, ask the parties to consider tax increases, ban deceptive terms, include pictures on package warnings, enact policies around liability, and, generally, to ask parties to exceed the minimum requirements of the treaty to best control the spread of tobacco-related addiction, disease, and death (Brandt, 2007; Daynard, 2004; Slama, 2004).

Beyond these important policy developments in tobacco control, advancements in smoking cessation, including a more comprehensive understanding of the treatment of nicotine dependence through neurochemical and behavioral research, have reduced tobacco-related morbidity and mortality by helping those who currently smoke to quit. Yet Houston and Kaufman (2000) provide a cautionary note:

Simply because progress is made on some fronts does not mean the problem has been solved or that attention to the global pandemic caused by tobacco use can be relaxed...casting off the influence of the tobacco companies, putting an end to their deception, and working together as a united health community will be necessary to forge a future without tobacco (p. 753).

1.7 Smoking Among People with Mental Illness

1.7.1 The Startling Statistics

While smoking rates among the general population have declined dramatically since the 1960s when Surgeon General Luther Terry first announced that smoking was deleterious to health (Schroeder, 2005), smoking rates among people with mental illness

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

have remained extremely high (Lamberg, 2004). Tobacco addiction is the most common co-occurring disorder for people with serious mental illness (Ziedonis et al., 2003).

Associations between smoking and psychiatric disorders have been reported in clinical and epidemiological studies. Such studies indicate that individuals with mental illness or addictions are two to three times more likely to be tobacco dependent than the general population due to physiological, social, and cultural factors (Ziedonis & Williams, 2003).

The more severe a person's psychiatric symptoms, the more likely that person is to smoke (Morris, Giese, Turnbull, Dickinson, & Johnson-Nagel, 2006).

Estimates suggest that individuals with mental illness or substance use disorders constitute 40.6% of smokers and smoke 44.3% of the cigarettes consumed in this country (Lasser et al., 2000). This amounts to 180 billion cigarettes and \$37 billion in tobacco industry sales annually (Prochaska, Hall, & Bero, 2008). Approximately 200,000 of the 443,000 people who die prematurely from smoking each year are people with mental illnesses or substance use disorders (Schroeder, 2009; Williams & Ziedonis, 2004). Depending on the diagnosis and how tobacco use is defined, it has been estimated that 50-90% of individuals with serious mental illness or addictions are tobacco dependent (according to Williams & Ziedonis, 2004; others who have reported prevalence rates approximately in this range include: Diwan, Castine, Pomerleau, Meador-Woodruff, & Dalack, 1998; Hughes et al., 1986, Lasser, et al., 2000; Ziedonis, Williams, & Smelson, 2003). Table 1 below illustrates the prevalence and quit rates of smoking based on a diagnosis of mental illness in the previous month.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Table 1 Smoking Status Based on Mental Illness in Previous Month

Diagnosis (in previous month)	% of U.S. Population	% Current Smokers	% Lifetime Smokers	% Quit Rate
Major Depression	4.9	44.7	60.4	26.0
Dysthymia	1.7	38.2	49.0	22.0
Bipolar Disorder	0.9	60.6	81.8	25.9
Post-Traumatic Stress Disorder (PTSD)	2.3	44.6	58.1	23.2
Alcohol Abuse or Dependence	2.6	56.1	67.5	16.9
Drug Abuse or Dependence	1.0	67.9	87.5	22.4
No Mental Illness	50.7	22.5	39.1	42.5

Adapted from Lasser et al. (2000). Smoking and mental illness: A population-based prevalence study. *Journal of the American Medical Association*, 284(20), 2606-2610.

1.7.2 Quitting Smoking and Mental Illness

Numerous studies suggest that people with mental illness can quit smoking and have a high motivation to do so. Seventy percent of people with mental illness want to quit, the same proportion as in the overall population (Lucksted, McGuire, Postrado, Kreyenbuhl, Dixon, 2004; Tsoh & Hall, 2004; CDC, 2000). A study by Prochaska et al. (2004) found that almost 80% of depressed smokers wanted to quit, and nearly one in four were ready to quit in the next month. People do not need to be free of the symptoms of mental illness in order to quit (Schroeder, 2009), and individuals being treated for depression can be helped to stop smoking without adversely affecting their mental health functioning (Prochaska et al., 2007). Studies indicate that a multi-component program

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

that combines NRT with motivational enhancements and relapse prevention is most effective (Evins et al., 2005; Schroeder, 2009; Ziedonis & George, 1997).

The overall rates of quitting among people with mental illness are substantial, but remain lower than in the overall population (Baker et al., 2006; el-Guebaly, Cathcart, Currie, Brown, & Gloster, 2002b). One reason is that nicotine replacement therapy (NRT), an efficacious treatment used widely in the overall population, is used only to a limited degree with people with mental illnesses who are trying to quit (Ziedonis, Williams, & Smelson, 2003). This is crucial, as people with mental illnesses have been found to smoke more cigarettes, to smoke them more efficiently (achieve higher nicotine levels), and to have significantly higher rates of tobacco addiction as compared to people who do not have mental illnesses (Ziedonis, Williams, & Smelson, 2003).

Furthermore, while people with mental illness may have a strong desire to quit, mental health clinicians are less likely to ask about their smoking status or provide cessation counseling (Himmelhoch & Daumit, 2003; Prochaska et al., 2004; Prochaska, Gill, & Hall, 2004; Thorndike, Stafford, & Rigotti, 2001). Mental health providers tend to have limited training in addressing tobacco use and often assume that people with mental health problems cannot quit smoking or that symptom management should take precedence over preventative health measures (Morris, Waxmonsky, Giese, Graves, & Turnbull, 2009; Sokol et al., 2004; Williams & Ziedonis, 2004). Tobacco use is ignored or even encouraged in mental health settings and is not seen as a disorder like other mental illnesses or addictions (Williams & Ziedonis, 2004). According to Williams and

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Ziedonis, this propensity to overlook tobacco use is stigmatizing and discriminatory:

Few recognize how ignoring tobacco perpetuates the stigma associated with mental illness and addiction when some ask, “Why should tobacco be addressed in mental health or addiction settings?” or “other than increased morbidity and mortality, why should we encourage and help this group to quit?” These questions reflect stigma towards this specific population as we do not ask these questions of the general population (2004, p. 306).

1.7.3 Other Factors Influencing the High Rates of Smoking Among People with Mental Illness

Overall, it appears that a complex combination of biological, psychological, and social and cultural factors lead to the high tobacco use and addiction rates among people with mental illness (Patkar et al., 2002; Schmitz, Kruse, & Krugler, et al., 2003).

Several biological hypotheses have been advanced regarding the high rates of smoking in this population. However, questions remain about causation in the association between nicotine dependence and psychiatric comorbidity. It is possible that there are separate, specific causal mechanisms behind the association of smoking and mental disorders, and vice versa (Schmitz et al., 2003). In broad terms, nicotine and other chemicals in tobacco have various and widespread effects on brain and neurotransmitter activity which can affect the symptoms of mental illness and neurobiological vulnerabilities (Ziedonis, Williams, & Smelson, 2003). More specifically,

Possible biological factors include an increased genetic vulnerability, a greater susceptibility to progressing from tobacco use to dependence because of a greater subjective experience of reward or pleasure, or that tobacco/nicotine helps some of the symptoms related to a behavioral disorder (Williams & Ziedonis, 2004, p. 1068).

Nicotine has also been found to alleviate certain psychiatric symptoms (Gilbert &

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Gilbert, 1995; Hughes, 1999; Ziedonis & George, 1997). Patkar et al. (2002) found that tobacco use can alleviate negative symptoms (such as blunted affect, poverty of speech, and inability to experience pleasure) in people with schizophrenia but not positive ones (such as delusions, auditory hallucinations, and thought disorder). Smoking may also help people to manage schizophrenia-related cognitive decline or medication side effects (Dalack et al., 1998).

Several psychological factors may also help explain why people with mental illnesses continue to smoke at high rates. It is possible that people who have difficulty coping with stress, anxiety, and depression are more susceptible to nicotine dependency, as it may temporarily relieve feelings of tension. Yet such a dependency may create a vicious cycle, since an inability to quit smoking is stressful and can thus lead to greater anxiety (Schmitz et al., 2003). Furthermore, although smokers report that cigarettes improve their mood, anxiety, and concentration, this may be because they do not recognize that they are using the tobacco to prevent or treat the unpleasant symptoms of withdrawal (Williams & Ziedonis, 2004). In general, cigarette smoking may be an attempt to self-medicate symptoms of depression, anxiety, boredom, aggression, loneliness, poor concentration, and other feelings common to this population (Greeman & McClellan, 1991; Williams & Ziedonis, 2004).

In terms of social and cultural factors, smoking has become an accepted and integral part of the culture in mental health and substance-abuse treatment centers and is a common collective social practice within these settings (el-Guebaly, Cathcart, Currie,

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Brown, & Gloster, 2002a; Solway, 2009; Williams & Ziedonis, 2004). According to the WHO (1998),

The culture of smoking in psychiatric settings is perceived to be an entrenched process that has been central to the history of mental institutions over the past three centuries with the development of asylums and their evolution into our current psychiatric inpatient facilities. Tobacco rations were an assumed part of day-to-day life in many institutions” (p. 867-868).

Additionally, cigarettes have traditionally been used as a reward for good behavior and as a way to relate to staff in psychiatric settings. Smoke breaks for staff and patients have become an “entitlement” and one of the only opportunities that consumers can relate to one another and with staff in “normal” and acceptable ways (Parks & Jewell, 2006). Reilly, Murphy, and Alderton (2006) asserted that “smoking is endemic within mental health facilities worldwide, with an entrenched smoking culture within these setting among both staff and patients” (p. 276). Thirty to thirty-five percent of staff in mental health facilities smoke, making the rates of smoking among staff considerably higher than in the overall population too (Bernstein & Stoduto, 1999; Parks & Jewell, 2006). Providers who smoke are less likely to spread messages about the importance of cessation (Fiore et al., 2008; Sarna, Bialus, Wells, & Kotlerman, 2009; Schroeder, 2005). Moreover, people develop daily routines around smoking that are hard to change. There are also social factors that are more common both among people with mental illnesses and people who smoke. For example, some mental illnesses, such as schizophrenia, are more common among people with low incomes (Mechanic, 2008), as is smoking (CDC, 2004).

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

1.7.4 *Schizophrenia, Depression, and Smoking*

There is less research on smoking cessation in people with mental illnesses despite the high rates of smoking in this group (Campion, Checkinski, & Nurse, 2008). While the academic literature on this topic has grown substantially over the last five years and now includes many articles that focus on mental illness broadly defined, many of the articles focus specifically on tobacco use among people with schizophrenia. Researchers have found tobacco use to be more prevalent among people with schizophrenia than those with other mood disorders (de Leon et al., 2002; Lasser et al., 2000). People with schizophrenia are 10 times more likely to smoke on a daily basis as compared to individuals in the general population (de Leon et al., 2002). Schizophrenia appears to be associated with an extremely high prevalence of tobacco use across countries and cultures independent of socio-cultural factors (Dalack et al., 1998; de Leon, 1996; de Leon & Diaz, 2005).

Approximately 1% of the United States population has received a diagnosis of schizophrenia (American Psychiatric Association, 1994) and *at least* 70% of these people smoke cigarettes (de Leon et al, 1995; Williams & Ziedonis, 2004). Compared to the overall population, people with schizophrenia smoke more cigarettes per day, use higher tar- and higher nicotine-containing cigarettes, extract more nicotine from cigarettes, have longer histories of smoking, and have substantially lower quit rates than smokers without current or past mental illness (Kelly & McCreadie, 1999; McChargue, Gulliver, & Hitsman, 2002; Olincy et al., 1997; Ziedonis et al., 1994). At the same time, the onset of

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

schizophrenia has been said to occur significantly earlier among those who smoke (Ziedonis et al., 1994). It has thus been speculated that vulnerability to schizophrenia may be associated with increased odds of starting to smoke (de Leon, 1996).

The other psychiatric condition that has received significant attention in the academic literature related to smoking is depression. Patients who have never smoked show lower rates of major depression than those who have ever smoked (Acton et al., 2001). It is common for smokers to have symptoms of depression or to develop depressive symptoms when they are trying to quit (Tsoh et al., 2000).

1.7.5 People with Mental Illness and the Tobacco Industry

Evidence also suggests that people with mental health problems, or what the tobacco industry calls the “psychologically vulnerable,” have been targeted as desirable, “downscale” consumers by the tobacco industry (Apollonio & Malone, 2005; Lasser et al., 2000). Documents from R.J. Reynolds describe people who smoke for “mood enhancement” and “positive stimulation,” and imply that smokers use nicotine to cope with depressive symptoms, for “anxiety relief,” to “gain self control,” to “calm down,” and to “cope with stress” (Lasser et al., 2000).

1.7.6 Smoking Policies in Mental Health Facilities

Given the high rates of smoking among people with mental illness, it is not surprising that tobacco use is a prominent issue for psychiatric hospitals and other locations where individuals with mental illness receive care. Psychiatric hospitals have

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

been excluded from JCAHO (Joint Commission) standards that require hospitals be smoke free. As a result, people commonly refer to stories in which people with mental illnesses entered a hospital as a nonsmoker and left as a smoker as a result of peer pressure (Campion et al., 2008), a lack of other activities to occupy time, and because of reinforcement by the institution (Lawn, Pols, Barber, 2002). Smoking in mental health and addiction treatment settings is a public health and environmental health issue (Ziedonis & Williams, 2003), yet restrictions or total bans on tobacco use in psychiatric settings remain extremely controversial (Cormac & McNally, 2008; Greeman & McClellan, 1991).

Despite the controversy and in response to the demonstrated health hazards of tobacco smoking and secondhand smoke, health care facilities are increasingly implementing policies that ban smoking on their premises (el-Guebaly et al., 2002a; Parks & Jewell, 2006). In 2008, the NASMHPD Research Institute (NRI) reported that 49% of facilities responding to their survey were non-smoking. Staff are sometimes resistant to these bans, and mental health staff are known to be significantly less positive towards smoking-related policies and treatments than their counterparts in other areas of healthcare (Cormac & McNally, 2008). Yet more smoking-related problems are generally anticipated than actually occur (Lawn & Pols, 2005; Parks & Jewel, 2006). Despite good intentions, the smoking bans have not been considered successful in encouraging abstinence once people leave the hospital setting (el-Guebaly et al., 2002a). Yet, this is not a reason to give up. Williams (2008) argues, “exempting mental health hospitals from

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

smoke-free laws aimed at protecting the public also has the potential to worsen health inequalities for people with mental illness and further their stigmatization” (p. 572).

1.7.7 Prevention and Awareness of Tobacco Use in this Population

Prevention and awareness strategies, while commonly used by the tobacco control movement and its advocates, are underutilized in this population. There is a sense that, given the associations between mental illness and smoking, tobacco use among people with mental illnesses could potentially be prevented if mental health conditions were properly treated (Breslau, Novak, & Kessler, 2004). Also, almost no MSA funds have been directed toward prevention and treatment for people with mental illness (Ziedonis & Williams, 2003). There have been calls to develop a comprehensive national plan to address tobacco dependence among persons with serious mental illness (Ziedonis, Williams, & Smelson, 2003). Such a plan, according to Ziednois et al. (2003), would require education and action, policy development, better knowledge about prevention and treatment and other clinical, program, and system issues, and would bridge the gap between leaders in the tobacco control, research, and behavioral health treatment communities.

1.8 Potential Movements on Smoking Cessation/Tobacco Control Among People with Mental Illness

1.8.1 The National Mental Health Partnership for Wellness and Smoking Cessation

The National Mental Health Partnership for Wellness and Smoking Cessation (“the Partnership”), a collaborative arrangement developed through the efforts of the Smoking Cessation Leadership Center (SCLC) at the University of California, San Francisco (UCSF), has helped create and lead a national action plan as is described above. The SCLC is a national program office of the Robert Wood Johnson Foundation (RWJF) that aims to improve smoking cessation rates and increase the number of health professionals who help smokers quit (SCLC, n.d.). To achieve these goals, the SCLC creates partnerships with groups of health professionals, such as dental hygienists, nurses, pharmacists, and emergency physicians, to address smoking cessation (SCLC, n.d.). The SCLC has been instrumental in promoting smoking cessation all over the United States, originating the phrase “30 seconds to save a life” and developing the blue “quit now card” that promotes the use of the toll-free telephone quitline (SCLC, n.d.).

Based on knowledge of the high rates of smoking among people with mental illness and an understanding of the need to establish a well-organized and focused effort to promote leadership, research, education, and consciousness-raising on smoking in this population, the SCLC received funding from the American Legacy Foundation to work specifically with the mental health community to address the disparities described above.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

The SCLC hired a consultant, Gail Hutchings, to identify organizations and leaders within those organizations that would be essential to the success of this initiative.

In March 2007, the SCLC convened national leaders, including mental health practitioners, mental health researchers, smoking cessation researchers, mental health advocates, smoking cessation/tobacco control advocates, and mental health consumers representing approximately 25 diverse mental health and smoking cessation stakeholder groups. These leaders gathered in Lansdowne, Virginia for a summit aimed at developing a national consensus on the need to: (1) increase opportunities for wellness among mental health consumers and staff, and (2) ensure that smoking cessation treatments and tools are readily available.

This two-day summit ultimately led to the formal creation of the National Mental Health Partnership for Wellness and Smoking Cessation. The Partnership members developed a national action plan, a mission statement, and a list of priorities and strategies that included: (1) person-centered education: embrace consumer-driven process; (2) promote provider-motivated education; (3) promote staff wellness and smoking cessation; (4) reach out to key players and stakeholders; (5) build infrastructure; (6) assess and strengthen the effectiveness of quitlines with consumers and staff; and (7) develop data. In broad terms, according to a mental health advocate and government official, the goal of the Partnership was to make smoking cessation among people with mental illnesses a “priority conversation” for “consumers all the way up to the national leaders.” Thus, the initial focus, according to this individual, was “just to get people used

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

to talking about smoking cessation in the mental health community” and to make the issue “visible” in as many ways as possible.

Confronted with the task of developing a mission statement and a strategic direction, one of the mental health advocates initially suggested during the summit that the Partnership designate a subset of its members to form an interim governance group (IGG), an advisory council that would do some of the legwork they felt was necessary to move the initiative forward. The idea was that this inner circle of leaders would, in essence, do the work needed to push the others along. In the words of one of the IGG members (which disbanded less than one year later in favor of efforts to engage the Partnership as a whole), the role of the IGG was to strategically look at the issue holistically and to encourage collective rather than individual actions.

Table 2 below provides a timeline of the significant tobacco control and mental health-related events that have taken place before and after the development of the Partnership.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Table 2 Timeline of Significant Tobacco Control and Mental Health Events

Date	Event
1963	Community Mental Health Act passes as part of President John F. Kennedy's New Frontier. This Act provided federal funding for community mental health centers and led to the deinstitutionalization of many people with mental illnesses that had been receiving care in in-patient hospital settings.
1964	First <i>Surgeon General's Report: Smoking and Health</i> provides the public with the first definitive conclusions regarding the connection between smoking, lung cancer, and other diseases.
1965	Congress requires that health warning label be placed on all cigarette packaging and tobacco advertisements.
1970	Congress prohibits tobacco advertising on television and radio.
1970s	Modern U.S. mental health consumer movement begins, in parallel with the deinstitutionalization of people with mental illness.
1976	President's Commission on Mental Health establishes and acknowledges the activities of consumer-run groups across the U.S.
1990	Robert Wood Johnson Foundation initiates a focus on substance abuse, and in particular, tobacco use.
1990	The Americans with Disabilities Act (ADA) is enacted. The ADA is a law that employers must make reasonable accommodations that will allow people with disabilities, defined as "a physical or mental impairment that substantially limits a major life activity," the same civil rights provided to those without disabilities, including mandating accommodations for employment.
1993	A review paper by Alexander Glassman links depression, alcoholism, and schizophrenia to smoking, and calls for psychiatrists to see tobacco use as clinically relevant to their practice.
November 1998	Master Settlement Agreement (MSA), an agreement between U.S. tobacco companies and the attorney generals of 46 states is reached.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

	The MSA is the largest civil agreement in U.S. history. The MSA creates restrictions on practices by the tobacco companies and requires them to compensate the states for the costs of providing health care to people with smoking-related illnesses.
1999	The American Legacy Foundation is created with funds from the MSA.
1999	<i>Mental Health: A Report of the Surgeon General</i> is published and calls for the need to integrate mental health and primary care services.
November 2000	Lasser and colleagues article published which documents the high rates of smoking among people with serious mental illness and substance abuse disorders. The researchers find that people with mental illnesses and substance abuse disorders consume 44.3% of U.S. cigarettes.
November 2002	The Substance Abuse Mental Health Services Administration (SAMHSA) <i>Report to Congress on Co-Occurring Addiction and Mental Illness</i> is published. This report includes tobacco and mental illness as a subtype of co-occurring disorder.
November 2002- June 2003	A series of meetings addressing tobacco use among persons with mental illness and addictions brings together, for the first time, researchers, clinicians, administrators, and prevention specialists to consider options for addressing the needs of underserved groups of smokers (Ziedonis, Williams, & Smelson, 2003).
2003	The President's New Freedom Commission on Mental Health report titled <i>Achieving the Promise: Transforming Mental Health Care in America</i> is published which calls for a need to remedy a "system in shambles" and to focus on recovery.
January 15, 2003	The Smoking Cessation Leadership Center (SCLC), a national program office of the Robert Wood Johnson Foundation, is established.
October 2003	Clubhouse of Suffolk awarded a grant to address the special needs of individuals with serious mental illness who struggle with tobacco addiction (leading to the creation of the popular Smoke Alarm video).
2004	The National Association of State Mental Health Program Directors

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

	(NASMHPD) annual meeting in San Francisco initiates a relationship between NASMHPD and the SCLC.
2004	The federal government supports the establishment of a national toll-free phone line (1-800-QUIT-NOW) that gives people who use tobacco free access to state-run “quitlines.”
February 2005	World Health Organization Framework Convention on Tobacco Control (WHO FCTC) established.
2006	Gail Hutchings hired as a consultant by the SCLC in an effort to initiate a partnership with the mental health community.
May 2006	The FDA approves varenicline (Chantix), the first prescription drug created specifically for the treatment of tobacco dependence.
June 27, 2006	Surgeon General’s Report: <i>The Health Consequences of Involuntary Exposure to Tobacco Smoke</i> is published.
July 10, 2006	NASMHPD releases position statement on <i>Smoking Policy and Treatment at State Operated Psychiatric Facilities</i> .
October 2006	NASMHPD publishes <i>Tobacco-Free Living in Psychiatric Settings</i> toolkit.
October 2006	NASMHPD publishes report <i>Morbidity and Mortality in People with Serious Mental Illness</i> .
2007	The National Summit on Mental Health and Wellness organized by SAMHSA takes place and results in the development of the “10 x 10 initiative” with the goal of reducing mortality for people with mental illnesses by 10 years within 10 years.
March 22-23, 2007	At the SCLC organized summit in Lansdowne, Virginia, the National Mental Health Partnership for Wellness and Smoking Cessation is born.
May 3, 2007	<i>USA Today</i> publishes an article on the 25-year mortality gap between the general population and people with mental illness.
June 11, 2007	The program Consumers Helping Others Improve their Condition by Ending Smoking (CHOICES) receives Mental Health America’s Innovation in Programming award.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

October 2007	The National Conference on Tobacco or Health (NCTOH) demonstrates great interest in mental health topics.
October 25, 2007	NPR airs segment, “Despite Worries, Psychiatric Hospitals Ban Smoking.”
November 18, 2007	Dr. Steven Schroeder’s op ed piece “A Hidden Epidemic” is published in the <i>Washington Post</i> .
December 5, 2007	First National Mental Health Partnership for Wellness and Smoking Cessation communiqué (newsletter) distributed to partnership members and other interested individuals/organizations.
December 10, 2007	<i>Mental Health Weekly</i> , a leading publication for the mental health field, publishes issue focused on smoking and cessation.
2008	NASMHPD’s Research Institute (NRI) reports that 49% of facilities responding to their survey are smoke-free.
May 2008	Publication of <i>Treating Tobacco Use and Dependence: 2008 Update of the Clinical Practice Guideline</i> .
July 2008	SAMHSA in-service training on tobacco organized by the SCLC takes place.
December 3, 2008	<i>Time</i> magazine publishes article, “Why do the mentally ill die younger?”
January 2009	<i>Smoking Cessation for Persons with Mental Illness: A Toolkit for Providers</i> (a national update of the 2007 version from Colorado) is released.
February 2009	The <i>Journal of the American Medical Association</i> publishes a review piece in its Clinical Crossroads section by Dr. Steven Schroeder titled, “A 51 Year Old Woman with Bipolar Disorder who Wants to Quit Smoking,” demonstrating increased interest among clinicians on this topic.
February 2009	The American Psychiatric Nurses Association devotes an entire issue of its journal, the <i>Journal of the American Psychiatric Nurses Association</i> , to smoking cessation topics.
March 2009	100 Pioneers for Smoking Cessation Virtual Leadership Academy is

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

	launched. The program invited 2008 SAMHSA grantees to apply to participate.
April 1, 2009	The federal excise tax on a pack of cigarettes increased from \$0.62 to \$1.01.
April 13, 2009	National webinar training takes place on Rx for Change Mental Health Peer Curriculum, <i>Tobacco-Free for Recovery: Assisting Mental Health Consumers with Tobacco Cessation</i> .
July 1, 2009	The Food and Drug Administration (FDA) requires that two smoking cessation drugs, Chantix and Zyban, carry a “black box” warning, the agency’s strongest safety warning, over side effects including depression and suicidal thoughts.

NOTE: While some of the events included in this table may not necessarily belong among the most significant in the history of the mental health movement, the tobacco control movement, or efforts to address the high rates of smoking among people with mental illness, this timeline is intended to provide a context for understanding the chronology of milestones, events, reports, and policy changes referenced throughout this dissertation.

1.9 Language and Definitions

Before proceeding, it is important to discuss the terminology used throughout this dissertation. A number of terms require exploration, explanation, and a critical examination of their roots and meanings, as I am fully aware that word choice can have personal and political implications. Language is of critical importance in the area of disabilities and disability movements (Murphy, 1987), including the mental health field and its movements. “While those outside the group may see such distinctions as arcane, for many of those ‘inside,’ naming is part of the collective carving-out of social identity,

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

movement goals, and ideological orientation” (Gordon & Rosenblum, 2001, p. 7).

1.9.1 Definitions of Mental Illness

Mental illnesses, like other illnesses, are social constructions, and “hypothetical constructs of our own creation” (Conrad, 1980, p. 105). Mental illness has been constructed and described in countless ways, at least in part “because the search for mental disturbance is not viewed as independent of the ‘production’ of it” (Schatzman & Strauss, 1966, p. 4). There remains great uncertainty about what mental illness “is” and how best to measure it. “In fact, one striking feature of modern psychiatry is the widespread disagreement over very fundamental problems” such as the identification of mental illness (Schatzman & Strauss, 1966, p. 5). This remains true today.

Mental illnesses are alternatively referred to as mental health problems, mental disorders, psychiatric illness or disorder, severe mental illness, severe and persistent mental disorders, psychological distress, serious psychological distress, psychiatric impairments, chronic mental illness, and behavioral health problems (“behavioral health” is typically employed as an umbrella term that encompasses both mental health and substance abuse). A “serious mental illness” is defined by the President’s New Freedom Commission as “a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criterion specified within the DSM [the *Diagnostic and Statistical Manual of Mental Disorders*, a book that outlines the diagnostic criteria for mental health disorders]...that has resulted in functional impairment which substantially interferes with or limits one or more major life activities” (PNFC, 2003, p. 2).

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

Among the countless views that exist regarding mental illness, the position that is considered most radical is based on a social constructionist perspective (Berger & Luckmann, 1966) and holds that mental illness does not truly exist in any “real” objective sense but is instead constructed by psychiatrists and psychologists through interpretive and interactionist processes for the purposes of labeling those who are deviant as a mechanism of social control. Szasz (1970) called this “the manufacture of madness.” This perspective, highlighted by the anti-psychiatry movement, is extremely skeptical of the effectiveness of psychiatry and views psychiatrists’ relationships with patients less as treatment than as supporting the interests of the psychiatric establishment (Schatzman & Strauss, 1966).

At the other end of the continuum is the more common or visible perspective that defines mental illness as a disease with specific signs and symptoms as noted in the American Psychiatric Association’s (APA) *Diagnostic and Statistical Manual of Mental Disorder* (the current version is the DSM-IV). This perspective, based on the medical model, says that mental illness can be identified by experts in the mental health field and “managed” through counseling and medication. In general, the definition of mental illness has considerably broadened in the last century, and the treatment of many forms of mental illness has become more humane and less stigmatized.

Epidemiologists use three general sets of constructs to determine who has a mental illness. One focuses on signs and symptoms, one on difficulties in functioning, and one on whether a person has sought treatment for a mental health condition. Yet there

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

exists very little overlap between these three constructs. Less than 2% of Americans meet the criteria for all three constructs, which further demonstrates the challenges in quantifying mental illness (Frank & Glied, 2006). Moreover, some researchers calculate the prevalence of mental illness based on one-year prevalence (the percentage of the population that could be diagnosed with a mental illness within a given year, based on various screenings developed using diverse definitions of mental illness). Researchers also utilize information on diagnosed cases of mental illness (referred to as treated prevalence) to calculate the proportion of the non-institutionalized population who have visited a health professional and received a diagnosis of mental illness, and to examine the lifetime prevalence of mental illness (the percentage of the population that has been diagnosed with a mental illness during their lifetime). As will be noted in the next chapter, in recruiting for the study for this dissertation research project, I defined people with mental illness as people who were currently receiving any type of mental health services given the various challenges in defining what constitutes “mental illness” as compared to “mental health.”

People with substance abuse problems also smoke at extremely high rates. The prevalence of tobacco use is as high as 74% to 88% in this population (Kalman, 1998). Tobacco use has also been an endemic part of substance abuse treatment settings and culture (Fuller et al., 2007; Prochaska, Delucchi, & Hall, 2004). There are extremely high rates of co-morbidity of mental health and substance abuse or what is called “dual diagnosis” due to overlapping genetic vulnerabilities and the involvement of similar brain

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

regions (National Institute on Drug Abuse [NIDA], 2009). It is very difficult to disentangle the overlapping symptoms of drug addiction and other mental illnesses. While some researchers attempt to distinguish between people with mental illness and those with other disorders such as substance abuse, people with substance use issues have been included in many of the statistics cited above. This research does not attempt to make a capricious distinction between those with mental health and substance use problems, but rather examines the issue of smoking in the mental health community in particular given that it was the focus of the SCLC's and the Partnership's initial efforts. It is important to acknowledge that while the substance abuse community is in many ways different from mental health, there are enough similarities to suggest that the results of this study may generally apply to the substance abuse field and people with substance use issues.

Finally, smoking itself can be considered a psychiatric disorder. Both nicotine dependence and nicotine withdrawal are included in the DSM-IV. When categorized in this way, nicotine dependence is the most prevalent mental disorder (Campion et al., 2008).

1.9.2 People Who Experience Mental Illness

It can be difficult to determine what terminology is most appropriate to describe a person who is experiencing or has experienced mental health problems at any one precise moment in time. This is a common and well-recognized problem in the mental health community given the heterogeneity of mental health conditions and the mental health

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

field. In the words of David Mechanic (2008):

We would not, for example, sensibly talk about *people with physical conditions*, because almost everyone in the population will have several acute physical conditions each year (like the common cold) and many have one or more chronic diseases. Meaningful discussion requires specificity, because it is one thing to have acne and quite another to have AIDS. However, it has been much more conventional to talk about mental illness in a global fashion, even though the conditions involved vary in character, severity, the extent of disability they cause, and in many other ways. Because people are less likely to make these distinctions, the concept of mental illness associates *any* emotional difficulty with the stereotypes of severe psychoses and encourages an image of people who are unpredictable and incapable of caring for themselves. In reality, some psychiatric conditions are like the flu or a gastrointestinal disorder; they are relatively short-lived and do not greatly disrupt one's life. Others are more like serious heart disease and cancer, causing great discomfort and disability, and sometimes threatening life (p. 43).

Based on Mechanic's above explanation and the fact that it is commonly used among leaders in the field and as part of influential publications in mental health, I will often use the generic phrases "people with mental illness" or "people with mental illnesses" to describe people with less severe mental illnesses such as dysthymia (chronic, low-grade depression), or with "severe mental illnesses" (SMI) such as schizophrenia and bipolar disorder. I consciously use the phrase "people with mental illness" because it embraces person-first language that emphasizes the personhood at the core of mental illness.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

From the National Alliance of the Mentally Ill, the NIMH, and the Surgeon General's attempts to destigmatize mental illness, to the growing Mental Health Consumer/Survivor Movement, to the landmark legislation of the Americans with Disabilities Act of 1990 that prohibited discrimination against people with psychiatric disabilities in employment, education, and public affairs, public policy and attitudes have been slowly shifting over that time to a recognition of the common humanity—the personhood—that remains at the core of those with severe mental illnesses (Davidson, 2003, p. 12).

Although the APA changed the terminology used in the DSM from “schizophrenic” to “person with schizophrenia” when it published the fourth edition, the former term is regrettably still used in the literature and sometimes by clinicians in the field. I intentionally do not use phrases like “schizophrenic” or “the mentally ill” in my own writing, but it is sometimes used within direct quotations throughout this work. I also intentionally do not use the terms “client” or “patient” to avoid evoking the social control mechanisms that some believe are a creation or byproduct of the health care system and the (mental) health care establishment.

I have also chosen in some cases to use the phrase “mental health consumers” interchangeably with “people with mental illnesses.” The President's New Freedom Commission report (2003) uses the term “consumer,” which it defines as “people who use or have used mental health services (also known as mental health consumers, survivors, patients, or clients)” (p. 4). The term “mental health consumer” is commonly used at this time within the mental health community and is associated with empowerment, influence over the health services delivery system, and control over of one's own care.

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

I fully acknowledge and would agree with those who argue that people with mental illness have limited agency due to the structure of society and the health care system and that this terminology may be used to give people with mental illnesses a false sense of control over and choice in their lives. People who take this perspective, often those who are involved with the more “radical” mental health movements, sometimes refer to people with mental illness as “survivors” or “ex-patients,” to acknowledge the long history of mistreatment and discrimination generated by an oppressive and dehumanizing mental health system (Bassman, 2001; Chamberlin, 1977). The term “mental health consumers” can also be critically parsed to imply that “consumer” suggests that the responsibility for managing one’s own symptoms and mapping the course of one’s treatment is placed solely on the shoulders of the person with mental illness. In this way, if a consumer fails to get “better,” it may be viewed as his or her own fault. Yet, I have chosen to use this phrase with respect for the wish to foster hope and empowerment in the mental health community, and because it is regularly used by leaders in the mental health field and by people with mental illnesses themselves (PNFC, 2003; Solway, 2007; Solway, 2009).

Other terms have arisen, based on the phrase “mental health consumer.” For example, “prosumers” (professionals-consumers) has been used to describe people with mental illness who are also mental health professionals (Frese & Davis, 1997). Moreover, consumerism is used to describe activities such as self-help groups (efforts for people to come together as a group to resolve mutual individual needs), the organization of people

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

with mental illness and their families into effective political interest groups, and to emphasize the voice of consumers in the context of a centrally planned mental health delivery system (Frank & Glied, 2006).

1.9.3 Tobacco

Based on the definition from the National Health Interview Survey (NHIS), those who have smoked more than 100 cigarettes during their lifetime are considered current or former smokers (CDC, 2008). Smoking prevalence can be measured by calculating the percentage of people who are “some days smokers” or “everyday smokers.” There are assessments available, such as the Fagerstrom Test for Nicotine Dependence, that can be used to determine whether a smoker is “tobacco dependent.” It is common for an individual to be considered a current smoker if he or she has smoked in the last month (Lasser et al., 2000). Tobacco can be smoked in the form of cigarettes, cigars, clove cigarettes, bidis, and pipes, or can be used in other forms such as chewing tobacco or snuff. Cigarette smoking is the most common form of tobacco use in the overall population and among people with mental illnesses. Thus the terms “tobacco use” and “smoking” are used interchangeably throughout this dissertation.

1.9.4 Stigma

Goffman called stigma “a special kind of relationship between attribute and stereotype” (Goffman, 1963, p. 4) and referred to those who do not have the attribute, such as mental illness, as “normals.” The Surgeon General’s Report on Mental Health

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

(USDHHS, 1999) and the President’s New Freedom Commission on Mental Health Report (2003), among many other publications in the mental health field, regularly mention the importance of reducing this stigma so that people can access the care they need. Chapman and Freeman (2008) noted that several authors have suggested that Goffman’s notion of stigma as resulting in spoiled identity “is consonant with how the meaning of smoking had changed in societies with widespread tobacco control” (Chapman & Freeman, 2008, p. 26).

1.9.5 Recovery

Mental illnesses often have an unpredictable course and uncertain outcomes. Yet the term “recovery” has become part of everyday parlance and discourse in the mental health field. Recovery is “best understood as a process, not an outcome” (Frese & Davis, 1997, p. 244). The President’s New Freedom Commission refers to recovery as a process that allows people to fully participate in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life with a disability. For others, recovery implies the reduction or complete remission of symptoms. While remission may not be possible for every client, Frese and Davis (1997) note that providers “embrace a recovery framework when they assist a person in realizing his or her potential as a unique human being who is not defined by an illness” (p. 244). SAMHSA, the government agency tasked with developing and funding programs, policies, and grants that serve people with mental illnesses and substance use disorders, created 10 fundamental guiding principles of recovery: self-direction, individualized and person-centered, empowerment,

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

holistic, non-linear, strengths-based, peer support, respect, hope, and responsibility (SAMHSA, 2004). These guiding principles were developed to facilitate a shift in how people with mental illnesses see themselves and the ways they are viewed within society (Anthony, 1993).

The word recovery has also evolved and taken new forms. For example, the term “procovery” is sometimes used because it is thought to emphasize forward potential, as distinguished from the more common definition that is at times thought to refer exclusively to a prior state of health (Crowley & Anthony, 2000). The discourse around recovery can also be seen as a further attempt to medicalize mental illnesses. It highlights the social control element of medicine that tries to “normalize illness and return people to their functioning capacity in society” (Conrad, 1980, p. 109).

1.9.6 The Mental Health Community and the Smoking Cessation Field

Finally, in this dissertation I regularly use the phrase “mental health community” to refer to mental health organizations, advocates, consumers, clinicians (e.g., psychiatrists, clinical psychologists, psychiatric social workers, mental health counselors, psychiatric nurses, therapists, peer counselors, or others who provide clinical services to people with mental illnesses), and policymakers who work, receive care in, or advocate for the field of mental health. Schatzman and Strauss (1966) stated that they are dissatisfied with the use of the term “community” to describe psychiatry “because it could not, as currently used, help us conceptualize the many ‘communities’ and aggregates which view or use psychiatry” (p. 8). While I agree that many diverse interests

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

are encompassed within the term “mental health community,” the mental health arena attempts to create a sense of agreement about its interests, which some have argued represents more agreement than actually exists (Mechanic, 2008). The term community is also used because of the strong sense of unity and mutual obligation in the mental health arena. For example, one of the leaders I interviewed for this study repeatedly noted that she was a “mental healer,” while other leaders and advocates routinely referred to their being part of the “mental health community.” Although the individuals and groups that constitute the mental health community are extremely diverse and have unique viewpoints, those within it often refer to the mental health field as having a shared culture and a sense of values that permeates relationships and practices.

I use the phrase “smoking cessation field” to refer to educators, researchers, advocates, clinicians (including smoking cessation counselors and treatment specialists), and policymakers in the area of smoking cessation. I chose “smoking cessation field” because people who work in smoking cessation come from public health, clinical care, and primary care, among other fields, and are therefore potentially more likely to share a sense of community or feel a sense of connection with these broader fields.

1.10 Concluding Remarks

The unpredictable courses of mental illness and the public’s fears about people with mental illnesses causing disruptions to the social order have resulted in entrenched discrimination and stigma around mental health problems. Historically, people with

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

mental illnesses have been denied the most basic human rights because of their “need” to be managed and controlled. As a result of this deeply engrained paternalism and prejudice, many people with mental illnesses have experienced abuse and mistreatment that can result in psychological trauma and often in health disparities too. In general, the expectation that mental illness should be prioritized ahead of and/or instead of treatment and prevention of general health conditions has resulted in shortened life expectancy and insufficient opportunities to achieve wellness and quality of life.

This dissertation has the following six aims:

1. To understand the experiences of people with mental illness related to tobacco use.
2. To examine the initiation, evolution, and effects of the relationship between the mental health and smoking-cessation communities.
3. To identify the ways in which smoking among people with mental illness is addressed and framed by the mental health field, the smoking cessation field, the National Mental Health Partnership for Wellness and Smoking Cessation, and the media.
4. To examine the role of mental health consumers in efforts to address the high rates of smoking among people with mental illness.
5. To examine if, how, and why the partnerships between the mental health and smoking cessation fields meet the definition of a social movement.
6. To explore possibilities for, and tensions in, addressing the health disparities for people with mental illness generally, and the potential results of such efforts on the status of people with mental illnesses within society, including structural issues and barriers.

Chapter 2 will describe the theoretical perspectives that will serve as a lens in examining these aims, and the methodologies used to gather and analyze data. Chapter 3

Chapter 1 | Health Disparities Among People with Mental Illness: Background and Introduction

will describe the findings from focus groups with mental health consumers regarding their experiences with tobacco and quitting. Chapter 4 explores shifts in framing within the mental health and smoking cessation fields, the National Mental Health Partnership for Wellness and Smoking Cessation, and the media that have resulted in an increased focus on physical health, and the effects of smoking in particular on the health and well-being of people with mental illnesses. Chapter 5 will review the possibilities and prospects for a social movement formed specifically around tobacco cessation for people with mental illnesses and the ways in which such a movement may benefit from the broadening and expansion of the mental health and tobacco control movements. Chapter 6 will offer a discussion of the findings, and in particular, the ways in which the perspectives of leaders in the mental health community and smoking cessation fields overlook the role of structural and policy issues that are so integral to the experiences of smoking and quitting for people with mental illnesses. Finally, Chapter 7 will offer concluding remarks about the possibilities for culture, social, structural, and policy change, opportunities for new research, and projections for the future.

Chapter 2 | The Theoretical Frameworks of Social Problems and Social Movements and Study Research Methods

“I don’t think this engenders any more needs, any more research. It’s just a matter of taking what we know and translating that into a workable model for this particular population. So all the components are there, it’s just a matter of putting them together.”

- Smoking Cessation Advocate and Provider

2.1 Introduction

This dissertation is grounded in a rich body of theoretical and methodological literature. This chapter begins with a focus on two separate but interrelated bodies of theoretical literature in sociology, social problems (which will be the basis for examining the results presented in Chapter 4) and social movements (which will be the basis for examining the results presented in Chapter 5) that explore how issues become conceived as problems and what happens in and through the development of coordinated actions around these problems. Then, this chapter will outline the various research methods based in the grounded theory approach that were utilized in gathering and analyzing these data to address this study’s research questions, as well as the strengths and limitations of these approaches.

2.2 Theoretical Frameworks

Sociologists have long been interested in what comes to be defined as a social

problem, what issues develop into social movements, and the ways in which changes in policies and practices are shaped by an issue's social problem status and movement development. This section describes the relevant theoretical literature with a specific focus on theories of social problems and social movements and the connections that exist between them. Although there is disagreement over whether social problems are outcomes of social movements (Mauss, 1984) or whether social movements are outcomes of social problems (Schneider, 1985), this chapter is written from the second perspective, that social problem definition is necessary for the mobilization and the development of social movements. For this reason, the social problems literature will be examined first.

2.2.1 Theories of Social Problems

The study of social problems is an increasingly rich and promising body of theoretical literature within sociology. Sociology has long been concerned with how social problems come into existence and how they are framed. In particular, the sociology of social problems was traditionally concerned with issues such as the sociology of poverty, crime, delinquency, mental illness, and other devalued and deviant social experiences and behaviors (Maynard, 1988).

Yet the very definition of social problems has been contested, and varies considerably according to different theorists and their approaches. The writings of C. Wright Mills on the differences between troubles and issues were an important contribution to the development and definition of social problems. In *The Sociological Imagination* (1959), Mills differentiates between “troubles,” which “occur within the

Chapter 2 | Theoretical Framework and Research Methods

character of the individual and within the range of his immediate relations with others,” and “issues” which “have to do with matters that transcend these local environments of the individual and the range of his inner life” (Mills, 1959, p. 8). For example, in comparing the experience of one person in a community who is without a job, and a situation in which millions of individuals are unemployed, Mills states that in the second scenario the “correct statement of the problem and the range of possible solutions require us to consider the economic and political institutions of the society and not merely the personal situation and character of a scatter of individuals” (Mills, 1959, p. 9).

Similarly, Gusfield differentiates between individual problems and public problems, and notes that public problems are “social problems” because public problems include a claim to change through public action and the involvement of the political elite. Many human problems are still private, and are not considered social problems because they have not yet been constructed in ways that make them require public actions.

Gusfield notes that the United States has a culture of public problems.

It is part of how we think and how we interpret the world around us, that we perceive many conditions as not only deplorable but as capable of being relieved by and as requiring public action, most often by the state (Gusfield, 1989, p. 431).

Therefore, social problems are very much intertwined with social institutions, and these institutions are often where people turn to cope with public problems. They are also related to the historical context and the structural dimensions that interact with cultural interpretations of personal and public experiences (Gusfield, 1989).

Spector and Kitsuse (1973), in defining social problems in a processional way,

Chapter 2 | Theoretical Framework and Research Methods

note that social problems are “the process by which members of groups or societies, through assertions of grievances and claims, define a putative condition as a social problem” (p. 145). Spector and Kitsuse suggest that social problems theory has three elements: (1) a theory of interests because many of the groups that participate in the process of definition are doing so to protect or pursue their own social, political, or economic interests; (2) a theory of moral indignation because some groups attempt to define a condition as a social problem because it offends their values and they believe the condition should not exist at all; and (3) a theory of natural history because they see social problems as a sequence of activities that move through distinctive stages.

Broadly speaking, three paradigmatic approaches are common to the study of social problems: (1) the functionalist (Merton, 1971; Merton & Nisbet, 1971), (2) social constructionist (Becker, 1966, Blumer, 1971; Fuller & Myers, 1941), and (3) political economy (Estes, 1979; Hilgartner & Bosk, 1988; O’Connor, 1973) approaches. Thus, social problems are examined from both the micro and macro levels. One of the most significant differences in these approaches, and one of the issues that is most contentious in this body of literature, is whether social problems are verifiable “objective conditions” or whether they are “subjective conditions” that are examined and constructed through a social process of claims-making conducted by social actors. “Sociologists have long debated whether social problems reside in the conditions of society, the social construction of analysts, or some combination of both” (Conrad, 1997, p. 139).

2.2.1.1 Functionalist Approach

The functionalist approach assumes that social problems are objective conditions

Chapter 2 | Theoretical Framework and Research Methods

and dysfunctions (Kitsuse & Spector, 1973). Merton (1971) noted that a social problem is “a substantial discrepancy between widely shared social standards and the actual conditions of life” (p. 799), and that a social problem is a combination of social disorganization (inadequacies or failures in a social system) and deviant behavior. From this perspective, deviance, dysfunction, and social strain are objective and identifiable conditions that indicate the existence of a social problem.

2.2.1.2 Social Constructionist Perspective

Yet other theorists have questioned whether there is something “more” that happens that transforms a condition into a “social problem.” Fuller and Myers (1941) were the first to make this assertion, stating that objective conditions are necessary, but not sufficient, for a social problem to exist. Fuller and Myers called this conception of social problems the value-conflict perspective. Becker (1966), in agreeing with this value-conflict perspective of social problems, suggested that a process is involved in making a problem “social.” At the same time, Becker noted that group definitions of social problems usually reference some empirically verifiable social conditions such that groups typically get upset over “something.”

These notions of social problems opened the way for the constructionist view. Berger and Luckmann (1966) first described the constructionist approach in *The Social Construction of Reality* where they argued that even knowledges that are considered to be commonsense or “everyday reality” are derived from and maintained by social interactions and processes. In a significant departure from functionalist notions of social problems, Blumer (1971) and Spector and Kitsuse (1973) utilized this perspective and

Chapter 2 | Theoretical Framework and Research Methods

focused on the process of development of collective, subjective, and changing definitions of social problems in which empirically verifiable claims are not deemed necessary.

Blumer's three premises of symbolic interactionism, which can be used to describe how meaning is created, are: (1) human beings act toward things on the basis of the meanings the things have for them; (2) the meaning of such things is derived from, or arises out of, the social interactions that one has with one's fellows; and (3) these meanings are handled in and modified through an interpretive process used by the person in dealing with the things he encounters (Blumer, 1969).

The constructionist view focuses on the significance of "definitional activities," noting, "social problems are the definitional activities of people around conditions and conduct they find troublesome, including others' definitional activities" (Schneider, 1985, p. 209). Thus, from this perspective, language, knowledge, and meaning are crucial. In a critique of the social constructionist perspective, Woolgar and Pawluch (1985) argue that social constructionist explanations apply varying levels of skepticism toward the objectivity of problems (Maynard, 1988), which they call "ontological gerrymandering" (Woolgar & Pawluch, 1985, p. 218).

Influenced by nineteenth-century empiricism and positivism, the sociology of knowledge helped to lay the groundwork for social constructionist ways of thinking by suggesting that knowledge is a social product. The sociology of knowledge, developed by Mannheim in 1936, helped to emphasize some important questions concerning what knowledge is, what knowledge consists of, how knowledge is produced, and whose knowledges have priority (McCarthy, 1996). Mannheim was greatly influenced by the

Chapter 2 | Theoretical Framework and Research Methods

Enlightenment ideas of freedom and progress. While some knowledges are privileged over others, such as the dominating knowledges of the elite and the discriminatory ways of knowing that privilege the white male experience (Collins, 1990; Omi & Winant, 1986; McCarthy, 1996), there is an awareness based on this perspective that knowledges are often complex, constructed, and unique. The sociology of knowledge is of great significance to the discipline of sociology overall and plays an important role in understanding which societal conditions become defined and acted upon as social problems.

2.2.1.3 Political Economy

Social problems are also analyzed through political economy perspectives. The political economy perspective builds on the ideas of Karl Marx who believed that the means and relations of production are central to understanding and explaining society and human action (Marx, 1885). From this perspective, a social problem cannot be understood in isolation from the larger (and evolving) political and economic environment in which it exists. Furthermore, the political economy perspective emphasizes the role of political power in the identification of a social problem. Within a political economy paradigm, the state, which is composed of major social, political, and economic institutions (Estes, 2001), plays a critical role in regulating the definition(s) of and solution(s) to social problems (Dickinson & Russell, 1986; Gordon, 1990; O'Connor, 1973). The state is an instrument for advancing class interests (Marx, 1867). There is a fundamental contradiction that certain problems create for the state in its simultaneous efforts to serve its accumulation and legitimation functions under capitalism (O'Connor,

1973). Therefore, a social problem from this theoretical perspective is a situation that does not allow the state to create or maintain conditions in which profitable accumulation can take place while at the same time addressing the social needs and harmony necessary for an ordered society.

2.2.1.4 Framing of Social Problems

Furthermore, social problems grow and are framed in specific but far-reaching public arenas including governments, courts, television, movies, newspapers, magazines, books, radio, political campaigns, advocacy organizations, research, religious organizations, foundations, and professional groups (Hilgartner & Bosk, 1988). Framing allows for the transfer of information from these various sources to human consciousness (Entman, 1993). “It is in these institutions that social problems are discussed, selected, defined, framed, dramatized, packaged, and presented to the public” (Hilgartner & Bosk, 1988, p. 59). The survival of social problems “depends on the continued existence of groups or agencies that define some conditions as a problem and attempt to do something about it” (Kitsuse and Spector, 1973, p. 415).

Gusfield (1989) said that the people who serve/work in these groups or agencies, such as those who work in the mental health and smoking cessation fields, are part of the “troubled persons professions” (p. 432) and that these groups form collectively what Hilgartner and Bosk (1988) call the “social problems industry” (p. 69). These individuals and groups are often given authority or expert status by the state to name a particular condition a social problem (such as mental illness or tobacco dependence) or to serve as gatekeepers who interpret and act upon the situations and conditions that are deemed to

fall under their justification (Gusfield, 1989; Katz, 1996). For example, studies of the medicalization of deviance illustrate how professionals create the problems they “own” and treat (Schneider, 1985) and the ways in which industries are created that are “entrepreneurs for medicalization” (Conrad, 1980, p. 117). The state also plays a role in defining and acting upon social problems by funding social programs and research on particular issues and by creating and enforcing policies to address issues that it sees as “problematic.” The state, for example, has played a substantial role in funding programs, research, and policies to help people quit smoking and for the treatment of mental illnesses.

2.2.1.5 The Process of Defining a Situation as a Social Problem and Taking Action

Consequently, the reason why one condition becomes a social problem, while another condition does not involves a complex combination of factors and definitional and interpretive processes. As a result, efforts to define situations as social problems are not always successful (Gusfield, 1989). For the most part, the extent of possible harm, the level of importance, and the marketability of the issue *do not* make conditions rise to the level of social problems (Hilgartner & Bosk, 1988). Instead, “the fates of potential problems are governed not only by their objective natures but by a highly selective process in which they compete with one another for public attention and social resources” (Hilgartner & Bosk, 1988, p. 57). This is because a discrepancy exists “between the number of potential problems and the size of the public space for addressing them that makes competition among problems so crucial and central to the process of collective definition” (Hilgartner & Bosk, 1988, p. 59). As a result, competition between problems

Chapter 2 | Theoretical Framework and Research Methods

is intense and occurs on two levels: (1) within each substantive area, and (2) with all other possible social problems that are vying for the attention of the public (Hilgartner & Bosk, 1988).

Finally, the division between social problems and social movements is also blurry and complicated. Therefore, social problem theories are often tied to or appear quite similar to theories of social movements. In fact, there is discussion in the social problems theory literature regarding whether the definition of social problems is sufficiently distinct from social movements theory to warrant continued attention (Schneider, 1985). For example, Blumer (1971) said that social problems pass through five stages, or a “career”: (1) the emergence of a social problem, (2) the legitimation of the problem, (3) the mobilization of action with regard to the problem, (4) the formation of an official plan of action, and (5) the transformation of the official plan in its empirical implementation. The organization and form of a social movement occurs at the more advanced stages. A mobilized social group is able to bring about a change in the status of a social problem (Gusfield, 1989), and, as mentioned, social movements often exist in order to attempt to make or unmake phenomena as social problems. Gusfield suggested that the study of social problems needs to be more closely aligned to the study of how social movements and institutions affect and are affected by the interpretations, language, and symbols that result from a situation being perceived of as a social problem.

2.2.2 *Social Movements*

Social movements are of great sociological interest because they are a major source of social conflict and social change. Social movement theories, which are rooted

Chapter 2 | Theoretical Framework and Research Methods

in the Marxist tradition (Tucker, 1978), suggest that it is through conflict and challenges to the state that social movements emerge. In classical sociology, Marx (1845) wrote persuasively regarding the power of social movements to create a revolution through which the working class could exert power over the ruling class and communism could prevail. The literature on “social movements” proliferated in the late 1960s when the civil rights movement and other activities and events of the time brought attention to the power of individuals in organizing for social change. The field of social movements theory developed as a result of the work of academics that identified with, were active in, and/or wanted to study the movements of the 1960s and 1970s. Unlike Marx’s notions of a revolt from below, most social movements today appear to be more concerned with reform than large-scale revolution, yet they still maintain a primary focus on how marginalized and oppressed groups create social change through organized social action.

Although there have been efforts to create unique approaches in the study of social movements, and new theories have developed over time, there is still a lack of agreement regarding what defines a “social movement.” For the purposes of this dissertation and in an attempt to clearly and simply state the perspective through which these data are examined, the social movement definition utilized here is: a collective action focused on a particular political or social issue for the purposes of social change. This definition, of course, generates more questions than answers. What is collective action? What is social change? When does one “know” that a social movement has emerged? While there is a tendency to equate social movements with organized efforts to fight societal injustices, social movements do not emerge solely to challenge the state.

Chapter 2 | Theoretical Framework and Research Methods

They also address other areas such as institutions and beliefs that are forged within the private sector of society. Social movements were traditionally focused on economic concerns and labor issues, but over time, have come to direct attention to other issues such as human rights, the environment, peace, and more recently, health. It is somewhat taken for granted that social movements are effective in creating change.

The questions raised in the previous paragraph are the types of questions that social movement theorists have long grappled with. One fundamental difference in opinion, for example, in considering what defines a social movement, is that some social movement theorists believe that small changes constitute a social movement whereas others believe that a social movement only exists if it is followed by a new social order. Johnson (1995) defined a social movement as a “sustained, organized collective effort that focuses on some aspect of social change” (Johnson, 1995, p. 262). In the words of Meyer and Whittier (1994), “social movements are not self-contained and narrowly focused unitary actors, but rather are a collection of formal organizations, informal networks and unaffiliated individuals engaged in a more or less coherent struggle for change” (p. 277).

Theories have developed around several aspects of social movements including: what social movements are, why movements emerge, why they emerge when they do, why people join or leave movements, and when and how actors secure resources. “There is disagreement among sociologists about the appropriate or most important analytic mechanisms for explaining the growth, decline, and change of social movements” (Zald & Berger, 1978, p. 828), and thus the different theoretical approaches provide distinctive

Chapter 2 | Theoretical Framework and Research Methods

conceptions of these mechanisms. Like social problems theory, the theoretical literature on social movements includes numerous perspectives and renditions, many of which I will highlight below. These include classical theories, resource mobilization theories, political process theories, political economy perspectives, and collective identity theories that describe and explore social movements from the micro and macro levels.

2.2.2.1 Classical Theories

Classical theory approaches based on social psychological perspectives were the first social movement theories to emerge. The classical theory of social movements included collective behavior, frustration-aggression theory, relative deprivation theory, and mass society theory. The classical model, a product of the Chicago School of Sociology, states that structural strain from rapid social change result in a disruptive psychological state and individual grievances which ultimately lead to a social movement (Jenkins, 1983; McAdam, 1982). This theory argues that social movements provide collections of individuals with an opportunity to relieve emotional strain and distress. Based on these classical theories, social movements are seen as being irrational, emotion-driven, and disorganized (McAdam, 1982).

Classical theories of social movements have been criticized as too simplistic and for over-emphasizing the psychological aspects of movements (Jenkins, 1983; McAdam, McCarthy, & Zald, 1988). The inadequacies and inaccurate assumptions of the classical tradition, and of social psychological perspectives on social movements more generally, became evident in the 1960s and 1970s when massive movements arose, such as the civil rights and the feminist movements. These movements were not focused on economic

Chapter 2 | Theoretical Framework and Research Methods

crises like previous movements, but “involved concrete goals, clearly articulated general values and interests, and rational calculations of strategies” (Cohen, 1985, p. 673). As a result of these critiques and experiences, social movement theorists turned their attention to macro-level and structural explanations for movement emergence.

2.2.2.2 Resource Mobilization Theory

Resource mobilization theory offers an alternate interpretation of social movements based on the organizational perspective and is appropriate for the examination of the National Mental Health Partnership for Wellness and Smoking Cessation and other issues concerning smoking and mental illness. This theory suggests that grievances themselves are secondary to the development of a movement and that social movements form because of long-term changes in group resources, organization, and opportunities for collective action (Brown et al., 2004; Jenkins, 1983). Generally speaking, resource mobilization theorists argue that the success of social movements depends on resources and the ability to utilize them effectively.

Resource mobilization theorists describe social movements as “collections of political actors dedicated to the advancement of their stated substantive goals” (McAdam, 1982, p. 22). “The most distinctive contribution of resource mobilization theory has been to emphasize the significance of outside contributions and the cooptation of institutional resources by contemporary social movements” (Jenkins, 1983, p. 532). Resource mobilization perspectives emphasize continuities between movements and institutionalized actions, the rationality of movement actors, the strategic problems confronted by movements, and the role of movements as agents for social change

Chapter 2 | Theoretical Framework and Research Methods

(Jenkins, 1983). From this perspective, social movements “are not a form of irrational behavior but rather a tactical response to the harsh realities of a closed and coercive political system” (McAdam, 1982, p. 20) such that “organization and rationality are thus the catchwords of this approach” (Cohen, 1985, p. 676).

Resource mobilization theory, according to Zald and McCarthy (1977), suggests that the outcomes of a coalition (or partnership) or social movement are a function of coalition activities, processes, and the organizational bases of support and political climate. Based on this theory, Jenkins (1983) asserts that the success of a movement or coalition can be assessed in terms of changes in public policy, the politics of decision-making (who is included, how decisions are made), and the distribution/allocation of resources. While traditional social movement theories are focused on both movements for personal change and movements focused on institutional change, resource mobilization sees social movements as extensions of institutional change. Resource mobilization theories focus on attempts to change “elements of social structure and/or the reward distribution of society” (McCarthy & Zald, 1977, p. 1218), organize against the elites by unorganized groups (Gamson, 1975), or represent the interests of groups excluded from the polity (Jenkins & Perrow, 1977). A group’s potential for mobilization depends in large part on the degree of preexisting group organization.

Resource mobilization theory has been criticized for overemphasizing the importance of outside resources. For example, McAdam (1982) called resource mobilization a “deficient alternative” to the classical model of social movements in that it continues to leave unanswered questions such as which resources are significant (p. 20).

Chapter 2 | Theoretical Framework and Research Methods

McAdam also noted that this theory places too much importance on elite institutions and does not give enough attention to the aggrieved populations. Klandermans (1992) suggested that resource mobilization theory does not adequately explain what makes people define their situation in a way that makes them want to participate in a movement. He noted: “resource mobilization theory, in the meantime, investigated the ‘supply of social movements organizations but overlooked the fact that the presence of movement organization does not itself produce grievances and convince people that movement participation is effective” (Klandermans, 1992, p. 77).

2.2.2.3 Political Process and Political Economy

Political process theory is similar to the resource mobilization theory in that both theories reflect an elite understanding of power in which relatively powerless groups experience trouble gaining access. The political process theory of social movements, which focuses on political rather than psychological phenomena, was developed as a reaction to resource mobilization theory (McAdam, 1982). This approach identifies opportunities and constraints in the political environment and their influence on movement emergence and activity (Brown et al., 2004; Tilly, 1978; Tilly, Tilly, & Tilly, 1975). It defines a social movement as a sustained challenge to state policy that has observable origins, peaks, and declines in activity and uses a combination of conventional and non-conventional collective actions (Meyer & Whittier, 1994).

According to political opportunity theory, the success of a social movement depends not only on the movement’s resources but also on the resources in the social systems, including the state, and how these resources are used in support of or in

Chapter 2 | Theoretical Framework and Research Methods

opposition to movement goals. This perspective places emphasis on the complex interactions between the movement and the larger social environment. In essence, political process theory is focused on weakening entrenched authority and reducing the power disparity by creating new political opportunities for relatively powerless groups to fight against the existing authority. This theory has also been met with criticism, including suggestions that the political opportunity approach does not fully explain shifts in the structure of political opportunities (McAdam, 1982).

Other macro theories of social movements are based on political economy perspectives. Political economy approaches, in general, as mentioned within the context of the social problems literature, are built upon Marxist theories that focus on the economic contradictions that exist in industrial societies that cause conflict and grievances. Political economy approaches typically emphasize the specific historical nature of the economic and political environment in the development and progression of a movement.

For example, Quadagno's (2004) theory of stakeholder mobilization states that in order to be effective in the political arena, stakeholders "share with the politically powerless a need for leadership, an administrative structure, incentives, some mechanism for garnering resources and marshalling support, and a setting where grassroots activity can be organized" (Quadagno, 2004, p. 28). Although dominant groups may have privileged access to politics and elected officials, they also require these same resources to exert their political influence. Quadagno notes that the structure of the state systematically organizes political activity, and thus, "prospects for reform are enhanced

Chapter 2 | Theoretical Framework and Research Methods

when a coalition is organized in ways that closely mirror the representative arrangement of the American state” (p. 40).

Other political economy scholars examine the role of the state in the development and progression of social movements (O’Connor, 1973; Quadagno, 1987; Tilly 1975, Tilly, 1978; Tilly, 1979). Some state theorists, such as Habermas (1973) and O’Connor (1973), focus on the fiscal crises of the state under advanced capitalism as important to movement development. O’Connor wrote that the state must fulfill the roles of accumulation and legitimation (O’Connor, 1973), and these conflicting roles can lead to a “legitimation crisis” through which the state becomes more vulnerable to a social movement (Habermas, 1973; O’Connor, 1973). For example, Piven and Cloward (1977) followed the success of “poor people’s movements” and the ability of these movements to secure access only during regime crises created by major economic disruptions.

2.2.2.4 Collective Identity and Culture

Sociologists who write about social movements have turned to collective identity theories as a response to the broad criticism that previous theories have overlooked the significance of culture (Melucci, 1995). Melucci, in fact, suggested that social movements have shifted their focus over time from class, race, and other more traditional political issues, to culture itself.

In the past twenty years, emerging social conflicts in advanced societies have not expressed themselves through political action, but rather have raised cultural challenges to the dominant language, to the codes that organize information and shape social practices. The crucial dimensions of daily life (time, space, interpersonal relations, individual and group identity) have been involved in these conflicts, and new actors have laid claim to their autonomy in making sense of their lives (Melucci, 1995, p. 41).

Class consciousness and identities were the predominant set of relationships and modes of identity in Europe during the time of early sociological writing because societies were largely homogenous. In contrast, issues of race, ethnicity, and national origin are of great current significance in the United States. The cultural issues around social movements can be understood through the concept of intersectionality and through Pat Hill Collins' (1990) theory of interlocking systems of oppression. Collins' work describes the importance of examining the ways in which race, class, gender, age, ability, and other ways of being and experiencing the world intersect and shape experiences, insights, and the distribution of economic and political power (Estes, 1979). Furthermore, cultural issues around social movements are also informed by feminist theory. The theoretical literature on feminist perspectives is expansive and ever-growing, and has had a significant impact on the development of our understanding of creating social change in highlighting women's ways of knowing and women's (and men's) experiences in the world (deBeauvoir, 1953; Collins, 1990; Hooks, 1994; and many others).

Similarly, in focusing on cultural influences on social movements, Melucci (1995) focused on collective identity, the process of "constructing" an action system developed by collective actors. Collective identity is an interactive and shared definition produced by several individuals (or groups) that are "concerned with the orientations of action and the field of opportunities and constraints in which action takes place" (Melucci, 1995, p. 44). Collective identity is relational and is a process that involves cognitive definitions focused on the ends, means, and field of action, a network of relationships between

Chapter 2 | Theoretical Framework and Research Methods

actors, and an emotional investment that makes individuals feel a common unity (Melucci, 1995). “Social movements develop collective identity in a circular relationship with a system of opportunities and constraints” (Melucci, 1995, p. 47).

Polletta and Jasper (2001) define collective identity as an individual’s cognitive, moral, and emotional connection with a broader community, category, practice, or institution” (p. 285). Collective identity can answer four kinds of questions or concerns: (1) why collective actions come into being when they do, (2) people’s motivation to act, (3) a movement’s strategic choices, and (4) the cultural effects of social movements (Polletta & Jasper, 2001). Changing identities is often a primary movement goal (Polletta & Jasper, 2001), and collective identity is a learning process that leads to the formation and maintenance of a unified empirical actor (a social movement.)

Collective identity ensures the continuity and permanence of the movement over time, and any social movement group must continually manage its collective identities. Even identities that predate the movement can be reconstructed. In theorizing about why people join or leave movements, Simon et al. (1998) suggested that identity is a critical component of why people join, participate in, and leave social movements. These authors state that the independent pathways to social movement participation are a calculation of the costs and benefits of participation, the identification with the movement and its collective identity, or adoption of a distinct activist identity.

2.2.2.5 New Social Movements

With this focus on cultural issues, some theorists began to question whether, on a societal level, we have started to experience a *new* kind of social movement which

Chapter 2 | Theoretical Framework and Research Methods

combines political goals with more culturally-oriented efforts focused on race, gender, age, and class (Polletta & Jasper, 2001). “Over the last decades, multiculturalism, identity politics, and more broadly, struggles for recognition have dominated the political landscape” (Hobson, 2003, p. 1), what McAdam, Tarrow, and Tilly (2001) call “contentious politics.” These movements, which include expressive and identity issues and “cultural rights” (Hannigan, 1991, p. 320) as explicit movement goals, along with the instrumental and power-oriented goals that have been associated with conventional politics, have been called New Social Movements (NSMs) (Williams, 1995). New social movements have developed in post-industrial western societies since the mid-1960s and were caused and/or influenced by post-modernism, the collapse of socialism, and a turn to an individual rather than a collective societal orientation, among other historical, political, and cultural changes.

While a great debate exists over whether the focus on identity and culture constitutes something truly “new” about new social movements, it is evident that these movements are concerned with cultural issues of individual autonomy and identity, ideology, and politics, rather than economic issues alone. “The NSMs have all raised the theme of the self-defense of ‘society’ against the state (and the market economy), since they all, in one way or another, struggle for a ‘postbourgeois, post patriarchal,’ and democratic civil society” (Cohen, 1985, p. 664). As a critique, Klandermans (1992) stated that new social movements theory failed to see that structural changes do not automatically generate social movements and has not focused on what makes people define their situation in such a way that inspires them to participate in a movement.

Chapter 2 | Theoretical Framework and Research Methods

Health social movements (HSMs) are an example of a category of new social movement. Brown and Zavestoski (2004) define health social movements as “collective challenges to medical policy, public health policy and politics, belief systems, research, and practice which include an array of formal and informal organizations, supporters, networks of cooperation, and media” (p. 679). These movements, as the name implies, are centrally organized around health-related issues and focus on: (1) access to or the provision of health care services; (2) health inequality or inequality based on race, ethnicity, gender, class, and/or sexual orientation; or (3) disease, illness experience, disability, and/or contested illness (Brown et al., 2004). Thus, health social movements can be divided into three potentially overlapping types: health access movements, constituency-based health movements, or embodied social movements (Brown et al., 2004). The National Mental Health Partnership for Wellness and Smoking Cessation’s efforts are focused on health access, whereas some of the efforts led by mental health consumers to reduce health disparities are “constituency-based.” A vast array of health social movements exist as a result of unique historical contexts, politics, and ideological motives, and “social movements dealing with health are very important influences on our health care system, and a major force for change in the larger society” (Brown et al., 2004, p. 51).

2.2.2.6 Social Movement Organizations

Recently there has been increased interest and interaction in the fields of social movements and organizations resulting in the emergence of organizational studies (McAdam & Scott, 2005). Consequently, there is now a more specific focus on “social

Chapter 2 | Theoretical Framework and Research Methods

movement organizations” (SMOs), the more formally organized and structured component of a social movement. The notion of the social movement organization is based on the idea that social movements are typically characterized by the involvement of multiple SMOs since social movements and phenomena resembling them occur in organizations (Zald & Berger, 1978). Social movement organizations are “the carrier organizations that consciously attempt to coordinate and mobilize supporters” (McCarthy & Zald, 1973). The environment of movement organizations consists of both the broader movement and the broader society such that movement organizations actively respond to the ebb and flow of sentiment in the larger society, to its relations with other movement organizations, and to success or failure (Zald & Ash, 1966). Over time, social movements have changed:

Social movements have...shifted from classical social movement organizations with indigenous leadership, volunteer staff, extensive membership, resources from direct beneficiaries, and actions based on mass participation, towards professional social movement organizations with outside leadership, full time paid staff, small or nonexistent membership, resources from conscience constituencies, and actions that “speak for” rather than involve an aggrieved group (Jenkins, 1983, p. 528).

As a result, advocacy organizations are less likely to work together and instead attempt to find niches through which to be distinguished from the competition and secure funding.

In examining SMOs, Zald and Ash (1966) posited that different organizational structures are effective for different tasks (Jenkins, 1983). For instance, a major debate exists between proponents of a centralized bureaucratic model of social movements and those arguing for a decentralized, informal model (Gamson, 1975; Jenkins, 1983; McCarthy & Zald, 1973). Those in support of a centralized bureaucratic model suggest

Chapter 2 | Theoretical Framework and Research Methods

that the formalized structure provides for a clear division of labor and maximizes mobilization by turning diffuse commitments into defined roles.

Those in support of an informal model for social movement organizations with a minimum division of labor suggest that this model is more effective because it maximizes mobilization by providing extensive interpersonal bonds that generate solidarity and reinforce ideological commitments while at the same time being highly adaptive (Gerlach & Hine, 1970). Organizational structures can and do evolve over time, and most SMOs have a structure that falls somewhere between the bureaucratic and decentralized models (Jenkins, 1983). Overall, “social movements manifest themselves, in part, through a wide range of organizations. These organizations are subject to a range of internal and external pressures that affect their viability, their internal structure and processes, and their ultimate success in attaining their goals (Zald & Ash, 1966, p. 327).

2.2.2.7 Framing Processes

Furthermore, another area within the field of social movements that has gained significant attention is the area of framing processes, especially as a result of the new wave of interest in movement ideation and interpretive issues (Benford, 1997; Goffman, 1974; Spector and Kistuse, 1973). Frames are the interpretive packages that movements develop to mobilize potential adherents and constituents and capture a number of cultural processes (Snow et al., 1986). Meaning is critical to the framing perspective. Meaning is constructed, deconstructed, and reconstructed through a social process (Benford, 1997). Participants in social movements must align their frames to achieve a common definition and a way of solving it (Goodwin, Jasper, & Polletta, 2001, p. 1). Theories around

Chapter 2 | Theoretical Framework and Research Methods

framing suggest that social movement actors identify problems, define solutions, motivate action, and set action agendas in ways that resonate with the personal experiences, values, and expectations of potential constituents. Thus, framing is significant because the framing process can turn, as was described above in the section on social problems, what might otherwise be seen as a personal problem into a social issue (Brown et al., 2004).

For instance, the media are important to movement emergence because they help spread the ideas of the movement (frames), recruit members, and spread information about movement activities (Hubbard, DeFleur, & DeFleur, 1975; Ross & Staines, 1972). “Because mass media coverage is decisive in informing elite and mass publics about movement actions as well as in forming the morale and self-image of movement activists, the mass media are important actors in political conflict” (Jenkins, 1983, p. 546). Dorfman (2003) described the role of media advocacy in shaping public opinions about health and the ways in which the media can serve as a tool for public health advocates.

Social movements typically intend to address their message to two distinct groups: (1) power holders and (2) the general public; and the media can be helpful in spreading this message. The media can often be influential for movement recruitment as well. Furthermore, an analysis of social networks helps shed light on movement recruitment:

The findings indicate that differential recruitment is not merely a function of dispositional susceptibility, but is strongly influenced by structural proximity, availability, and affective interaction with movement members. The findings also indicate that a movement organization's network attributes function as an important determinant of its recruitment strategies and growth (Snow, Zurcher, &

Ekland-Olson, 1980, p. 787).

2.2.2.8 Collective Action Frames

One common type of frame is the collective action frame. Benford and Snow (2000) define collective action frames as emergent action-oriented sets of beliefs that inspire meaning and legitimize social movement activities and campaigns:

Collective action frames are constructed in part as movement adherents to negotiate a shared understanding of some problematic condition or situation they define as in need of change, make attributions regarding who or what is to blame, articulate an alternative set of arrangements, and urge others to act in concert to affect change (p. 615).

The recent proliferation of scholarship on collective action frames and framing processes in relation to social movements indicates that framing processes have come to be regarded, alongside resource mobilization and political opportunity processes, as a central dynamic in understanding the character and course of social movements (Benford & Snow, 2000). Collective action frames are action-oriented and interactive.

Borrowing from this literature on collective action frames, Deborah Stone (1989) described how situations come to be seen as caused by human actions and amenable to human intervention. Stone noted that conditions, difficulties, or issues do not have properties inherent in them that make them more or less likely to be seen as problems or to be expanded, but instead, political actors *deliberately* portray them in calculated ways to gain support for their “side.” Political actors thus “compose stories that describe harms and difficulties, attribute them to actions of other individuals or organizations, and thereby claim the right to invoke government power to stop the harm” (p. 282). These political actors seek to define a problem through policy by constructing it as an issue

Chapter 2 | Theoretical Framework and Research Methods

which humans can control by developing causal stories about how and why these events or conditions occurred.

Injustice frames create collective action frames (Gamson et al., 1984). Injustice frames are a way of viewing a situation or condition that expresses indignation or outrage over a perceived injustice and that identifies the blameworthy people that are responsible for it so that grievances are transformed into demands (Gamson, 1992; Klandermans, 1992). Like other types of frames, injustice frames motivate action and communicate a sense of agency. There have been critiques of the framing perspective as a whole. Benford (1997) suggests that the sociology of social movements has failed to demonstrate that collective action frames, as a central theoretical concept, affect mobilization in any case study or in any empirical way, and that “‘frame’ has become a cliché in the study of social movements” (p. 415). Instead, he said, it is common for theorists and scholars to work backwards from successful mobilization to the methods of framing and frames that activists preferred and then posit causal linkages between the two.

2.2.2.9 Countermovements

Many other theories have developed over the years regarding social movement organizations, and social movements more generally. One of these theoretical areas of significance to my dissertation research is that for most contemporary social movements, a movement that makes contradictory claims also exists. These “countermovements” develop because “any social movement of potential political significance will generate opposition” (Meyer & Staggenborg, 1996, p. 1630). While these countermovements or reactionary movements generate additional attention on the specific issue, their efforts

Chapter 2 | Theoretical Framework and Research Methods

can complicate the issues of framing, messaging, and direction that are primary to the theories, and that theorists consider so important for social movement success.

All in all, the above literature review illustrates that there is no single theory that perfectly explains how issues become social problems or that perfectly describes all social movements or any social movement. For example, “scholars of social movements have become increasingly aware that individuals behave according to a perceived reality” (Klandermans, 1992, p. 77). The sociology of knowledge, described above, demonstrates the complicated ways in which this perceived reality can translate into the perceived or “real” existence of social problems and/or social movements.

2.3 Dissertation Research Methods

This section outlines the ways in which data were gathered and analyzed to examine this study’s research questions. First, the theory and process behind the methods of grounded theory and situational analysis will be described. Then, the chapter will conclude with the details regarding the various sources of data collection, participant recruitment, and other data collection strategies that are utilized.

Overall, this study is a cross-sectional, exploratory qualitative study. In the words of Denzin and Lincoln (2005):

Chapter 2 | Theoretical Framework and Research Methods

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (p. 3).

Qualitative research methods were chosen because of the current dearth of literature on this topic (Creswell, 2007) related to leader, mental health consumer, and media perceptions of the high rates of smoking and opportunities for quitting among people with mental illness and the social construction of tobacco use in the mental health community. In this dissertation multiple sources of data including individual interviews, focus group interviews, observations, and newspaper articles were collected and analyzed. These various sources of data allow for a detailed and multi-faceted understanding of this complex public health issue. In Chapter 6 and elsewhere in this dissertation, the four sources of data described below will be examined together through data triangulation and the results from the various data sources will be discussed in relation to one another and to the academic literature.

This research aims to explore the perspectives of various stakeholders that are involved in or influential in the process of mobilizing around tobacco use among mental health consumers. These stakeholders include: mental health consumers themselves (people currently receiving mental health services for a variety of conditions), the leaders/experts in the fields of mental health and smoking cessation (including advocates, providers, government officials, and researchers) who have taken on the challenge of

leading efforts to address this issue, and the media, which plays an important role in delivering messages on this issue to the general public. This next section will provide an overview of grounded theory and situational analysis, qualitative research methods that were chosen because of their sensitivity to meaning, power, and joint collective action.

2.3.1 Grounded Theory and Situational Analysis

This study was designed using grounded theory methodology (Charmaz, 2006; Clarke, 2005), a technique developed by Barney Glaser and Anselm Strauss (1967). Grounded theory allows for the generation of a theory of a process, action, or interaction that is grounded in data obtained from interviews and observations with participants who have experienced the process. When using grounded theory, the researcher must attempt to set aside theoretical ideas or notions that might bias the interpretation of the information being collected.

In this approach, data collection and analysis are ongoing and iterative. The transcripts are read closely and segments of text are compared to one another (Clarke, 2005; Glaser & Strauss, 1967; Morse et al., 2009; Strauss & Corbin, 1990). Through this close reading, the researcher develops codes and categories, first through a process of open coding, where data are coded for major categories of information, and then through axial coding, where the research identifies one open code and then creates categories around that core phenomenon. Throughout the data collection and analysis process, the researcher codes to capture “emergent” issues and processes, constructs maps, compares transcripts, and engages in memo writing and theory development (Charmaz, 2006; Clarke, 2005; Creswell, 1998).

Chapter 2 | Theoretical Framework and Research Methods

A unique aspect of grounded theory is that researchers engage in theoretical sampling in which they use their insights about data that has been collected to make informed decisions about which types of data should be collected next (Glaser & Strauss, 1967). The goal of theoretical sampling is to arrive at a point where the researcher feels confident that their theorizing accurately reflects data collected (Charmaz, 2006; Clarke, 2005), a point that Glaser and Strauss (1967) call “saturation.” Saturation typically takes place over the course of approximately 20-30 interviews (Creswell, 1998).

Charmaz “shifted the grounds” of grounded theory by shifting the method to a social constructivist perspective (Charmaz, 2005; Charmaz, 2006; Charmaz, 2009).

Constructivist grounded theory:

Assumes a relativist epistemology, sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance towards our actions, situations, and participants in the field setting -- and our analytic constructions of them (Charmaz, 2009, p. 129).

Constructivist grounded theory assumes that knowledge rests on social construction.

Constructivists are able to “enter participants’ liminal worlds of meaning and action in ways classical grounded theorists do not,” and are able to locate participants’ meaning and actions in larger social structures and discourses of which they may be aware or unaware (Charmaz, 2009, p. 131). This approach to grounded theory, while similar to Corbin and Strauss’s (1990) conception to the approach in many ways, also allows for more flexibility and places greater emphasis on “the views, values, beliefs, feelings, assumptions, and ideologies of individuals than on the methods of research” (Creswell, 2005, p. 65).

Chapter 2 | Theoretical Framework and Research Methods

Clarke (2005) also added to and expanded understandings of grounded theory methodology through the development of situational analysis. Situational analysis, according to Clarke (2005), reclaims grounded theory from its “positivist underpinnings” (p. xxiii) and pushes grounded theory “around the postmodern turn” (p. 19). Clarke outlines six suggestions for pushing grounded theory/symbolic interactionism around the postmodern turn: (1) recognizing the embodiment and situatedness of knowledge producers; (2) focusing on the broader “situation” as the site of action and analysis; (3) embracing and permitting multiple analyses to represent differences, complexities, and multiplicities; (4) moving from theory as product to theorizing through the development of sensitizing concepts and integrated analytics; (5) generating empirical analytic maps of situations throughout the analysis; and (6) attending to the multiple forms of discourses to expand the domains of social life (Clarke, 2005).

Situational analysis offers three opportunities for mapping of differences, multiplicities, and representations (Clarke, 2005; Clarke, 2009). Situational maps present the major human, nonhuman, discursive, and other elements that are a component of the research situation. These maps encourage the analysis of relations among actors and actants. (See Appendix C for a situational map on smoking among people with mental illnesses and Appendix E for a relational map). Secondly, positional maps present the major positions that are taken and not taken in the data, highlighting concerns and controversy around the issues under study. (See Appendix D for two positional maps that present the positions on smoking for mental health consumers and for leaders in the mental health community). Finally, social worlds/arenas maps offer a meso-level

Chapter 2 | Theoretical Framework and Research Methods

interpretation of the situation by presenting the collective actors, key nonhuman elements, and the arenas of commitment and discourse (Clarke, 2005; Clarke, 2009). (See Appendix F for a social worlds/arenas map of the mental health community and smoking cessation field).

Overall, data collection and analysis for this dissertation occurred in an iterative process. I conducted line-by-line open coding and axial coding to capture issues and processes, engaged in constant comparisons within and between interviews, and engaged in memo-writing and mapping throughout the data collection and analysis process to capture the salient “categories” or themes (Charmaz, 2006; Clarke, 2006; Creswell, 2007; Strauss & Corbin, 1990). I conducted all interviewing, coding and analysis, and shared and refined emerging analytic findings through conversations with colleagues at the SCLC as well as graduate students and faculty at UCSF as a form of validity checking (Charmaz, 2006). All interviews were digitally recorded and transcribed verbatim. The software program Atlas.ti was used to facilitate data management and coding.

2.4 Sources of Data and Data Collection Processes

The sources of data for this dissertation include individual interviews with leaders in the fields of mental health and smoking cessation, focus group interviews with people with mental illness, participant observation, and frames analysis. Data derived from the various methods are analyzed independent of, but are also considered in conjunction to, data collected from the other methods described in this methods section to understand, when feasible, the similarities and differences that exist among leaders, mental health

Chapter 2 | Theoretical Framework and Research Methods

consumers, and the media regarding the high rates of smoking among people with mental illness and what might be helpful in assisting individuals to quit.

2.4.1 Individual Interviews with Leaders in Mental Health and Smoking Cessation

First, data were collected through individual interviews with leaders in mental health and smoking cessation to better understand the views, opinions, and experiences of key stakeholders in these fields on a national level. These interviews were an attempt to understand what can be done to make strides in providing effective smoking cessation strategies for people with mental illness, the role of the National Mental Health Partnership for Wellness and Smoking Cessation in public health efforts to lower the rates of smoking among people with mental illness, and ideas for future directions for the Partnership and the fields of mental health and smoking cessation. In particular, data collected through individual interviews with leaders help to address the following research questions which will be explored in Chapters 4, 5, and 6:

- Why did the mental health community historically overlook the high rates of smoking among people with mental illness, and what are the potential implications for the current public health efforts of the mental health and smoking cessation fields for changing social and cultural practices around tobacco use?
- What is the process through which smoking among people with mental illness has been constructed as a social problem among leaders in the fields of mental health and smoking cessation?
- What are the strengths and weaknesses of the mental health community and the smoking cessation field that can be utilized or might be barriers to addressing this issue?

I conducted in-person or telephone interviews, based on participants' location and availability, with national leaders in the fields of mental health and smoking cessation

Chapter 2 | Theoretical Framework and Research Methods

(these are referred to throughout this dissertation as the “leader interviews”). Human subjects approval was granted for this project by the UCSF Committee on Human Research (CHR) in early October 2007 (H1090-31566-02), and all participants returned a signed consent form and were given the opportunity to have any questions answered before the interviews began. An informational email explaining the study was sent to all of the people who were their organization’s representatives to the National Mental Health Partnership for Wellness and Smoking Cessation. Steve Schroeder, Director of the SCLC, sent this email to those people working in the field of smoking cessation, and Robert Glover, Executive Director of NASMPHD, sent it to those working in the field of mental health. The email came from these individuals because they are well-recognized experts in their respective fields, and it thus could be assumed that people might be more likely to open the email. Those who did not respond to the initial emails received two reminder emails.

These interviews were conducted over a three-month period from October through December 2007. The participants were interviewed using a nonstandard semi-structured interview protocol that I developed and pre-tested with four key informants (see Appendix A). The interview protocol included approximately 18 questions, some of which had multiple parts. Most questions were open-ended so that participants could freely discuss the topic and shape the conversation without being confined to a limited range of responses. In a few cases, participants were asked to provide a numerical response to a closed-ended question. The interview outline was maintained throughout data collection, but the interview questions evolved and were refined throughout the

Chapter 2 | Theoretical Framework and Research Methods

interview process. Interviews lasted approximately 30 to 75 minutes in length and were conducted at times convenient for the participants.

Once all interested member of the National Mental Health Partnership for Wellness and Smoking Cessation were interviewed, other participants were invited to participate for the purposes of theoretical sampling. Participants were asked in the initial email used for recruitment for the study and in the interviews whether they were familiar with other individuals with an extensive knowledge of mental health and/or smoking cessation that they thought should be included in the study. Some of the additional leaders identified through this approach were then recruited for participation based on their position/affiliation within the mental health community or smoking cessation field and their expert knowledge on the topic. These interviews occurred through the same process as was described above. The only difference is that these participants were not asked questions about the National Mental Health Partnership for Wellness and Smoking Cessation because they were not involved in the initiative at the time of the interview, unless they had significant background knowledge regarding the Partnership's activities.

Of the 44 leaders who received a request to participate in this research project, 28 were members of the National Mental Health Partnership for Wellness and Smoking Cessation and 16 were recruited based on recommendations from other research participants. In total, 26 people agreed to participate and were interviewed, and 18 did not respond to requests to participate. Half (n=14) of the members of the Partnership and three-quarters (n=12) of the leaders recruited through snowball sampling were interviewed for this study. Saturation was achieved once 26 interviews were conducted.

Chapter 2 | Theoretical Framework and Research Methods

This sample was chosen to explore the insights of a highly involved group of individuals who were very knowledgeable on the research topic. Thus, no attempt was made to achieve maximum diversity. Fourteen participants were female and 12 were male. Ten worked mainly in the area of mental health, 6 worked mainly in the area of tobacco cessation, and 10 participants worked specifically in the area of smoking among people with mental illnesses. The participants were predominantly white and ranged in age from approximately 45-70 years. Each participant was highly educated (many had completed a doctoral education) and had at least five years experience, and some had several decades of experience, in the areas of smoking cessation and/or mental health. Many lived and worked near Washington DC and were involved in the policy process. The participants were executive directors of national mental health advocacy organizations, smoking cessation experts at the state and national level, mental health providers such as psychiatrists, psychologists, psychiatric nurses, and social workers, quitline providers, and government officials. Refer to Table 3 below for information on the type of work participants were engaged in.

Table 3 Numbers of Leaders Interviewed According to Type of Work

Type of Work	# of people interviewed
Mental health advocate	6
Mental health clinician	7
Mental health government official	3
Rep. for a mental health professional org.	2
Mental health researcher	4
Smoking cessation researcher	6
Smoking cessation provider	5
Smoking cessation advocate	6

*Some interviewees matched multiple categories. For this reason, the total is greater than the 26.

2.4.2 Focus Group Interviews with Mental Health Consumers

Second, focus group interviews were conducted with people with mental illnesses, broadly defined as adults currently receiving outpatient mental health services, another group of individuals with key insights and experiences into this issue. These interviews are essential to understanding the perspectives of the various stakeholders since mental health consumers are the intended beneficiaries of the Partnership’s efforts. Thus, it is critical to explore the experiences and constructions of reality for people with mental illnesses since these insights are important for the construction of problem definition and ultimately for the efforts’ success. These data were collected to explore the following

Chapter 2 | Theoretical Framework and Research Methods

research questions which will be discussed in Chapters 3 and 6:

- What are the experiences of mental health consumers around tobacco use, and what can be learned from these experiences?
- Do people with mental illnesses conceive of smoking as an important concern and/or a “problem,” and if so, what do they think can and should be done about it?
- What is the process through which people with mental illnesses quit smoking?
- What is the role of people with mental illness in shaping strategies and priorities for addressing the high rates of smoking among people with mental illness, and how can the experiences and perspectives of mental health consumers be incorporated into attempts to mobilize efforts around this issue?
- In what ways do the Partnership’s efforts reflect the perspectives and insights of consumers and where do disconnects exist?

The participants of the focus groups were recruited from the adult and older adult programs at a large social service agency in the San Francisco Bay Area. All participants were currently receiving outpatient mental health services from this agency and living in the community. To begin, I met with the staff of the older adult division of the organization and talked to them about the project and passed out informational flyers and sample study consent forms. I was then invited to give a short informational talk to the participants in the agency’s day program for older adults with mental illnesses. I also gave a presentation regarding the study to all management-level staff at the organization so that those serving the agency’s adult division could also receive the relevant study information. The UCSF Committee on Human Research granted approval for this project in June 2007 (H480-32721-01). This project was also reviewed and approved by the recruitment site’s research committee.

After the informational flyers were posted and after the discussions with people

Chapter 2 | Theoretical Framework and Research Methods

with mental illnesses and staff, I began to receive phone calls from those who had heard about the study and were interested in participating. I spoke with each potential participant by phone and gave each caller more information about the study and the consent procedures. If participants were eligible to participate, I asked about their smoking status and assigned them to the appropriate group to attend.

Five focus groups lasting about 1.5 hours each were organized during a two-week period in late July and early August 2008. The groups were divided according to the participants' smoking status. Initially, the groups were organized such that one group was for current smokers (individuals who consider themselves to be currently using tobacco), one group for former smokers (individuals who had not used tobacco in at least the previous month), one for smokers trying to quit, one for people who had never smoked, and one group that was open to people of any smoking status. The order in which the sessions occurred was: former smokers, trying to quit, never smoked, current smokers, and then finally, the group open to those of any smoking status. At the end of each group, all participants received a \$15 gift card.

The timing of the group sessions allowed for a better understanding of the participants and their insights and needs related to smoking before ultimately interviewing the current smokers (the participants that the Partnership's efforts are trying to reach). I wanted my sampling procedures to stratify the participants and to take into account the possibility of comparisons within and between these groups based on smoking status. Ultimately, I determined that the largest population, and the group with the most relevant knowledge and experiences, was the current smokers. Thus, the last

Chapter 2 | Theoretical Framework and Research Methods

group, which was originally intended to be open to any smoking status, was in the end comprised only of people who currently used tobacco. The final group, to engage in theoretical sampling and to achieve increased diversity, included a person who chewed tobacco to explore the perspectives of a tobacco user who does not smoke cigarettes. For this group, I also recruited from a satellite site of the social service agency that served adults and older adults who were more likely to be African American and of low income.

While the plan was to recruit five to 10 people for each group, the number of actual participants from group to group varied from one to seven. The only group for which recruitment was ultimately a challenge was the group for those trying to quit. While originally eight people called expressing interest, were deemed eligible to participate, and signed up to attend this group, only one person ultimately showed up at the time and day the group was scheduled. As a result, this became a one-on-one individual interview rather than a focus group session. In hopes of still organizing a focus group for those trying to quit, I set another date for the group, but this time, no one expressed interest. I discuss my interpretation of the low rates of participation in this group more fully in Chapters 3 and 6.

The inclusion criteria included that participants were currently receiving mental health services at the social service agency, that they spoke English, were available during the appropriate focus groups' days/times, and were able to provide informed consent as determined by the social service agency staff. The issue of the potential participants' ability to provide informed consent is important given that some participants were being treated for severe mental illnesses and may have had mild cognitive

Chapter 2 | Theoretical Framework and Research Methods

impairment from their conditions (and in some cases, as a result of their medications). Furthermore, because people with mental illnesses are often targeted for participation in research studies with limited knowledge of how their participation or the study results may affect them personally or influence their lives, I conducted this study with an openness about the influence (or lack of influence) of this project on the lives of subjects. For example, some potential participants thought the group was intended to help them quit smoking, and I had to reiterate that the purpose was only to discuss their views on tobacco use and not to encourage or provide information on cessation, although I did bring some information about local resources and the quitline in case people did want referrals/information.

Four of these five groups took place in a small conference room at the main campus of the social service agency, and the final group met in the cafeteria of a satellite site of the organization just after the lunch hour. Before the group discussion began, participants completed a background information questionnaire that asked their gender, age, ethnicity, highest level of education achieved, and smoking status. Originally, this information sheet also asked about mental health diagnosis, but the research committee for the social service organization directed me not to include this question. They warned that participants might not know their diagnosis or might make up a diagnosis, thus making the information unreliable. Moreover, in thinking about it more thoroughly, I realized that diagnosis is a capricious classification given the various opinions that exist within the mental health community about what constitutes a mental illness and what differentiates one illness from another (Mechanic, 2008).

Chapter 2 | Theoretical Framework and Research Methods

Yet, depending on the specific diagnosis, there may be distinct differences in treatment, providers' level of attention and engagement, an individual's understanding of and awareness of his or her own diagnosis, and an individual's likelihood of identifying as a person with a mental illness. For example, people with schizophrenia or bipolar disorder are likely to have long histories of treatment within the mental health system, often in a combination of inpatient and outpatient settings. Participants with diagnoses generally considered less severe and debilitating often receive care exclusively in outpatient settings and are more likely to work and to participate in other activities. Although some participants mentioned their diagnosis within the groups, and I can approximate, based on my recruitment strategies, that the group members represented a diverse set of mental health problems characteristic of the social service agency's clientele, I did not feel strongly that I needed to know the diagnoses. I assume, for the purposes of this project, that the fact that the participants were receiving mental health services suggests that they, their provider, or a family member or friend have identified that they have a "mental health problem" which requires treatment and care. I chose to focus within the interviews on the collective experience, the lived experience, and the subjective understandings of people who are receiving care for a mental health problem and the ways in which those experiences intersect with and connect to their feelings about and experiences with tobacco use.

A total of 26 participants were recruited in all five groups combined (10 women and 16 men). The age range of participants was 41 to 82 years old, with an average age of 62 years. The relatively high average age is a result of the fact that so many participants

Chapter 2 | Theoretical Framework and Research Methods

were receiving services from the older adult division (which serves all individuals 55 years and older at the agency). Ultimately, a majority of the participants came from the older adult division because those individuals were part of the day program. As a part of the day program, participants are picked up by an agency vehicle in the mornings and spend several days a week at the organization. Thus, these participants were already in the building at the times the first four groups were held. The people receiving care in the adult division, on the other hand, had to travel to the agency on their own in order to participate.

In terms of racial and ethnic diversity, 14 participants were white, 10 participants were black, one participant was Hispanic, and one participant identified as biracial. There was also diversity in terms of highest level of education attained. Three participants had some high school, four were high school graduates, two had received an associate's degree, 10 had completed some college, four had a bachelor's degree, and three participants had a master's degree. See Table 4 for information on the demographics of focus group participants.

Table 4 Demographics of Focus Group Participants

Demographic variable	Categories	Number of Participants (N=26)	% of Participants
Smoking status	Former smokers	7	27%
	Trying to quit	1	4%
	Never smokers	7	27%
	Current tobacco users*	11 (6 and 5)	42%
Gender	Male	16	62%
	Female	10	38%
Race	White	14	54%
	Black	10	28%
	Hispanic	1	4%
	Biracial	1	4%
Education	Some high school	3	12%
	High school graduate	4	15%
	Some college/associate degree	11	42%
	College graduate	4	15%
	Masters degree	4	15%

*Eleven current tobacco users participated in the focus group interviews. These eleven people participated in one of two groups.

The focus groups were guided using a unique, nonstandard semi-structured interview protocol (see Appendix B). The interviews were digitally recorded and transcribed verbatim. Participant observation was also conducted during each group and at the recruitment site. Observations were spoken into the digital recorder at the end of each group and then were transcribed to create field notes of the experience.

2.4.3 *Fieldwork/Participant Observation*

Third, I conducted fieldwork and participant observation by attending meetings, educational, and recreational events around smoking or mental illness, and events with and for people with mental illness in the San Francisco Bay Area, in an attempt at “being

Chapter 2 | Theoretical Framework and Research Methods

there” (Geertz, 1988). These data were collected in an effort to explore the following research questions that will be addressed throughout this dissertation:

- How does the Partnership frame the issue of smoking among people with mental illness?
- To what extent does the Partnership between the mental health community and the smoking cessation field fit the definition of a social movement?

The fieldwork and observations took place at a variety of locations including local advocacy and self-help organizations and programs, smoking cessation education groups, adult and older adult day centers, smoking cessation/tobacco control meetings, trainings, and public health and educational events. I gained entrée by learning about public events online, through word of mouth, and through the SCLC. When necessary, I asked permission from the event organizers to participate. When observations occurred in non-public locations or closed meetings, consent procedures approved by the UCSF CHR were used to protect human subjects. This included distributing a project information sheet and then asking participants to provide their verbal consent for participation. If anyone stated that they would prefer not to be observed, participant observation was not conducted at that site.

More specifically, my fieldwork and observations included observing activities, conferences, training, and activism around mental health and smoking cessation in a variety of settings including:

- The summit in Lansdowne, Virginia organized by the SCLC in March 2007 that ultimately led to the formation of the National Mental Health Partnership for Wellness and Smoking Cessation
- Telephone call with the National Mental Health Partnership for Wellness and Smoking Cessation Interim Governance Group (IGG) (organized call for decision

Chapter 2 | Theoretical Framework and Research Methods

makers in the Partnership)

- Observations at the social service agency that served as the recruitment site for the focus group interviews
- Relevant conference sessions including sessions at the 2008 American Public Health Association annual meeting, the 2008 and 2009 UCSF Center on Tobacco Control Research and Education (CTCRE) Annual Symposium on Tobacco Control, a conference on mental health and smoking cessation in Marin called “Tobacco Use in the Mental Health Community: Creating Quit-Friendly Environments” in October 2008, and sessions on smoking cessation and physical health at the National Alliance on Mental Illness (NAMI) convention in San Francisco in July 2009
- Attendance at a four-week smoking cessation education and support group led by Suzanne Harris, RN, at the UCSF Tobacco Education Center
- Trainings including a smoking cessation training for psychiatrists held at UCSF, a smoking cessation training (including a hands-on course on smoking cessation aids) for pharmacy students at UCSF, the Bringing Everyone Along conference calls organized by the Tobacco Cessation Leadership Network in Spring 2008, the NAMI “Ask the Doctor” call on smoking featuring Dr. Schroeder in March 2008, lectures offered by the UCSF CTCRE, and training events offered by National Mental Health Partnership for Wellness and Smoking Cessation partner organizations
- Activities related to my work as the mental health fellow at the SCLC, including the development of a smoking cessation curriculum for mental health peers and a webinar based on this curriculum, and strategy meetings of the National Mental Health Partnership for Wellness and Smoking Cessation and the SCLC through SCLC staff meetings, the SCLC National Advisory Committee (NAC) meetings in September 2007 and September 2008, and the SCLC Annual Meeting in May 2008
- Substance Abuse Mental Health Services Administration (SAMHSA) and SCLC co-sponsored webinars on mental health and smoking cessation in March and April 2009
- Local advocacy group meetings that included family members, providers, and people with mental illness discussing mental health issues
- This research is also informed by books I have read that provide personal accounts of living with mental illness such as *A Mind that Found Itself* (Beers,

Chapter 2 | Theoretical Framework and Research Methods

1908), *On Our Own* (Chamberlin, 1977), and *An Unquiet Mind: A Memoir of Mood and Madness* (Redfield Jamison, 1995) as well as the documentary *When Medicine Got it Wrong* (Cadigan & Murray, 2009). This research is also informed by observational experiences from other studies I have conducted including observations at mental health consumer-run drop-in centers and my work and volunteer experiences in the mental health arena.

Data from the field included thoughts and memos that were digitally recorded while in the field as well as written notes. This fieldwork and participant observation provided me with an opportunity to examine the culture and practices in mental health and smoking cessation settings in detail through immersion into the social worlds of these arenas and the interpersonal and care practices for people with mental illness. These observations provide a context for understanding data collected from the other sources and were helpful in creating the timeline of relevant events (See Table 2).

2.4.4 Frames Analysis

Finally, I conducted a frames analysis of newspaper articles from the six newspapers with the widest circulation in the U.S. as of March 2006: *USA Today*, *The Wall Street Journal*, *The New York Times*, *Los Angeles Times*, *Chicago Tribune*, and *Washington Post*. The frames analysis of these newspapers is intended to examine the following questions that will be explored in Chapter 4:

- How does the media (specifically, leading U.S. newspapers) frame smoking among people with mental illness?
- What are the social, cultural, political, and economic factors that are brought forth in the framing of the issue?

The terms “mental illness” or “mental health” and “smoking cessation” or “tobacco” were typed into the newspapers’ website search bars. This retrieved all articles

Chapter 2 | Theoretical Framework and Research Methods

from these papers that contained a combination of the search terms and were published between 1999 and February 2009. This 10-year period was chosen because it begins with the release of *Mental Health: A Report of the Surgeon General* in 1999 (USDHHS, 1999) which focused on recovery and the possibilities for physical and mental health for people with mental illnesses, and also because the influential study by Lasser et al. which found that people with mental illnesses and substance use disorders consume 44.3% of U.S. cigarettes was published the following year (2000). According to many mental health and smoking cessation leaders, this article started a trend toward increased awareness and attention to smoking in this population as a “problem” worthy of attention.

Each retrieved article was skimmed to determine its relevance to the topic. In many cases, duplicate articles were retrieved or articles came up in the searches that were unrelated to the topic. In cases where I was unable to retrieve articles from the newspapers’ websites (some websites only allow for the search and retrieval of very recently published articles), the website LexisNexis was used to find articles from these same papers with the same terms that were published in the designated timeframe. This method ultimately yielded a collection of 46 articles. The distribution of these 46 articles within the six newspapers is illustrated in Table 5 below.

Table 5 Number of Articles Published in Six Leading U.S. Newspapers from 1999-2009 on Mental Health/Mental Illness and Smoking/Tobacco

Newspaper	Number of Articles
Chicago Tribune	8
Los Angeles Times	10
New York Times	11
USA Today	6
Wall Street Journal	4
Washington Post	7
TOTAL	46

Once all relevant articles were collected, each article was read closely three times following the procedure outlined in Winett (1995) and utilized by Menashe and Siegel (1998). The purpose of the first read was to understand the point/theme of the article and whether an argument was made/what argument was made. During the second read, I highlighted and noted arguments, images, language, catch phrases, and actors included in the article. Finally, in the third read of each article, I examined the article in relation to the others while searching for common features as well as differences in presentation in comparison to the other articles.

This frames analysis charts trends in the frequency of articles on this topic (i.e., how many articles are published on this topic in a given year in the six newspapers) as well as the content and themes of the articles. Within each article, this analysis examines

Chapter 2 | Theoretical Framework and Research Methods

the framing of the issue of smoking among people with mental illness, including when and how statistics and direct quotations are used, whose perspectives are included (consumers, providers, families, advocates, policymakers, etc.), and to what extent the article included ideas for recommendations/strategies/solutions that address the public health needs of this population. Dorfman (2003) describes content and frames analysis as:

An example of how research can be applied to identify a deficit or strength and then provide direction for filling the deficit or capitalizing on the strength. When content analysis delves deep, beyond simply counting the presence or absence of a topic, it can address the fairly complicated substantive issues – attributions of causality and treatment responsibility – that appear in news stories. These framing analyses can help media advocates pinpoint areas to address as they create news to advance healthy public policy (Dorfman, 2003, p. S225).

The frames analysis component of data collection is instrumental to understanding the social construction of the social problem of the high rates of smoking among people with mental illness through the media and highlights issues around framing and meaning that are instrumental to social movements.

Next, I will discuss the limitations of the above research methods.

2.5 Study Strengths and Limitations

As is the case with all research, there are strengths and limitations to this work. The participants in this study represent a nonrandom sample of leaders in the fields of mental health and smoking cessation from across the country and mental health consumers living in and receiving care from a social service agency in the San Francisco Bay Area. These are purposive samples selected for specific analytic reasons. While the

Chapter 2 | Theoretical Framework and Research Methods

results of the leader interviews cannot necessarily be generalized to other professionals in the fields of mental health and/or smoking cessation, the leaders were selected based on their position and reputation as experts in their fields. Similarly, although the focus groups with mental health consumers represent the voices of only 26 people living with mental illness, theoretical sampling allowed me to gather diverse insights and perspectives of mental health consumers receiving mental health services in the community where it is most common to receive care.

Also, in qualitative research, a key aim is to achieve “saturation,” a point where the same perspectives on a phenomenon are voiced by the participants and no new findings are emerging. In the tradition of grounded theory, a sample size of 26 participants (the sample size for both the individual interviews with leaders in the field of mental health and smoking cessation and the focus group interviews with people with mental illness) is appropriate if saturation is achieved, which it was in both components of this dissertation research. In the case of the focus groups with consumers, an attempt was made to achieve diversity through stratified sampling methods.

The leader participants were relatively homogenous in terms of ethnicity, education level, and socioeconomic status, though there was variation based on participants’ job title, gender, and type of work. This sample represents the demographics of those who hold elite leadership positions in the fields of medicine, policy, advocacy, and academics.

Because the interviews with leaders were primarily among those involved with the Partnership who agreed to participate, it is possible that the viewpoints of those

Chapter 2 | Theoretical Framework and Research Methods

involved with the Partnership are biased towards more positive feelings about the Partnership and its activities. Those who may have been more critical of the Partnership were possibly not as likely to have participated based on my recruitment methods (nor would they be likely to be involved in the Partnership at all). While it was not my intent to create a heroic narrative in describing the Partnership but to gather the insights of those most knowledgeable on this subject, it is true that many of the Partnership members who were interviewed had positive feelings about the initiative and remained optimistic and hopeful about future developments and the possibilities for culture change (Solway, 2009).

I conducted all interviews as well as all coding and analysis. The questions were developed and pre-tested with assistance from colleagues in the mental health and smoking cessation fields and codes and findings were shared and explored with these colleagues and classmates as well. Moreover, the focus group participants were recruited through only one social service agency. While the agency was large and provides mental health services to diverse populations of all ages, different responses may have been elicited from individuals recruited through other settings.

Data collected from people with mental illness were obtained through focus groups. Focus groups create a comfortable space for people to share their thoughts and concerns about a topic. While it may at first seem preferable to conduct one-on-one interviews to delve more deeply into the topic with each person individually, particularly when using a grounded theory approach, the focus group format allowed participants to take time to get comfortable and to share their views when ready. Another benefit of the

Chapter 2 | Theoretical Framework and Research Methods

focus groups was that participants could converse with one another. Often, one participant would comment and then another participant would say, “That was different for me, and here’s how.” The focus group format allowed for a range of experiences and insights to be expressed. A limitation is that participants could only assume a certain level of anonymity. Within the group, we used first names only and participants had the option of going by whatever name or pseudonym they wished (each person had a name tag and said their name into the recorder each time he or she spoke).

Furthermore, I was unable to collect information on the diagnosis (or diagnoses) of the people receiving mental health services who participated in the focus groups, unless the participants mentioned it within the context of their responses. Lawn, Pols, and Barber (2002) theorized that there may be differences in smoking needs and patterns according to a person’s psychiatric diagnosis that might be worthwhile to take into account. It is also possible that the strength of self-identification as a person with a mental illness may be important. I did not include any measures to determine how strongly individuals identified as a person with mental illness or as a mental health consumer. Finally, I did not assess for nicotine dependence, and allowed participants to join a focus group based on their self-identified smoking status.

Also, the focus group interviews all took place within the San Francisco Bay Area. Thus, the perspectives included are of people with mental illnesses who live in and receive care in an area of the country that is known to be generous in providing necessary social services to those in need. The state of California as a location of recruitment is noteworthy because the prevalence of smoking in California is 14.3%, compared to the

Chapter 2 | Theoretical Framework and Research Methods

national average of 19.8% (CDC, 2009). California's tobacco control programs are seen as an enormous success. Furthermore, California is also unique because of its passage of Proposition 63, the Mental Health Services Act, in 2004. The Mental Health Services Act places a 1% tax on Californians with incomes over \$1 million. This money is used to increase funds, personnel, and other resources to support county mental health programs and to reach statewide mental health goals (California Department of Mental Health, 2009). No other state has such a pot of money available specifically for mental health services, and California's mental health programs benefit from this increased support.

Furthermore, the frames analysis is based on articles published in six leading U.S. newspapers. This is a large sample of newspapers (given that these papers, in combination, publish hundreds of articles every day), yet articles published in other forums, such as blogs, websites, television, or other news sources, or including other terms to describe mental illness and smoking, were not included in the sample.

Qualitative research methods were used for this dissertation because the issue of smoking among people with mental illness has not yet been explored from the perspectives of mental health consumers, leaders in the fields of mental health and smoking cessation, and the media. They were also used to better understand the multiple knowledges around this topic. The research methods utilized here allow for a detailed understanding of this interesting and complex issue. In order to make sense of these data, I developed open-ended questions around which to structure the interviews. All interview questions were pre-tested with other graduate students, with staff at the Smoking Cessation Leadership Center, and with mental health and smoking cessation experts who

Chapter 2 | Theoretical Framework and Research Methods

work closely with the SCLC. Different questions might have evoked different responses, and other methods of data analysis could have contributed to new interpretations of these data.

Overall, the use of qualitative methodology allowed for the gathering of rich data from diverse sources. Additionally, this is the only study that explores the insights of leaders in mental health and smoking cessation around initiatives to address the high rates of smoking among people with mental illness. While two studies have qualitatively examined the experiences of smoking and quitting among people with mental illnesses, this study is unique in that it also involves interviews with people with mental illness who are former smokers and those who never smoked. Next, while frames analysis of newspaper articles on tobacco is common, this was a first attempt to examine articles published in leading U.S. newspapers specifically on the topic of mental health and smoking cessation. Finally, there have been no previous attempts made to triangulate data from these various sources that allows for a more complete picture of various stakeholder perspectives on the high rates of smoking among people with mental illness.

2.6 Conclusions

All in all, the central sociological theoretical areas explored in this dissertation are social problems and social movements. Specifically, I will examine the process through which the high rate of smoking among people with mental illness has come to be seen as a “problem,” as well as efforts to promote the broader concepts of wellness and recovery based on the social constructionist perspective. Then, using resource mobilization

Chapter 2 | Theoretical Framework and Research Methods

theories as a point of departure, this dissertation will examine the ways in which the mental health community and the smoking cessation field have been motivated to mobilize around this issue both separately and collectively, the tensions and challenges that have emerged, and the ways in which the mental health and tobacco control movements have shifted to the point where this issue could be problematized. The sources of data for this project, including transcripts from interviews (individual and focus group), field notes, and articles in leading U.S. newspapers, were analyzed and the results of these data will be presented in the next three chapters in order to elucidate these issues, shifts, and tensions.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

“It’s really like a catch 22, I can’t really get rid of the stuff if I wanted to because there’s so many factors against me.”

- Mental Health Consumer (Current Smoker)

3.1 Introduction

This chapter is based on findings from focus group interviews with mental health consumers conducted in July and August 2008. It examines the socially constituted realities around tobacco use for people with mental illnesses and “how smoking fits into the lived experience of people’s lives, embedded in the (sub)cultural contexts in which they live, work, and play” (Poland et al., 2006, p. 62). Specifically, this chapter explores the following research questions:

- What are the experiences of mental health consumers around using tobacco, trying to quit, and quitting, and what can be learned from these experiences?
- Do people with mental illnesses conceive of smoking as an important concern and/or a “problem,” and if so, what do they believe can and should be done about it?
- What is the process through which people with mental illnesses quit smoking?
- What is the role of people with mental illness in shaping strategies and priorities for addressing the high rates of smoking among people with mental illness, and how can the experiences and perspectives of mental health consumers be incorporated into attempts to mobilize a movement around this issue?

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

The lived experience of mental illness is a common focus in social science research. Davidson (2003) notes about schizophrenia, “we know of no other illness that so regularly attracts attention to first person accounts” (p. 15). Yet there is a dearth of information on the experiences of people with mental illness related to tobacco use. With the recent interest in smoking among people with mental illness, some groups have started to survey their members (people with depression and bipolar disorder) about tobacco use. Two other qualitative research studies have been published based on interviews with smokers with mental illnesses about their tobacco use, but did not include participants who had never used tobacco or who had quit (Esterberg & Compton, 2005; Lawn, Pols, & Barber, 2002).

To start the flow of conversation, each focus group participant was asked to write a word or draw a picture on an index card that described what they imagined when they thought about smoking/tobacco use. Each participant then shared what he or she had written or drawn on the card. This exercise proved to be an excellent starting point for deeper conversations about smoking and elicited many interesting responses. Particularly noteworthy were the similarities and differences between the perspectives of never-smokers, former smokers, those trying to quit, and current smokers.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Table 6 Words and Images Conveyed by People with Mental Illnesses Concerning Tobacco, By Smoking Status

Never Smokers	Former Smokers	Trying to Quit	Current Smokers
A very nasty habit	Warm	Nicotine	Peace and stress-free
Cancer and ill health	Fireplace		Peace and tranquility
Hell	Heat		Stress
Not healthy	A cigarette with smoke permeating everywhere		Wonderful
Never smoked!	Relaxing		Happy and carefree
	A grave		Free
	Angst		Happy face, “happy,” and “calms me down”
			Hands holding a cigarette and a leaf
			Heaven
			Slavery
			Pacifier
			Bittersweet

In general, the never-smokers stressed the negative effects of smoking, especially those related to health. A few participants expressed through the words on their cards that they were proud to have never smoked. Many former smokers, on the other hand, associated smoking with more positive traits such as warmth and relaxation. Many of these participants appeared to be reminiscent about their previous tobacco use and the good feelings it brought to them. Yet one former smoker drew a grave and another wrote “angst,” suggesting a relationship with tobacco that may be uneasy and complicated and

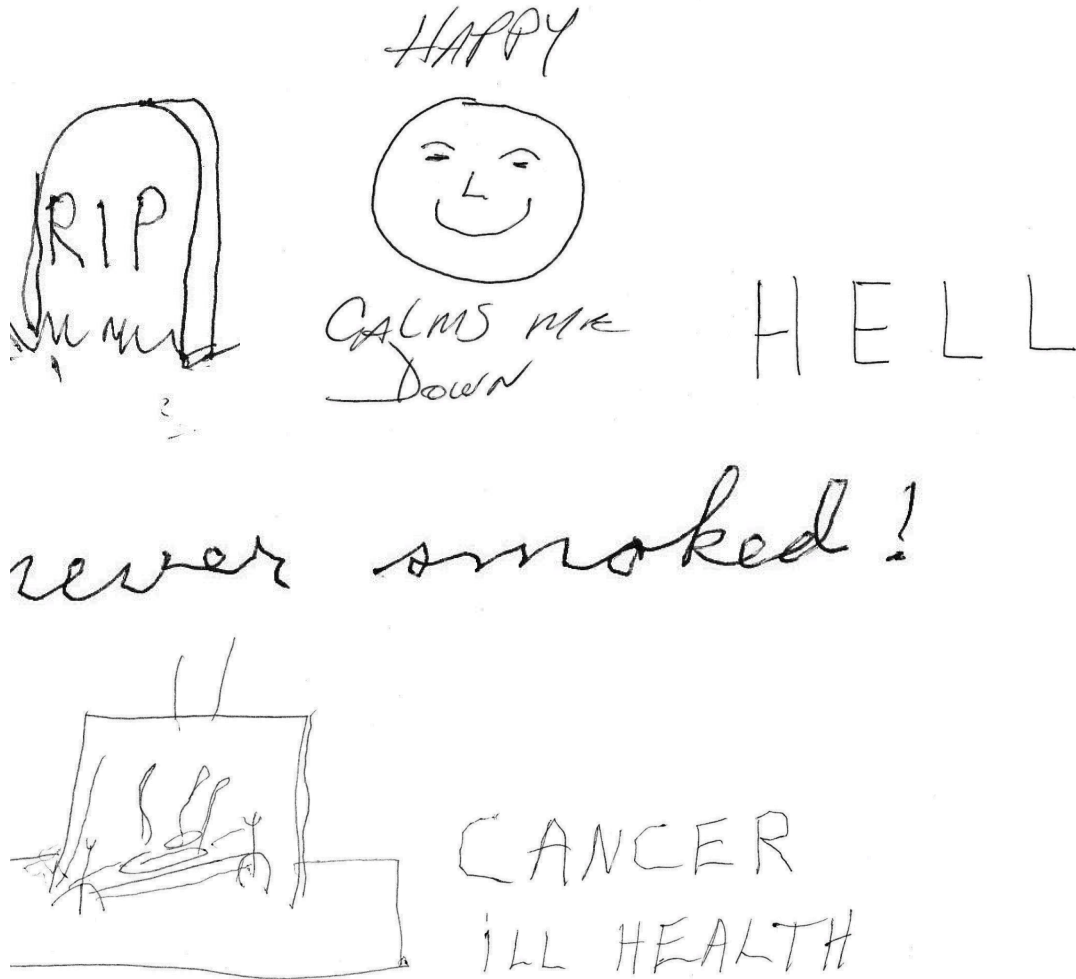
Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

may highlight why they chose to quit. The sole participant in the trying to quit group expressed throughout her interview the problems manifested by her strong cravings to continue to smoke and wrote “nicotine” on her card.

Finally, the current smokers, as a group, expressed an even stronger tension. For example, one participant wrote “heaven” on her card and another wrote “slavery.” One participant wrote “bittersweet” with both figurative and literal meanings. She described why she chose this word:

Because when you first start smoking it’s bitter, you don’t like the taste. But as you go on...coming back into the back of the mouth it’s sweet. Tobacco is sweet and you get to liking that part of it. But as a former registered nurse, I also know that it’s not good for you, the tar.

One participant drew a cigarette, noting that he loves cigarettes and describing his affection for them, warmly recalled watching them burn and the strong feelings when the smoke went into his lungs. Interestingly though, another group member also drew a picture of a cigarette, but had written short notes all over the card such as “I want to quit smoking,” “stop smoking,” and “addictive behavior,” suggesting he may have been writing down messages that were motivating him in his thinking about quitting as the other participants spoke. Examples of some of the words and images that were written on the cards from the various groups are displayed below.



As noted previously, all participants identified as using or having used tobacco in the past smoked cigarettes except one. This one participant used smokeless tobacco products and noted that he chose chewing tobacco because it was cheaper than cigarettes, easier to conceal, and had a calming effect.

Although the questionnaire did not include a question to participants about how

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

long they had smoked, most current and former smokers described smoking for a long time, in some cases several decades. Many participants described starting to smoke when they were between the ages of eight and 12 years old. The youngest age was six (he said he was influenced and taught to smoke by older siblings). Another subset of participants started smoking between the ages of 17 and 21, either in college or when they began living on their own. Many smokers said they started to smoke because their parents or friends were smoking and they wanted to take part. “I think when you’re a kid – when adults, particularly your parents, say, ‘Don’t do this’ and ‘Don’t do that,’ you assume, ‘Well, this is good. I’m going to have a part of this.’ ” A small subset of participants started smoking after leaving college. The only exception was a participant in his 40s who had started smoking within the last year to handle his emotions, both positive and negative. “My feelings get to the point to where I’m mad, I’m sad, I’m glad, I smoke a cigarette so I can relax.”

As mentioned in the description of methods in Chapter 2, participants were not asked about their diagnoses per the recommendation of division directors and administrators at the social service agency where I conducted the focus group interviews. While the majority of participants did not talk specifically about their mental illnesses, approximately one-third (n=10) did reveal their diagnoses unsolicited in the groups (sometimes before or after the group officially started or ended). These diagnoses included: bipolar disorder (n=3), depression (n=3), PTSD (n=1), schizophrenia (n=1), and anxiety (n=2).

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Several codes and categories emerged from these focus group discussions about tobacco. In this chapter, I organize these findings around four major categories: (1) the lived experiences of never smoking, smoking, and the process of quitting; (2) the experience of tobacco use for mental health consumers; (3) outside forces influencing tobacco use from the perspectives of mental health consumers; and (4) tensions and complexities in addressing smoking among people with mental illnesses. The overarching themes that emerged from these data were that smoking provides mental health consumers with: (1) the perception of normalcy and (2) feelings of control. The need to avoid feeling “different” resulted in the participants choosing to smoke, even if it meant fitting in with a fringe rather than a mainstream population. The drive to create a sense of control through smoking stemmed from the lack of control they had over their lives as a result of their illnesses, the lack of control over the intense stress they experienced on a daily basis, and the lack of control they had in their social relationships. People chose to quit if and when continuing to smoke failed to meet these needs or when they were made aware of serious health concerns.

3.2 Never Smoking, Smoking, and the Process of Quitting

“It’s a habit that you can break, but it’s hard if you don’t want to do it.”

- Mental Health Consumer (Former Smoker)

Because this study included focus group interviews with those who have never

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

smoked, former smokers, individuals trying to quit, and current smokers, it is possible to better understand the process that people with mental illnesses go through in choosing not to smoke, in starting to smoke, and in quitting.

3.2.1 Never Starting to Smoke

As mentioned above, one focus group was composed of mental health consumers who had never smoked. Given the staggering rates of smoking among people with mental illnesses, it is interesting to explore why some mental health consumers do not start smoking and the ways in which they may be similar or different from those who do. Some of the most obvious differences between those who never smoked and the current and former smokers are that the nonsmokers who were interviewed tended to be around nonsmokers when they were growing up and appeared to take messages regarding the health-related effects of tobacco use very seriously. These nonsmokers described being very committed to their health and making health-promoting activities a top priority. They also talked openly and vividly about learning the perils of smoking. Several of the younger participants recounted seeing “anti-smoking films” at school that left a lasting impression.

When I was coming up, especially in high school, I learned especially from the health courses and then we had a video on the consequences of smoking and the video showed, you know, the dangers of – the consequences of smoking, what can affect your lungs, how bad it can look and how critical it can harm you. So for that reason I decided to stay away from cigarettes.

Some of the participants who were older and attended school before the mid-

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

1960s and were unaware of the negative health effects of smoking, had other reasons for not engaging in the behavior. One participant described having a negative experience the first time he smoked a cigarette when he was just five years old. After thinking cigarettes tasted terrible then and having the same impression when he tried smoking again in high school, he said, “I never felt any inclination to smoke after that.”

Some participants said they never started because they witnessed the ill health effects on their loved ones:

My mother died of cancer and I think my father died of heart disease. Both of them smoked. My father smoked cigars, my mother smoked cigarettes. And I see what my mother went through being diagnosed with cancer, having one lung taken... That’s why I never – that’s mainly why I never smoked because I seen the effects of it.

Other participants mentioned that they were involved in activities of held convictions that made smoking less appealing, including an interest in exercise and “a strong sense of overall health.”

It’s never been a temptation to me, but like for dealing with depression and anxiety, I used to exercise and I had interests that were things I could keep myself busy with. Also I had a very strong sense of my overall health so I wouldn’t do things that I thought were bad for my health and that alone was enough to keep me from doing anything [smoking].

Nonsmokers described a desire to respect the rights and wishes of smokers while also protecting themselves and their rights and desires to avoid the harmful effects of cigarette smoke exposure. This was particularly important because many of the nonsmokers live in very close proximity to smokers. This likelihood is especially high for mental health consumers who often live in structured group settings such as board and

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

care facilities and Single Room Occupancy units (SROs) with other mental health consumers who are highly likely to smoke. While smokers described feeling misunderstood by nonsmokers, the people who participated in the nonsmoking group expressed empathy towards smokers. One participant in the focus group for nonsmokers said, “I seen the complications that they go through smoking and they tried to stop, a couple of them tried to stop, but they go right back to it and it’s a hard drug – it’s a hard drug to kick.” Or another participant described why he could empathize with smokers because of his understanding of addictions and his experiences with his own “weaknesses”:

I can empathize with smokers. A lot of them just probably fell into it not realizing what they were getting into. Nicotine is a very powerful addiction from what I’ve read because there are benefits that you get from it. It improves concentration and relaxation. Some people smoke to curb their appetite. And I have my weaknesses so I can understand from my own difficulty in dealing with my weaknesses, I can understand how other people – if they’re dealing with something, if they were dealing – well, for my case, I’ve had to deal with pain. If smoking in some way relieves pain it could be very difficult to quit.

In general, it was interesting that some of the people with mental illnesses who never smoked were, like the person above, extremely empathetic to the experience of smokers. Those who expressed empathy appeared to be able to understand or relate to the experience of having a “weakness,” and the ways they sought to deal with the issues they experienced. Those who tended to “otherize” smokers (the “they versus I” mentality) tended to have a weaker identity as a person with mental illness and did not necessarily see a connection to their own life in these discussions about tobacco.

3.2.2 *Smoker Perspectives and Attitudes About Tobacco*

Several of the mental health consumers who smoke described how they do not think about smoking when they are not around cigarettes, but as soon as they are near a smoker and start to feel upset or anxious, they get a strong craving. For some, when the desire to smoke comes, they are willing to smoke any kind of cigarette to get “that feeling,” whereas others described being extremely brand-conscious. For example, one woman said that she cares about the looks of her cigarette. “If they make it pretty, I’ll smoke it.” Overall, there was less emphasis on health among the current smokers. They described having a cigarette as a form of relaxation that was very enjoyable, and these positive qualities outweighed the negative effects of tobacco use.

Several participants felt inundated by what they saw as repressive, omnipresent messages instructing them not to smoke. One mental health consumer said, “...The Attorney General coming on TV telling you don’t smoke, don’t smoke, don’t do this, don’t do that, don’t do this. They got signs all around on the freeways and everywhere, you see that.” Like the nonsmokers, current smokers expressed an interest in not being around other smokers when they were not smoking. One participant noted (and several others also mentioned that this was true for them as well) that she will walk to the other side of the street while waiting for the bus to avoid standing close to someone who is smoking so she does not put her health at further risk.

Smokers had the sense that the people who do not smoke cannot understand their desire to engage in tobacco use. For instance, some participants mentioned to me that, as

a nonsmoker, I could never understand how strong the addiction to smoking can be and how hard it is to quit.

3.2.2.1 Thinking About Quitting

Seven people originally signed up to participate in the focus group for those “trying to quit.” There was no identifiable difference between this group and any of the others. People expressed equal interest and signed up in approximately the same numbers as in the other groups, yet unlike the other focus groups, only one person actually showed up at the scheduled date and time. This was the second of the five proposed focus groups, and after realizing that the single participant would indeed be the only participant, I wondered whether recruitment was the problem or whether I had made a timing or logistical error.

In organizing the last three groups and then analyzing the transcripts, it became readily apparent that there was something truly unique about signing up to participate in the “trying to quit” group, as opposed to, for example, the “current smokers” groups. Many of those who participated in the current smokers groups (more than half) stated that they wanted to quit. Some were quite serious about it, taking certain steps to prepare themselves to quit like reducing one cigarette at a time or spending more time around nonsmokers. Seven of the 11 total participants in the current smoking group wanted to quit but did not identify with “trying to quit.” In rereading the transcripts, it became evident that there exists a major difference between the notions of “trying to quit” and “thinking about quitting.” It was as though those who had signed up for the “trying to

quit” group felt that by attending, they would be making a commitment to quit. They did not feel completely “ready” to actively engage in this process. It is also noteworthy that the literature commonly states that it can take multiple quit attempts to quit for good (Fiore, et al., 2008). According to my participant observation including participation in training events, quitting is often framed as an iterative process through which people must learn how to live tobacco free.

The one person who did attend the trying to quit group was extremely motivated to quit given her serious health concerns, and she felt ready to quit. Yet after several attempts she began to feel that she could not be successful without help from others. She said that she attended the focus group because she wanted to take advantage of any opportunity that might afford her additional motivation to quit.

3.2.2.2 Motivating “Thinking About Quitting” for Those Not Yet Ready to Quit

One participant acknowledged that, “every one of us sitting here know that smoking is no good,” and it was clearly the case from the focus groups that the “problem” of smoking is not that mental health consumers are unaware of its consequences. For those participants who were not ready to quit, I asked what they would need to hear in order to quit. These individuals felt that they had heard *enough* about the health consequences of smoking and could benefit from hearing other pieces of motivation and advice. One participant said she would need to hear, “I’m stronger than this, and I’m better than this. It’s not that serious....If you don’t get it done today the road’s not going to come to the end, there’s always tomorrow if you’re here.”

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Health scares were also a potential source of motivation for those not ready to quit. For example, one current smoker said, “I’m trying to give it up. I’ve got asthma, emphysema, bronchitis, heart condition, and high blood pressure. I ain’t got no business with it.” Another participant said he would need to hear that it takes time to prepare to quit, just as it takes time to become “a smoker.”

Yet those who were not ready to quit had little hope that anything could be said or done that would push them to quit. When one participant was asked what it would take for him to quit, he quickly replied, “When they stop making cigarettes.” He was convinced that he would not quit until there were no longer cigarettes at his disposal (a theme that suggests not only the control of cigarettes on his life but also the force of the tobacco industry, to be discussed later in this chapter).

3.2.3 Motivating Contemplation for Those Who Are Thinking About or Who Have Quit

In the focus groups with smokers, the participants were specifically asked about what might motivate them to quit smoking. Some of the participants had long contemplated quitting, while others were very content to continue to smoke. Many people described their motivation for quitting as being deeply personal, suggesting that what serves as a motivating force for one may not be effective for motivating others to quit.

Many participants said that they no longer found cigarettes enjoyable, but were frustrated by failed attempts to quit smoking, and felt “the easiest thing to do is to give up.” Those who still enjoyed cigarettes felt that they would need to replace tobacco use

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

with something that “gives me the same satisfaction.” Most participants had not found anything that fulfilled the same needs and desires.

Thus, as many participants described hearing from a doctor that they were experiencing a health problem or were at serious risk of health problems, and especially if it was known that these health problems were a result of or were exacerbated by smoking or had no known cure, people began to think about quitting. For instance, the participant in the trying to quit group described her escalating breathing problems. Her doctor, whom she was to see the week after the focus group meeting, said that she would need to go on oxygen by her next visit if her breathing did not improve. She said:

I have some vanity. I don't want to be walking around pulling an oxygen thing but what choice do I have – have I given him by my smoking? And by, you know, whatever, my unwillingness or just not being able to get myself to stop, you know, this is the position that I'm in.

While avoiding the oxygen tank was a strong motivation to quit, she was still not ready to make a concerted effort to try. Another participant was also very concerned about her health but felt unable to quit because her smoking was “bigger than I am.”

Every time I've had it I had to be in the hospital because I couldn't breathe. My chest was hurting and the ambulance had to come. And it's about smoking, I have to stop smoking, you know, or it's going to kill me, that's it. And I have a better chance of dying before another person that hasn't smoked just because I've smoked so long now. So I do want to stop. I don't want to die because of it, but it's – it's bigger than I am because it's just not that easy to stop. Not for me. I don't know about anybody else but not for me.

While their health concerns were not necessarily as chronic or debilitating, former smokers also noted that they were motivated to quit due to health problems or potential

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

health problems. One participant said he was “kinda grateful” for his bronchitis because he had been looking for a reason to quit and the diagnosis served as a motivation:

At that point I realized I had – I got bronchitis and the doctor said that if I kept smoking I would get chronic as opposed to what I had, acute bronchitis. So that was enough. I just gave my cigarettes away and that was the last of it.

Another former smoker said, “I was getting – my throat was getting very sore and it was becoming uncomfortable. And, of course, the cough was there and I decided this wasn’t for me, I had to quit. So I quit cold turkey. I just gave them up.” Even a participant who was smoking just a couple of cigarettes a day was motivated by the health risks to quit:

I would smoke just two a day at noon and I would never smoke any more than that, sometimes only one. I had control over them. Of course, I knew the problems they would cause, I was well aware of that, but I kept my smoking down to a limit of two but after a while I said, “Ay, you know, whether it’s two or ten you’re going to have the same problems.” So that’s another reason I quit.

It appeared, from what was stated by the former smokers, that they required a lower source of motivation to quit than the current smokers. This may be because time had lapsed since they had quit and they could not remember the details of the experience as vividly. It could also be because they had not smoked as long or as much or that there were other differing circumstances. Some participants quit after witnessing declining health among family members who smoked:

It was easy for me to quit, you know, even the first time, which is when I decided to give them up because I knew – I knew the problems. They killed my dad, and they were having an effect on me. So I says, “Well, you know, it’s probably time to quit,” and I quit.

In one case, a participant noted that his mother felt that her own cancer was a

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

result of secondhand smoke from her son's [the participant's] cigarettes:

Before my mom died she said after she had her breast cut off then she – she had got cancer of the lungs and she said, “It’s from too much second-hand smoke.” So that – you know, I felt bad, I wanted to try and quit when she said that but it’s pretty much like she – She told me that before she died.

While it was uncommon, there were some participants who were motivated to quit by factors other than their own health or the health concerns of family members. One smoker described the impetus to quit as fear of causing a fire because of his carelessness when smoking. Some participants mentioned they could be motivated by their peers to quit smoking.

3.2.3.1 Overcoming Obstacles to Staying Quit

Many of the smokers and those who had quit experienced significant barriers to attempting to quit and then “staying quit” (continuing to live tobacco-free). While the barriers described here may be common to all smokers trying to quit regardless of their mental health status, some may be specific to people with mental illnesses because they must manage the stressors caused by the unpredictability of their condition and because they may have fewer social and financial resources.

One participant described trying to achieve a sense of control over his emotions as a barrier to cessation. He found that while he was able to quit on several occasions, he would resume smoking to try to create the sense of emotional stability he desperately craved.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Well, I've quit for periods of time. Several months at a time a bunch of different times. I think part of it has to do with managing my emotions because, uh – I read this article about how cigarettes are like an all-purpose drug. If you want to calm down you smoke one, if you want to perk up, you smoke one. Like someone said something and I felt insulted so I – this last time, about two months ago, so I went and bought a pack of cigarettes.

In one case, a person trying to quit noted that because she is on Medi-Cal, she would have to complete a behavior modification program in order to earn a certificate which would qualify her for free NRT. Although she genuinely wanted to quit and was going through the steps to prepare to quit, she said, “If you got to go through all that then, you know, then I'd rather just keep smoking. But it's not as accessible as it should be if you want somebody to try it, the other methods.” Other current smokers who were trying to quit also expressed disappointment and frustration related to their experiences using NRT and the high costs and poor accessibility they associated with it.

Also, the sheer magnitude of the process of trying to quit appeared too large for some people to grasp, particularly for those who had heard how challenging it was for family members to quit and for those who could not conceive of a better or different life for themselves without cigarettes. One participant, for example, mentioned that he had been told, in a cessation education and support group that “the withdrawal symptoms are as bad as from heroin, there's just no way around it. It's hard to do it.” In general, people felt that there were many factors against them in their attempts to quit and as a result, felt a diminished sense of hope about their prospects for living a tobacco-free life.

3.2.4 Listening to Providers

In each focus group, participants were asked whether their doctors and other health providers regularly asked if they smoked. Most participants said that their doctors (e.g., primary care physicians and psychiatrists) did typically inquire about their tobacco use but that their mental health providers, including social workers and psychologists, often did not ask and did not know that they smoked. Yet at least one participant stated that her “worker” (social worker or case manager) attends doctors’ visits with her and knows about her health conditions and her need to quit and sometimes talks about it with her.

The sole participant in the trying to quit group was critical of the role of her providers in helping her to quit. While she noted that her doctors do ask about her smoking and recommend that she quit, she felt that a significant disparity exists between talking about smoking and actually “making any effort to help me stop.” For her, having someone ask about her tobacco use and telling her to quit was not enough. She said, “Many, many years they been talking to me about smoking. That’s all they been doing is talk – not really making any effort to help me stop, I don't think.” Desperate for additional support and information, she called the free telephone quitline at 1-800-QUIT-NOW and recounted her experience in making that call.

ES: Did someone tell you to call or how did you find out about –

S: No one told me to call, I knew. You see it on TV all the time.

ES: And was it helpful or was –

S: Yeah, they sent me a lot of literature on different things. Talked to me. Ask me did I want to talk on the phone for like thirty minutes. I had talked already about

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

fifteen or twenty minutes so – you know, but they have a counselor and stuff. And they followed up with me because they called me last year. They called me this year – this year they called me and asked me had I stopped and I told them no. Then they asked me did I want to again talk to a counselor and at the time I was busy, I was here, I think – I told them no. They said they would call me again like every six months to see if I stopped.

ES: Oh. So you'll hear from them again –

S: Uh-hum. [yes]

ES: Was the counselor friendly? Like was –

S: I didn't talk to her.

ES: You didn't get to talk –

S: The person that interviewed me and then they have another person that comes – that you talk to after they, you know, get all your information and you tell them how long you smoked and that you want to stop and why you want – Just like what you're doing [...]

ES: And did you tell them when you called – did you tell them about your schizophrenia? Did you mention that you –

S: No.

ES: No. Okay.

S: I didn't see what that has to do with it.

Although the amount of time that it took to complete the intake was too long and involved too many questions for S, she appreciated the information and follow-up calls. Interestingly, while she stated in her interview that she felt her psychiatric medications were the cause of her smoking (or at least the reason that she found it so difficult to quit), she did not see her schizophrenia or the prescribed medication as having an affect on her attempts to quit when she called the quitline for assistance and support. Consequently, it is possible that the quitlines and providers may not necessarily be asking the right questions to help their patients quit. Interestingly, this participant also serves as an employee of the social service agency and chose to share the information that she received from calling the quitline with other clients and colleagues.

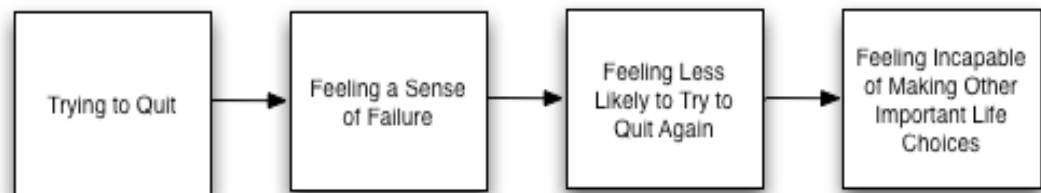
3.2.5 *Garnering Will Power and Inner Strength*

In all the groups, a common theme was that people described quitting as ultimately requiring will power, inner strength, and the right frame of mind. The power to quit was described as being inside the individual, and as such, there were “limits to what others can do” to help a person quit. Participants said things like, “talk, you know, goes only so far. It goes in one ear and out the other if I’m determined to keep smoking even though I know it’s not a good,” and:

When you see your lungs or any parts of your body that done deteriorated from that kind of stuff then you get to thinking mentally you don’t need to be doing it and if you are doing it then you need to find some kind of way to stop it.

Smoking was described as “mentally a state of mind,” and people described setting their mind on quitting and then never smoking again. People who struggled with quitting still said that they “really have to put [their] minds to it” as if they were not yet in the “right place mentally” to quit. Several participants were frustrated by prior attempts to quit smoking; these “failed” attempts suggested to them that they just did not have what it takes to quit. They associated their mental health condition with an inner weakness and a propensity for failure. These associations made them feel unable to lead a tobacco-free life, a process depicted in Figure 1.

Figure 1 The Process of Trying to Quit and Feeling a Sense of Failure



3.2.6 *Succeeding in Quitting*

The former smokers and those current smokers who had quit for some time used a variety of methods for quitting. Yet most people said they found success in quitting “cold turkey.” It was unclear if they chose to quit cold turkey (without NRT) because of the cost, because of a lack of awareness about cessation aids or education about nicotine, because of high motivation stemming from imminent health concerns, or whether they had negative experiences using various forms of NRT and felt that it did not work to help them quit. Many participants knew about some of the forms of NRT but generally expressed the sentiment that they did not think it was/would be helpful in quitting.

Only one participant, a woman who demonstrated a deep insight into her mental health condition, described her emotional struggle in quitting smoking and the way in which it affected her mood. As described below, she chose to quit during an extremely stressful time in her life. While she felt that things were much better as a result of her

quitting, she beautifully articulated the challenges she faced. Her story describes the ways in which quitting occurs in “real life.” While many current smokers felt that they would need to clear their calendars of all obligations and devote full attention to quitting, this participant’s experience demonstrates how quitting can happen while coping amid significant life changes and amidst serious responsibilities.

When I quit...I was angry. I was very uptight. I’ll use the word on tape, I don’t care. I was bitchy. It was very difficult for me because I was going through some stress and some things were going on in my life. I was a college student and a reservist and Desert Storm happened and they called me up to activate me. So I quit smoking while that was happening and it was very hard for me to do. Every day it was around me and available to me, and yet I didn’t want to start up again.

While this participant chose an extremely stressful time to quit, it was a time when her motivation was high and her attention was focused on other things.

3.2.7 “Seeing What It’s Like” and Relapsing

When people discussed relapsing and how they returned to smoking days, weeks, months, years, and sometimes decades after quitting, they talked about the desire to experience the pleasure of a cigarette again, and to “see what it was like” to smoke without feeling addicted. Many participants made it their goal to still enjoy cigarettes, on occasion, while also having “control over” their cigarette use. Yet in their search for this control by managing their smoking, people soon found themselves addicted again. Participants described the power of the first cigarette, and “then after that, it was all downhill.” One participant described how:

You are always looking for that same feeling which never did occur....When I started again I just smoked a couple for months and I just said ‘I’m not going to do that,’ and quit. And I probably will stay quit.

Another participant said, “...the feeling was gone, I couldn’t—I knew it would never come back. [cough] It was a ploy to get you to start.” At least five participants mentioned that in realizing that the thrill of the first cigarette would not return, they were able to quit again after a couple of months, but others went right back to smoking and continued to smoke at the time of the focus group sessions.

3.2.8 Accomplishing After Quitting

The participants in the former smokers group all had positive feelings about what quitting smoking had allowed them to do. A former smoker, a portrait artist, said that she could assert herself and get along better after quitting. Other smokers found that cigarettes were a distraction from the real goals they had set out to accomplish. One participant said that in graduate school, when she no longer had the distraction of fumbling for a cigarette, she was able to focus on her assignments in ways she had not been able to before.

3.3 The Role of Tobacco Use for Mental Health Consumers

“Without it [a cigarette], I feel naked.”

- Mental Health Consumer (Current Smoker)

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Cigarettes play an important cultural role in shaping and reshaping norms and relationships among the people who use them. In the case of smoking among people with mental illnesses, tobacco use also plays important and varied psychological, physiological, and social roles, roles that are potentially unique in some ways but also similar in other ways to those it plays for people without mental illnesses. Focus group participants described within the groups the ways in which they saw smoking intersecting with their mental illness. These included: as a tool for managing stress; as a facet of their striving to be “a part of” and coping with feelings of exclusion and difference; fulfilling a desire for calm, comfort, and support; as an instrument to help them feel more motivated and better able to concentrate; and as a mechanism for meeting the physiological and emotional needs of an addiction.

3.3.1 Managing Stress: Feeling Like a Prisoner

All in all, participants believed that smoking helped them to better cope with the stressors they experience as a result of their mental illness. Many participants described the remarkable number of stressors, or daily obstacles and demands in their lives associated with their mental illness, and the ways cigarettes helped to ease this stress. This was a result of numerous, and in some cases interconnected, cultural, social, physical, physiological, and financial factors. The stressors associated with being ill and learning to cope with mental illness and its attendant concerns, dealing with the health problems associated with smoking, and commonly associated with having minority status

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

and low income, took a toll on many participants. Unlike “the average person,” participants stated that people with mental illnesses have a “constant state we’re trying to just maintain.” They live in fear that they may experience a downward spiral in their mental health condition, and as a result, tend to focus on trying to maintain their current mental health status, when things are good, at all costs.

One participant described the stress of being on his psychiatric medications. He noted that he feels helplessly reliant on them, which making him feel like a prisoner.

Well, you’re kind of like a prisoner in a way because you have to have this medicine. Without the medicine I – oh, it would be horrible. So, you know, they pacify us, they give me medicine here once a week and without it, I can’t do anything.

Similarly, another participant described how the unpredictability of her mental health and the fear of the unknown contribute to daily stress that is unique to people with mental illnesses.

I think in general we are under more stress than Public Citizen 101, the regular person that just gets up in the world and goes out every day. When I wake up in the morning I have to wonder, “Is this going to be a bipolar day?” I have to wonder that as I go to my medicine cabinet to get my toothbrush. I have to wonder, “am I going to be manic today? Am I going to just be able to take my Depakote and make it through?” The average person doesn’t do that. The average person just gets up and brushes their teeth, you know what I’m saying?

Another participant suggested that stress often comes from not being able to do the things you would like to do; in particular, not having the resources or hope that would allow mental health consumers to cope during difficult times. He notes that cigarettes create a sense of comfort that he knows is not real but that makes him feel like he is “okay.”

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Well, when you're a mental health consumer there's a lot of things that you'd like to do that you can't do and it's frustrating....And cigarettes pretty much curb appetites for a lot of things. So if I don't have anything but a pack of cigarettes in my room, I can handle stuff....So cigarettes at least can take away – can create a fantasy that you're okay and, you know – I've been smoking over forty years so I know what – I know that with cigarettes I'm okay.

Some of the focus group participants, as this person describes, felt trapped by the number of things they could not do because of their mental illnesses and their identities as mental health consumers. It may be for this reason, that several participants mentioned that they smoke to exercise their sense of independence and freedom of choice. One participant stated that his desire to smoke is a right: “I want to keep smoking because I believe in individual freedom, and even though the whole world is down on cigarettes, I want to be able to smoke because it's in the – it's in the Constitution that I can do it!”

3.3.2 *Being “a Part Of”*

Some participants talked about the stress they experienced as a result of feeling excluded and misunderstood. Participants expressed that there is still much about mental health that society does not know or understand, especially that mental illness is a disability that can make it challenging to work and to lead what is commonly considered a “productive” life. Participants said that people typically do not understand what it means to have an invisible disability and to be forced to live by society's rules and standards.

A participant said that people within the mental health community generally make

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

it seem like “everything’s okay” by not putting pressure on mental health consumers to “go out and try to make it right, to have a job, to go to school... You’re okay here.” But he noted that the reality outside of the mental health arena is very different:

But, you see, this is not like it is out there. The people are wonderful [in the mental health community]...but out there, society just looks at us and they don’t understand, all right. They say, “Oh, yeah, you can work.”

While they may feel that they are the same as everyone else, many participants also feel like they are excluded and treated differently. Some of the participants felt that their tobacco use was a response to being treated differently, and perhaps that the mental health community’s historical acceptance of tobacco might be a result of this exclusion. Similarly, other participants described the ways in which society stigmatizes people with mental illnesses. A participant who described herself as having bipolar disorder said that she felt mental health consumers might turn to smoking because they are made to feel isolated, alone, and on the periphery and because they often lack viable resources to cope in other ways:

...I feel that mental health patients are made to feel apart from rather than a part of society and culture. So when you’re on the periphery or pushed to the periphery like that you’re isolated and made to feel alone. So you pick up whatever tools you can find if you’re on edge to try to feel a part of and make yourself a part of. Well, if you don’t fit in with the general population anymore then you look for what the fringe population is doing and the fringe population is smoking. Because the way that the advertisements are structured, they’re structured to certain groups and they try to make an image look a certain way and they have done that as has been shown in this group... So if you can do something like have groups where you can come to – do things where you can feel a part of and do it differently, find different ways to socialize, find different ways to network without a cigarette in your hand then you have some options, you have

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

some tools. If the only tool I have is a hammer then every problem I have I'm going to bang. But if you give me a bunch of different tools then each time I have a problem I can use a different one. So you expand my toolkit when you make me feel more a part of. Like I said, cigarette smoking is just – it is being dealt to people on the fringe groups, on the fringe of society right now.

In this statement, the participant uses the phrase “a part of” five times, reiterating the desire among people with mental illnesses to strive for inclusion and to avoid separation. This participant discusses the ways in which she has negotiated difference in her own life. In essence, she states that there is a sort of hierarchy of normalcy, and as a result of her mental illness, she feels marginalized and thus relegates herself to feeling that, at the very least, she can be a part of the fringe and fit in there. Her “toolkit” analogy suggests that smoking becomes an easy and accessible method for coping with everything until one has other “hammers” at his or her disposal, and she suggests that the tobacco industry supports this notion.

On top of managing their mental illness, many of the participants in the focus groups also experienced multiple other pressures and complexities in their day-to-day lives. Some had been students in high-pressure graduate programs, some had been family caregivers, and several had served in the military. Many participants described experiencing numerous tragedies in their lives, including extensive violence and the untimely death of loved ones. Other participants related the stress in their daily lives to their low socioeconomic status. “People who are financially better have less to think about, they have less to worry about. When you're on – I'm on SSI [Supplemental

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Security Income] and SSDI [Social Security Disability Insurance]. It comes with a certain level of worrying, I guess.”

3.3.3 *Creating Comfort*

As a consequence of the tensions, worries, and complexities in their lives, the participants described longing for feelings of calm and tranquility. While many participants recognized that smoking created a “false sense of comfort,” they still found it effective in helping them to manage their feelings and feel at ease. One participant described how cigarettes allowed her to avoid an oncoming anxiety attack.

When I was stressed, cigarettes would relax me. When I would start to have the start of an anxiety attack but not quite go into one I would feel like if I got a cigarette quick enough, it could take me out of going all the way to an anxiety attack. So I felt they were very helpful in that sense. They could somehow ground me and relax me.

Another participant described how she feels relaxed, comfortable, and talkative when she smokes.

A: I want to continue smoking because I enjoy the cigarettes, the smoking. When I smoke I feel relaxed, I feel comfortable and I talk more.

ES: That’s really interesting. You feel more comfortable just to talk?

A: Yeah.

ES: Does it help your confidence or –

A: Yes. I feel freer. More ideas come to my head and I think good. I think about good things. And I smile. I feel comfortable. I’m in good health. I can tell that I’m in good health and I just enjoy the cigarettes.

Several participants felt that cigarettes were capable of calming unwanted or difficult thoughts and feelings including: avoiding taking things too personally, reducing excessive worrying, and even managing hallucinations. One participant related how she

turns to cigarettes when experiencing auditory hallucinations:

I have auditory hallucinations... You'll be edgy and the cigarette takes some of the edge off. For me, like you sit there and try to calm yourself and talk yourself into saying that, no, you're not hearing nothing or you're not seeing nothing but you are, so you're going to keep smoking the cigarette. And also you think, "Okay, now I can get out of this and make it home... without your illness getting the best of you.

For some participants, particularly during stressful times, the cigarette was their source of social support. One described the stress experienced in graduate school feeling cigarettes helped her get through papers and deadlines. "So I felt that cigarettes was the only way I was going to get through, that they were my friends, and they pulled me through." Two others also used this analogy suggesting that smoking provided a level of comfort and support that was not achieved in their social relationships.

3.3.4 Doing More

Several participants described smoking as also providing them with the motivation to "go out and do more and finish a project." The participant who uses smokeless tobacco said that chewing tobacco improves his concentration. "To take a test, whatever. A written test, I just situate it in my mouth and it just – it improves my thinking and my – it makes me – calms me down." Many participants mentioned this connection to improved concentration, saying that smoking relaxed their self-doubts and intrusive feelings, allowing them to focus on the task at hand. Yet other participants said that smoking allowed them to forget about all responsibilities and just relax.

3.3.5 *Meeting the Needs of an Addiction*

Many of the consumers in the focus groups described the powerful nature of their addiction to nicotine. One participant described her strong need for cigarettes saying, “you feel like you’re going to die if you don’t have them.” While some participants used the term “addiction,” most tended not to use medical terms in describing their relationship to nicotine. For example, one focus group member called his need to smoke “a form of brainwashing.” While it is the nicotine that causes people to feel addicted to cigarettes, several participants talked about their body’s strong cravings for tobacco. Some participants described these cravings or addictions as something driven by genetics or some other internal mechanism, saying that the need to smoke is “not your fault, you’re just born with it.” They also related the need to smoke with other “needs” that they also saw as being problematic for health and quality of life. They questioned whether smoking was better for them as compared to other behaviors they could potentially engage in. Many participants stated that they felt that everyone has weaknesses, and if smoking is not your weakness, it is certain to be something else.

By and large, each of the participants, even those who had never smoked, were able to understand and describe the important role that tobacco plays in the lives of mental health consumers in pursuing relief from various conditions including pain, grief, anger, sadness, longing to fit in, and withdrawal. A nonsmoker who identified as having depression said that while he had not taken up smoking, he could easily understand why people with mental illnesses are tempted to smoke.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Oftentimes with depression – I’ve been diagnosed depressive – there’s anxiety and I can see anxiety prompting people to smoke because it’s relaxing. I understand that schizophrenics are more likely to smoke, there’s some kind of benefit to schizophrenia from the nicotine. For myself, when I’ve experienced severe depression I experience severe pain and I would have been interested in whatever could have relieved the pain. Smoking wouldn’t have done that and I wouldn’t have these – that could prompt some people. For me it wouldn’t have been a temptation because by that time in my life, I knew the dangers of smoking and I was very much into keeping myself healthy and so forth and so on. Just like alcohol was never a temptation for me, smoking wasn’t either.

There was an overall sense that “when I look at people with more deep-rooted problems, I see why they smoke.” The participants saw cigarettes as an effective and available tool, although not the only tool, for coping and for getting by. Until the deeply rooted problems that many people with mental illnesses experience, like low income and poor access to care, are addressed, smoking is an easily accessible strategy for coping, whether it is truly a craving for nicotine or a craving for inclusion and acceptance.

3.4 Forces Influencing Tobacco Use by Mental Health Consumers

“They’re in it to make money. They don’t give a shit about you.”

- Mental Health Consumer (Current Tobacco User)

Participants frequently described marketing/economic, cultural, and policy forces that shaped their decisions to smoke and/or to quit.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

3.4.1 *“Being Brainwashed” by the Tobacco Industry or Mental Health Consumers as Tobacco Consumers*

Participants were acutely aware of “being brainwashed” as a result of the advertising tactics used by the tobacco industry. They recalled events where they could obtain free cigarettes in some of the poorest neighborhoods in San Francisco, times when they received coupons by mail, and described in detail ways in which they saw the industry attempting to create a positive image by associating with popular household brand names.

M: Well, I mean like, you know, they have all these products like Kraft, you know, the cheese people, and they’re on TV with all these great little things they do, right, because that’s what they were told to do. It’s to – to do like really good works, even though you’re a tobacco company you fund this and this. They try to make them look really, really – you know, like they’re saints or something. But the thing is – I know I’m trailing a little bit here, but all I’m trying to say is without tobacco there is like thirteen or fourteen states that would go totally broke if they stopped production of tobacco. Politicians down South are not going to have that.

ES: But you’re saying the industry is pretty strong.

M: Oh, big tobacco, boy.

ES: Yes. Do other people have awareness of the influence of the tobacco companies?

[simultaneous comments]

V: I hear they’re targeting homeless people in [a nearby poor neighborhood]... That’s pretty vicious.

M: And young people.

ES: Very vicious. Yes, young people, of course, yes. And actually, people with mental health problems too. Yes.

M: Joe the Camel.

V: They paint... this picture that it’s as American as apple pie.

ES: Right, exactly. And also that it’s such a good stress reliever.

M: Yeah.

[simultaneous comments]

V: [..?..] They make it glamorous on TV and they say all the positive things about it but they leave off something, the little tag on the side of the box that

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

this is hazardous to your health. You don't see that on TV [V is referring to actors smoking on TV, not official tobacco advertisements on TV which have been banned since 1971].

M: Right. Right.

V: And so it leaves people with a false illusion.

ES: Yes. Anyone else feel that way?

V: And then generally when a person buys a pack of cigarettes they don't look at that because they don't look on the side, they don't look on the side.

ES: Right, they don't look at that label.

V: They don't look at it, they don't look at the warning.

ES: Right. Yes. Do other people notice that, the targeting from the tobacco industry?

M: Well, they made them stop with the Joe Camel and all that kind of stuff.

ES: Yes, right.

M: Because that was attracting younger people.

ES: Yes, some of the things they've gotten in trouble for.

V: But now I think it's a lot of subliminal stuff that's going on.

ES: Yes. I think they've gotten more advanced--

V: [...?] Like in a movie and you're watching the movie but it'll only be for a split second you see cigarettes -

As is highlighted in this group dialogue, the focus group participants were astutely aware of the tactics used by the tobacco industry to create “false illusions.” While participants did not talk about ways they were targeted by the tobacco industry because of their mental illness, it was evident that they felt targeted as “consumers” based on their gender, level of income, and veteran status.

I'm just going to say too that I think that this targeting persons such as the young persons or mental illness persons or minorities or anything like that when it comes to cigarette advertising is very reprehensible because they try to sell cigarettes on the basis of the fact they gave money to charities in poor neighborhoods, like ghettos. I know this going back some years in the 1980s and I found that very – they're like, disgusting.

Women recounted being offered free cigarettes in feminine flavors and styles in packets with feminine names like “Misty.” “They try to make it pretty for you so you can

buy it and it still ain't good for you, we know that. But they make it so pretty...slim, different color tips on it." A female former smoker reminisced about the marketing campaign for Virginia Slims.

They were about being an independent woman now 'cause you could smoke. They were not geared toward males, they were geared towards just the opposite, the whole idea of being a radical feminist and starting to be your own woman. You could be your own woman if you smoked, you know.

Another participant stated:

I have a problem with advertising in general in that they target and advertisers work on your psyche, they look for weaknesses. Having that beautiful woman or a man, for that matter, or a sexy-looking woman or man in the thing seems to equate the product with sexiness and everybody wants to be sexy. It gets inside of you and then they hook you that way. And something like cigarettes, they're hooking you – once they've convinced you that it's chic to smoke or whatever then the nicotine takes over and then you've got the addiction.

3.4.2 Changing Norms and the End of "Social Smoking"

While targeting by the tobacco industry has persisted since the inception of cigarettes, changes in cultural norms and values and shifts in the social, political, and economic climate have created powerful grounds for people to start or quit smoking. Several participants, given their connection with the armed forces, described the influence of the military culture on their smoking. Many participants remembered getting free packages or cartons of cigarettes as military personnel. Several individuals even recalled the brands of cigarettes they were given and what these cigarettes signified for people in the service. "So if you folded them up in your sleeve you were a Navy guy. You would take a pack of cigarettes and fold it up in your sleeve and then you were kind

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

of more manly than a non-smoker.” Participants reported that the military culture continues to support tobacco use today.

Yet participants also noted that smoking had lost some of its appeal within their social network. One participant described how norms around smoking changed in her community/social group of gay and lesbian men and women in San Francisco. Originally there was a motivation to smoke in order to fit in and feel comfortable in social settings. However, changes in norms and values around smoking ultimately turned tobacco use into a social barrier as smoking became seen as risky and unpopular.

I went in the military and everybody smoked and everybody was on – whenever you took a break you could socialize because there was a group of smokers and you all went in a group. We’d get off at the end of the day, we’d go to a bar, everybody in the bar smoked. You’d all sit there smoking all day long in a barroom. I was a lesbian in San Francisco and so we went to the gay bars all the time. That’s where our social life was. Everybody smoked in the barrooms. You didn’t go in the barroom if you didn’t smoke. You weren’t uncomfortable because there were so many smokers back then in the Castro and all those areas and stuff. All the bars back then, there was no prohibitions for smoking back then. Then as time went by, especially as the AIDS epidemic hit and all of the monetary influence of the people that were in the gay community in the Castro went away and there wasn’t any money anymore. All of a sudden the bars became healthy and you couldn’t smoke in the bars anymore, it wasn’t allowed and so forth and so on. There wasn’t anybody for me to take a break with and all of a sudden I was the only one smoking and I was the only one that was smelling of it on my clothes and I was noticing that people were reacting to me and I didn’t want to be the odd man out anymore. I was the one walking away to take a smoke break to get away from people all the time so I wasn’t bothering them. Finally one day that just got to me where I said, “What am I doing it for?” I started doing it to socialize and now it’s not working anymore for what I do it for.

Interestingly, although smoking continues to be considered a social activity, most

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

of the current smokers in the focus group mentioned that they typically smoke alone and prefer it that way. Only one participant described herself as a “social smoker.” She said she is driven to smoke in casinos because it is still very acceptable in those settings. She has less desire to smoke when she is not gambling (at times when she is less likely to be around other smokers).

While the nonsmokers tended to feel strongly that the shift to a smoke-free culture is a positive change overall, and one person even described it as “like a dream come true,” a participant in the nonsmokers focus group raised questions about the influences of this culture change on people who still smoke, and perhaps particularly those with mental illnesses:

I like the fact that it’s so much easier on me now not to be confronted on the bus and all over the place with people with cigarettes and everything. But I can’t help but wonder, because I haven’t heard anything about how these people that have the need to smoke – I haven’t heard anything on what’s happening to them with the fact that they have forbidden them to smoke in all these places. How are they doing? Are they uncomfortable? Are they committing suicide? I mean are they – are they resentful?

Yet the interviews suggest that current smokers are, for the most part, as pleased by the many changes in cultural norms and social policies that limit smoking as are people who do not smoke.

This change in the culture around smoking is also very evident in psychiatric hospitals. One participant recounted receiving treatment in a teaching psychiatric hospital nearly 30 years ago and:

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Being given cigarettes by the guards or whatever you want to call them. They would give you one or two cigarettes and allow you to go out for 20 minutes. You'd have a certain amount of courtyard time and you could go out there for a while and then you'd come back in.

Nowadays, another participant stated, when receiving care in a smoke-free hospital, you cannot smoke at all during your treatment:

They take your cigarettes away from you the second you get there and they put them up and you don't touch them until you go out. So you have these people that are just nasty for two or three days because they don't have their cigarettes. They're going through all these changes. Not only are they trying to deal with whatever they're being 5150'd [involuntary psychiatric hold] for but they're trying to deal with the fact that they can't get up in the morning and have a smoke.

On the whole, participants seemed to support these changes in hospital settings, but the major critique of this shift in policies was that, in some cases, NRT was not provided to ease the symptoms of withdrawal:

So say someone goes in for a 5152, a fourteen-day hold, and they're a smoker, can I go up to the counter on the second day and say, "Give me a Nicorette patch?" No, there's no alternative. I'm stuck there for 14 days and I'm being denied my cigarettes when I could have just come in from smoking two packs a day the day before and they don't offer you any alternative. That's what bothers me. I think that if you are a smoker and you're in the psych ward and you're asking for help, you're saying, "Please help me, I don't want to smoke, help me." If they gave you the Nicorette for the two weeks you're in there, by the time you got out you'd be a non-smoker.

For some, as is indicated in this quote, NRT is or has not been regularly provided to them during their hospital stays. In other cases, people were "given" the patch or gum while being treated as an inpatient but were not provided with education about how NRT works or how to use it safely, if lucky enough to have access to it, upon returning to the

community. Moreover, some participants said their cigarettes were taken away at hospital admission but were returned at discharge without any recommendation or discussion about quitting. Overall, many smokers receiving care in tobacco-free inpatient settings felt that smoking bans were a missed opportunity. Lack of access to NRT in the hospital or education about its proper use at home ultimately lowered their confidence in their ability to quit and led them to return to smoking soon after discharge.

3.5 Tensions and Complexities in Addressing Smoking Among Mental Health Consumers

“...It’s a lot better than other habits. That’s how I – that’s how I make it sound like it’s a good thing is I say there’s worse things than cigarettes.”

- Mental Health Consumer (Current Smoker)

A final theme that emerged from analysis of the focus group interviews is the tensions and complexities that exist in addressing smoking cessation among people with mental illnesses. In some cases, focus group participants described these tensions explicitly, while in other cases they were inferred. The tensions described in the interviews included: (1) feelings about the possibilities and probabilities of recovery, (2) the role of psychiatric medications in influencing behavior around tobacco use, (3) the financial cost of tobacco use and quitting, and (4) the hierarchy of health concerns that exist for mental health consumers. The next three chapters will further examine the ways in which these complexities around smoking among mental health consumers are

addressed by leaders in the field and covered by the media.

3.5.1 Recovering as the Exception to the Rule

As mentioned previously, a conscious shift has occurred in the mental health community from a focus on maintenance to an emphasis on wellness and recovery. Yet, when asked how they felt about their own prospects for wellness and recovery, the participants stated that they felt society still does not understand their illness or expect them to recover from their condition. They also expressed a diminished sense of hope regarding their own chances for a “normal” future. One participant said he felt that, as a society, we are more likely to believe in the rehabilitation of “ex-cons and people who have broken the law” than the idea that people with mental illness can return to and lead a full, “normal” life. As a result, some participants felt that cigarettes actually help to reduce or make more tolerable the feelings of hurt and disappointment that come with this realization. According to Manderscheid and Delvecchio (2008) “hope lies in personal recovery, self-actualization, and empowerment” and these components are missing for many people with mental illnesses (p. 5).

Sadly, the participants did not appear to internalize the uplifting messages of wellness and recovery that mental health advocacy groups have worked so hard to embrace. While they found other consumers’ stories of recovery inspiring, they saw these success stories as “exceptions to the rule”:

ES: There are stories of people who do recover. People who have mental health problems who quit smoking and also recover from their mental health problems

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

too.

M: Yeah, that is true but that's like serendipity, right?

ES: Well –

M: The exception to the rule. I went to a seminar, a bunch of us went, a bunch of mental health clients, we went there to hear this doctor on stage – “I used to be in mental hospitals, I used to be on medication. They told me I would never amount to anything.” Then he says, “Look at my life now. I am a doctor.”

ES: Yes.

M: So there –

ES: Was it motivating to hear that or –

M: Well, yeah, but I – but what a goal to achieve, being a doctor. That's way too high for me. So looking at the doctor I figured, well, that worked for him, but that's so rare. I don't – I don't understand how he did that. I really don't. How he came from...from being a mental health client to a doctor. But it does happen.

[A participant leaves the room]

M: And I – sure, I – I've seen mental health clients become case managers.

ES: Yes, you're right.

M: So it's possible. And I applaud this one lady upstairs [who works at the social service agency] that was first a client. She's a case manager.

ES: That's wonderful.

M: It's beautiful. It's the most neatest thing.

ES: Yes, that's really cool.

M: One of the neatest things I've seen in my life.

In describing other consumers' careers and their stories of success and recovery, M's statement that it is “one of the neatest things I've seen in my life” suggests that these stories are influential and motivating, but that they are still uncommon.

3.5.2 “Mixing Up” Medications and Smoking

Several participants felt strongly that certain psychiatric medications, while effective for addressing the symptoms of their mental illness, also contributed to their smoking. While participants did not talk with their providers about this perceived connection between medications and tobacco use, they were aware of a relationship

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

through their own experiences and the experiences shared by others.

One participant said she knew of many people who were struggling in their efforts to quit and who felt that “somehow the medication and the smoking is mixed up. Like if I could get off this Seroquel, I could stop smoking.” This experience was frustrating because while people had a strong desire to quit, they felt it was nearly impossible given their need for the medication, which helps people with bipolar disorder and schizophrenia to stabilize their moods. Another participant said that she has noticed that Neurontin, which is used to treat people who experience seizures and nerve pain, can also make it hard to quit.

The single participant in the trying to quit group felt that it was her medication that was ultimately getting in the way of a successful quit attempt. When she was asked why she believed that rates of smoking among people with mental illnesses are so high, she attributed it to medication use. “There’s not too many mentally ill people who don’t smoke and that’s because of the medicine they give you.” She said that the medications she takes for her mental illness and for pain (Zyprexa and Methadone) make her feel sedated, like she is “living in a fog,” which “makes me want to smoke more cigarettes.” Eventually, this participant found it necessary to reconcile her strong desire to quit with the realization that “I’m going to have to be on that medication so that’s – that’s a given.” She described her frustration in being caught in this catch 22. “It’s just like you think you going to die if you don’t have them, you know, and you know you might die if you do.”

While there is evidence that smokers on typical antipsychotics smoke less when

switched to an atypical antipsychotic with fewer side effects (Campion et al., 2008), this was rarely a topic of discussion during any of my observations and was not commonly reported in the literature on this topic.

3.5.3 *Paying for Tobacco*

While it was common for the participants in the nonsmoking focus group to mention the high price of cigarettes as a reason for not smoking, most former and current smokers appeared relatively unconcerned about the rising cost of cigarettes. Although many participants had low incomes and were not employed due to their mental health conditions, they did not see the cost of cigarettes as a deterrent to smoking. While some expressed that they would quit if the price of a cigarette went up to a certain, set point, they found that even when the price increased beyond that point, they would continue to smoke.

I would say, ‘If cigarettes go up another nickel, that’s it.’ And then they’d go up a dime and I’d still keep on smoking, you know what I mean? I would do it, say that I was going to do it, but then I wouldn’t hold true to it.

Others just accepted the fact that cigarettes would continue to go up in price and that price was not motivation for quitting. One participant reasoned that the escalating costs of cigarettes were the same for him as the increasing cost of gas (which was over \$4 per gallon at the time of the interview):

As far as me and the cost of cigarettes today, it matters but it don’t matter because I look at it – look at the economy now. Look at how much gasoline costs a gallon. Now when people are buying it for 26 cents a gallon, if you’d have told

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

them then that you're going to pay \$5 for a gallon they would say, "No, no way, I'm not going to buy it," but it eventually works its way in.

Other participants reasoned that cigarette smoking is a "lifestyle" and spending money on tobacco is just like spending money on other things you might want that bring you enjoyment, such as new clothes or travel, regardless of the cost.

To me, cigarettes is just like buying clothes. If you want something new, you going to see that you get something new. If you want a new coat, I don't care how much it costs, if you want that coat, you going to get it...Come on, you're going to spend it on something anyway, so what – why not get something that makes you feel good?

Yet these same participants expressed the sentiment that NRT, which is approximately the same cost as cigarettes, was prohibitively expensive. While they wanted to quit and were interested in trying different aids to help them quit, they felt they could not afford the cost of these medications, nor could they successfully overcome the structural barriers to receiving free or discounted NRT.

When participants could no longer afford "their brand" of cigarettes, they would first try switching to a less expensive brand or buying "singles" for a quarter. In more extreme cases when the money was tight and cravings intense, participants described their willingness to endure behaviors that they found degrading, humiliating, or unwise like "gutter sniping dirty cigarettes" [taking used cigarettes out of the gutter and smoking them]. They noted that they were concerned about picking up germs, and that this was something they would never do if they were not poor, addicted, and experiencing intense withdrawal symptoms. In the words of one participant, "if I don't have that cigarette I'll

go crazy until I find one and I'm willing to go to any lengths. I'll go to ashtrays in front of buildings if I don't have any." Quitting is not often perceived of as a feasible option, even when people can no longer afford to smoke.

3.5.4 Creatively Maneuvering Through the Health Hierarchy

Finally, one of the greatest tensions experienced by mental health consumers is what I have termed the "health hierarchy." The health hierarchy I developed describes what these participants see as the dangers of smoking as compared to the risks of other health behaviors that they may also choose, or feel encouraged or compelled, to engage in. The participants conducted complex, personalized analyses and calculations to determine the ways in which various behaviors might benefit or be a detriment to their own health and well-being, and then determined where smoking fell within this hierarchy.

For some participants (largely those who had never smoked or who had quit), smoking was seen as a major health concern considered more unhealthy and damaging than other behaviors. Thus, smoking was placed at the top of their constructed health hierarchy. For others though, specifically those who continue to smoke, tobacco use was considered "a lot better than other habits," and thus sits lower on their hierarchy.

At the same time, those who were trying to quit expressed a pervasive fear that quitting smoking would result in the acquisition of other unhealthy habits or behaviors. For example, some individuals who had quit recounted what happened when they were

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

no longer using tobacco. One participant described “turn[ing] to other vices” like drinking a lot of soda so that she “had a soda in her hand all the time. I just made sure instead of having a cigarette, I had a bottle.” She would also eat cookie sticks and Boston baked beans so that she could always keep her hands and mouth full. She gained some weight while she was quitting because of these practices, but she and others worried that these new behaviors might become the latest “problem” for her once she had quit.

Focus group participants, particularly those who currently smoke, described various activities and behaviors that they considered “just as bad as smoking.” From gaining weight, to getting numerous tattoos, to excessive shopping and hoarding, to marijuana use, current smokers constantly compared their own smoking to others’ behaviors which they saw as being equally or even more problematic and burdensome.

In particular, gaining weight presented a significant concern for many current smokers. They felt that smoking decreased their appetite and was therefore effective for weight management, and that quitting would inevitably result in overeating, leading to a host of other problems.

Well, I noticed that she [a friend who quit] is getting bigger and bigger and I don’t want – I have enough problem with my weight now and it’s like too hard on my knees. So I don’t want to do something that’s going to make me eat all the time. But I know that I’m going to be wanting to have something in my mouth. Hard candy may not do it. You know, I keep hard candy around but – I don’t know, I just have to figure out a way to stop, that’s all I could say.

Among those who had quit, it appeared that it was most common to substitute marijuana use for cigarettes. One participant questioned:

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Is it possible that cigarettes may be the wrong target? Because I'm seeing a linkage between pot and cigarettes and I think – I'm not saying I ever smoked pot and I'm not saying I never did either but I do know that pot – from people around me – that really messed them up. I haven't seen the same thing with cigarettes. In other groups that you've conducted, is there this kind of linkage between pot and cigarettes?

At least six participants, including those who identified as former smokers, also noted that they smoke marijuana (some quite regularly). This number could be substantially higher as participants were not specifically asked to share whether they were using/had used this drug. One participant said that when he started to smoke marijuana, he thought, “this is great, I don't smoke cigarettes,” while others commented, “if you're smoking pot, still – you're smoking, it's the same as cigarettes.” Participants in the focus groups had a strong desire to talk about marijuana use. They reported that marijuana helped to improve concentration. Marijuana use also served as a social activity, and participants felt it was less harmful for their health, less addictive, and more culturally permissible than tobacco use.

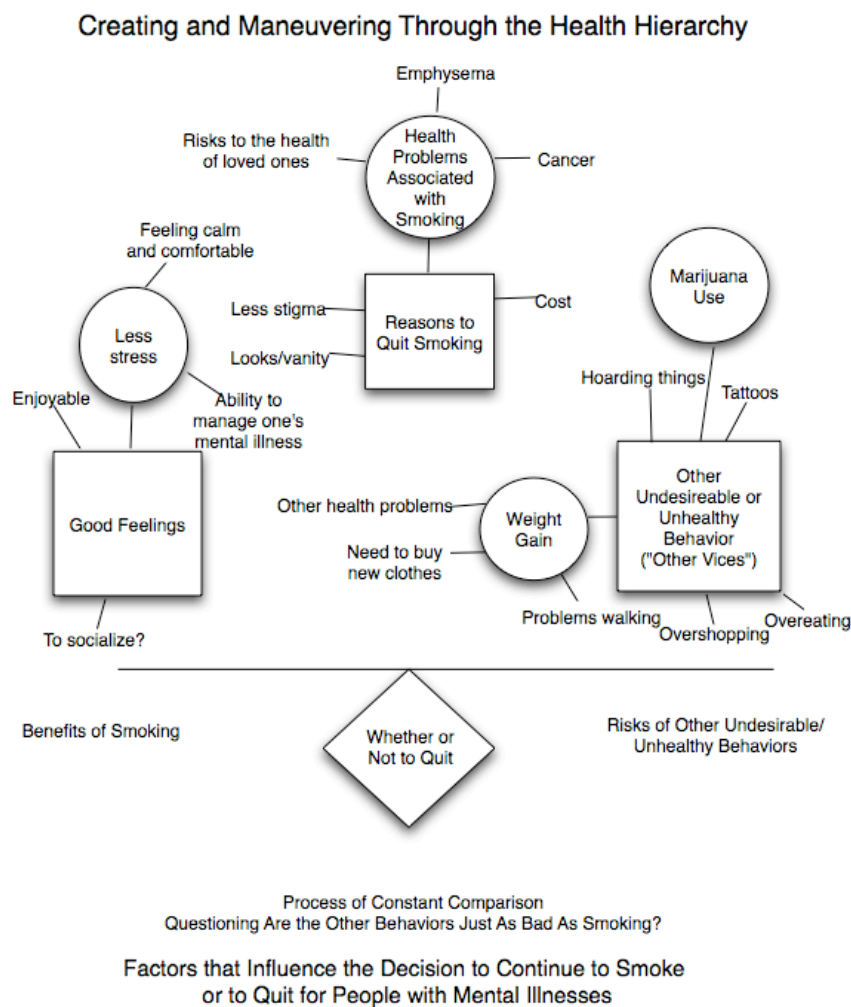
When you smoke pot, for me it went back to the socialization thing. I could be social and I could smoke... and I didn't have any of the chemicals that were in cigarettes. I was having breathing problems when I was smoking cigarettes that I didn't have when I smoked marijuana. Because there were chemicals and chemical treatments that are in the cigarettes that are made there and put there to make them addictive to you so that you will, indeed, smoke more. You don't find those in medicinal marijuana. So I think that that may make a person shift a little bit more or justify it a little bit more.

Figure 2 below presents a map of the process that people with mental illness may go through in negotiating the health hierarchy and determining which behaviors to engage in. This figure also illustrates the competing interests, thoughts, and priorities that

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

people with mental illnesses may consider in deciding whether or not to attempt to quit smoking.

Figure 2 Creating and Maneuvering Through the Health Hierarchy



All in all, these tensions and complexities suggest that smoking is even more than an expensive habit that is harmful to health and that addressing smoking among mental health consumers may perhaps, given the social, physiological, and psychological motivations for smoking, be even more complicated to address than smoking in the general population. The fear of getting “another habit that’s even worse” is a real concern for people with mental illnesses as is the belief that “it would be impossible to quit smoking out here in the free world” where cigarettes are so readily available. While this fear is not necessarily unique to people with mental illnesses, it may suggest that the risk and fear surrounding co-morbidity of mental illnesses and substance use disorders creates additional concerns for mental health consumers. The analysis of these focus group interviews also suggests that the connection between smoking and feeling good creates even greater challenges for people with mental illnesses who know very well what it means to not “feel good” and who do not want to place themselves in a risky position of feeling potentially unwell if there is any way to avoid it.

But you see, the thing is if I don’t smoke I would worry that I would get another habit that’s even worse, if there is such a thing. But I – like I say, I enjoy it too much. But, you know, it is an addiction that I don’t think I’ll ever be able to break – only temporarily because I guess I just have to have a cigarette. If I don’t have one I don’t feel good. But one thing I notice, you know, I don’t say it’s fine but it would be impossible to quit smoking out here in the free world because you see it [cigarettes] all the time.

3.6 Conclusions

This chapter highlights the realities of tobacco use from the perspectives of

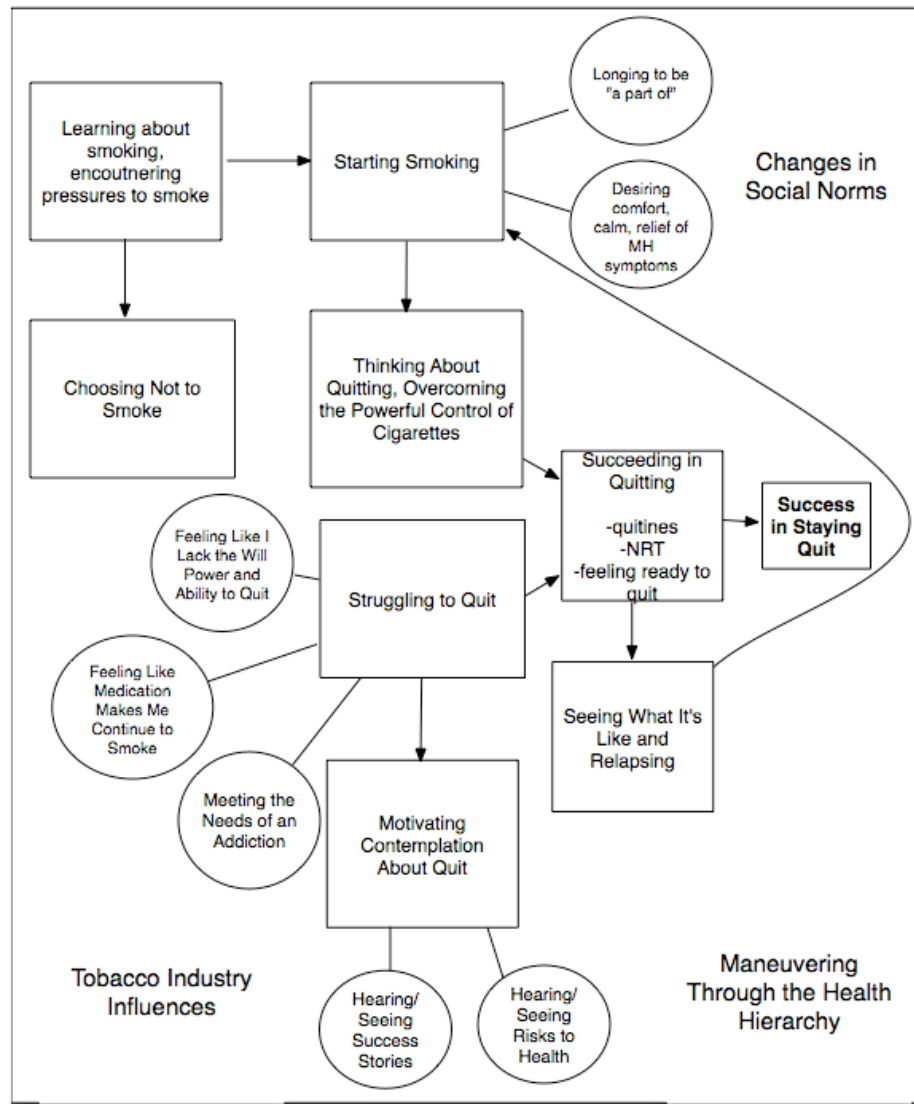
Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

mental health consumers. It also explores their feelings about quitting and their fears for the future; examines the language and meaning that people with mental illnesses use to understand the role of and describe their relationship with tobacco; identifies the external, macro-level forces that influence tobacco use among people with mental illnesses; and describes what they see as the barriers to encountering what they want out of life and the ways in which smoking helps them overcome these challenges (or whether smoking ultimately is the challenge to overcome).

Figure 3 below illustrates the process of and the factors that contribute to choosing not to smoke, starting to smoke, quitting, and relapsing as described by the focus group participants. As depicted in this figure, changes in social norms, the health hierarchy, and the tobacco industry's influence play a significant role in shaping the social environment that leads people with mental illnesses to smoke, never smoke, or to quit.

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

Figure 3 The Process of Choosing Not to Smoke, Starting to Smoking, Quitting, and Relapsing



Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

As mentioned, there were two previously published qualitative studies that explored the experiences of people with mental illnesses concerning smoking and quitting. The first study, conducted in 2002 by Lawn, Pols, and Barber, involved interviews collected and analyzed using grounded theory with 24 people living in the community who all smoked and had a diagnosis of schizophrenia, bipolar affective disorder, depression, or personality disorder. The authors attempted to make comparisons based on mental health diagnosis. The six themes that arose in their work were: (1) cigarettes as a symbol of control; (2) why quit? despair and hopelessness in the presence of mental illness; (3) smoking as self-medicating illness; (4) smoking for identity/cigarettes as a friend; (5) reinforcement and acceptance of smoking; and (5) quitting beliefs and attempts.

Similar to the results described in this chapter, Lawn, Pols, and Barber (2002) found the participants perceived little hope in recovery, saw cost as a main barrier to NRT use, and noted that their practitioners rarely asked about or mentioned their smoking. Unlike this dissertation research, Lawn, Pols, and Barber also found that the participants saw smoking as part of their identity and as a way to differentiate from family and friends, and viewed smoking and its health consequences as a way to end the despair they experienced. Interestingly, Lawn, Pols, and Barber did not mention that participants attributed their smoking, at least in part, to the role of the tobacco industry, a significant finding from my data.

Esterberg and Compton conducted the second study in 2005. Their study applied

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

the transtheoretical model for smoking behavior to 12 people with first episode and chronic schizophrenia-spectrum disorders who smoke. The themes they uncovered were (1) pros and cons of smoking; (2) beliefs about smoking cessation; (3) external influences on smoking and quitting; and (4) negative attitudes toward nicotine replacement therapies (NRT). The authors also identified two sub-themes: a lack of smoking cessation programs and reinforcement of smoking by significant others. The participants emphasized the many perceived benefits of smoking. They also found that there were differences among those who are “first-episode patients” versus chronic patients. Those hospitalized for schizophrenia for the first time demonstrated less insight into their smoking and had a lower perceived dependence on nicotine. This study’s had a younger group of participants (median age of 25 years) and included only current smokers with schizophrenia.

In concluding, mental health consumers live in a world where they are often forced to give up many rights and responsibilities due to society’s skepticism about their capabilities as a result of their conditions. For many current smokers, cigarettes are seen as an enjoyable choice and a pleasurable distraction from the drudgery and unpredictability of dealing with their mental illness as well as an activity/behavior that they see as having benefits that outweigh its potential risks and other dangers. The former smokers could describe the important influence that tobacco had in their lives and the ways in which their lives changed after quitting. The conversations with nonsmokers suggest that although mental health consumers may live in a world in which their mental

Chapter 3 | The Lived Experiences of Mental Illness and Tobacco Use, Dependence, and Cessation

health is considered central, physical health is also of utmost importance. Many mental health consumers consistently strive for health and wellness. Those trying to quit demonstrated the challenges in thinking about quitting and then actually attempting to do so and the ways in which structural and systemic forces impact their ability to achieve their goal. In the health hierarchy it is evident that some mental health consumers emphasize the other behaviors that they conceive of as being more destructive than smoking. But for many mental health consumers trying to quit, smoking is a true “problem” for which they are ever searching for a solution.

Overall, this chapter has emphasized the lived experiences of mental health consumers who are current, former, or never smokers, and the ways in which the social worlds within and outside of their lives contribute to their tobacco use or non-use. In the next chapter, I will explore some of these issues about smoking among people with mental illnesses from the perspectives of leaders and the media, and the ways in which these perspectives have shifted over time, resulting in the framing and reframing of this important issue. The results described above suggest that messages around control, choice, and normalcy (or being like others and a part of a group) resonate with people with mental illness, and may be useful in encouraging or motivating quitting among some who may be considering it. The experiences of people with mental illness described here also suggest that changes and progress in the mental health field as a result of its new focus on wellness and recovery have not yet brought dramatic changes to the ways mental health consumers see their possibilities for improved health.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

“I think the challenge is getting clinicians and consumers to understand that overall health is an important part of recovery.”

- Mental Health Advocate and Clinician

4.1 Introduction

The previous chapter described mental health consumers’ lived experiences with tobacco use, and the ways people with mental illnesses are affected by the cultural influences of the mental health community and by shifts in social norms around smoking. The chapter also illustrated how consumers interpret and reinterpret messages and their own understandings about tobacco use and its significance in their lives. Chapter 4 explores the experiences of leaders in the fields of mental health and smoking cessation within their various professional worlds as well as the media’s interpretation of this issue.

This chapter will explore the following research questions:

- Why did the mental health community historically overlook the high rates of smoking among people with mental illness and what are the implications for the current public health efforts in the mental health community and smoking cessation field?
- What is the process by which smoking among people with mental illness has come to be seen as a social problem in the mental health community and smoking cessation field?

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

- How does the Partnership construct the issue of smoking among people with mental illness?
- How does the media (specifically, leading U.S. newspapers) frame smoking among people with mental illness?
- What social, cultural, political, and economic factors on the micro, meso, and macro levels are brought forth in the framing of the issue?

This chapter explores shifts that have taken place in various professional worlds including: (1) the smoking cessation field, (2) the mental health field, and (3) the National Mental Health Partnership for Wellness and Smoking Cessation (the Partnership). It also examines how leaders in these fields construct their thinking and messages about the high prevalence of smoking among people with mental illnesses. Over time, each professional world has constructed its own reality about the “problem of smoking” through a process of assessing and reassessing priorities and interests.

Data presented in this chapter suggest that shifts in trends, awareness, and understanding in the mental health and smoking cessation fields have allowed key leaders in the professional arenas with “jurisdiction over the problem” to understand the high rates of smoking among people with mental illnesses as a social problem. These shifts have also paved the way for the emergence of the Partnership and have allowed for a deeper consideration of smoking cessation and its integration into broader policies and practices. Furthermore, the shifts in the mental health community and the smoking cessation field have resulted in the Partnership’s ability to frame the issue of smoking in varied and unique ways. The numerous frames and messages created by the Partnership

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

have resulted in increased education and awareness about this problem among mental health and smoking cessation practitioners, advocates, researchers, and government officials. Yet the Partnership has experienced challenges in constructing and presenting an effective, sensitive, simple, and unifying message that may ultimately hinder the Partnership's ability to successfully promote education and raise awareness about this topic among the general public.

The second half of this chapter presents findings from a frames analysis of newspaper articles related to mental health/mental illness and tobacco/smoking from six leading U.S. newspapers from 1999 to the present, and examine the shifts in framing and messages by the media on this topic. Through this frames analysis, it is evident that there is an overall lack of media attention to the debates about smoking among people with mental illness, benefits and challenges to helping people with mental illness to quit, and personal stories of quitting smoking and relapse. As a result, this “problem” does not appear to have reached the public's consciousness. This chapter concludes with a brief discussion of what these shifts and messages may suggest for the possibilities of a social movement focused on addressing the high prevalence of smoking among people with mental illnesses. This examination of the prospects for a social movement will be explored more fully in Chapter 5.

These data presented here are derived from a variety of sources, including telephone and in-person interviews with leaders in the fields of mental health and smoking cessation, participant observations, and articles published in leading U.S.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

newspapers. The results of analyses of multiple sources of data will be presented in this section based on an awareness that social problems grow and are framed in many diverse arenas (Hilgartner & Bosk, 1988).

I begin by examining the ways in which distinct shifts in the fields of smoking cessation and mental health have paved the way for the issue of smoking among people with mental illnesses to reach the attention of national leaders in these fields. I then describe the shifts that have taken place within the National Mental Health Partnership for Wellness and Smoking Cessation, and the ways in which the Partnership has served as a catalyst for innovative messaging and activities that address the smoking cessation needs of people with mental illnesses.

4.2 The Smoking Cessation Field

The smoking cessation field, according to several smoking cessation advocates and providers, is sometimes considered the long-ignored stepchild of the larger tobacco control movement. Schroeder and Morris (forthcoming) argue that there is a “false dichotomy” between those who focus on public health approaches to prevent the initiation of tobacco use and those who advocate for clinical approaches to helping people quit, and that efforts both to reduce initiation of smoking and to stimulate cessation are necessary. Tobacco control efforts have been extremely successful in reducing the smoking rates in the U.S. through policies such as increases in tobacco taxes

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

and ordinances requiring smoke-free public places (Brandt, 2007; Warner, 2006). The tobacco control movement has also helped to raise awareness of the tobacco industry's deceptive marketing tactics and has led to efforts to counteract the industry's messaging including successful prevention campaigns aimed at young adults (Brandt, 2007; Warner, 2006). These shifts and developments in the tobacco control field have eroded the social acceptance and tolerance of smoking and denormalized tobacco use resulting in its ultimate stigmatization. Many people have quit or never started smoking as a result of these strategies ((Fichtenberg & Glantz, 2002; Schroeder, 2005; Slama, 2004; Warner, 2006). In conjunction with these successful efforts, the smoking cessation field has raised attention to the treatment needs of those who currently smoke by developing pioneering and effective ways to help smokers quit (Fiore et al., 2008).

Tobacco control and smoking cessation advocates and providers have long maintained the goal of reducing the smoking rate in the United States to its lowest possible level to promote the public's health. Even when divided, tobacco control and smoking cessation are unified in that they each consider tobacco use to be a significant social problem worthy of attention and resources. With the large decrease in the rates of smoking over the last several decades has come the realization that there has been great success in reducing smoking among many Americans, but that some populations may not have been reached by traditional cessation and prevention strategies. For instance, the Lasser et al. (2000) study raised awareness among leaders in tobacco control and smoking cessation that people with mental illnesses consume a disproportionate amount

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

of cigarettes and comprise nearly half of the tobacco market.

As a result of this knowledge, and its track record in encouraging cessation among varied groups, the Smoking Cessation Leadership Center (SCLC) received funding from the American Legacy Foundation to focus its attention on addressing the high rates of smoking within the mental health community. The availability of new resources and the creation of a network of like-minded individuals interested in this issue created a more concerted and intensive effort by advocates in the smoking cessation field to examine and address the needs of this population.

It was long assumed that people with mental illnesses could not stop smoking because of the complexity and severity of their mental health concerns and the plausibility that smoking may provide benefits, such as relief of symptoms by self-medication, to people with mental health problems. Yet advocates and providers in the smoking cessation field were encouraged, based on research and clinical experience that provided evidence of mental health consumers' motivations for quitting (CDC, 2000; Lucksted, McGuire, Postrado, Kreyenbuhl, Dixon, 2004; Prochaska et al., 2004; Tsoh & Hall, 2004) and their abilities to quit (Baker et al., 2006; el-Guebaly et al., 2002b; Schroeder, 2009), to find ways to address the specific (or perhaps not so specific) needs of this population.

Many smoking cessation providers and advocates noted in their interviews, for example, that they have learned the importance of being flexible with regards to their expectations about quitting and when necessary, modifying existing models of care when

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

working with people with mental illness. In the words of a smoking cessation advocate, the smoking cessation field has learned to move beyond a one-size-fits-all model to explore the possibilities of tailored interventions to break down existing barriers to treating people with mental illnesses:

Well, I think what I would put my finger on from the tobacco control side is what I think we've done is sort of artificially constructed a barrier for people with mental illness. By that I mean that we've over time developed a certain set of expectations based on our literature and based on different research findings about the best way to provide treatment for people. That may be too inflexible for people with mental illness.

This smoking cessation advocate then described a valuable lesson that she learned in adjusting her expectations and in learning to be more patient:

So I think if there's a lesson learned it's how to adjust what we think we know to make it work better and to not become so impatient with people with mental illness, to really see it as a long-term process and be willing to invest that time and effort over a longer period of time. I think we just have gotten into this kind of "hurry up" clinician model and that's just not going to be sufficient for a lot of people with mental illness. I would say that's certainly something that I've learned and connected to that is that we're not talking about a completely different model, we're talking about something that's just more flexible and can suit the pacing of people with mental illness more appropriately.

These comments suggest that smoking cessation leaders and advocates have started to examine their own approaches to helping people quit and have begun to consider potential modifications to meet the unique needs of people with mental illnesses. A reexamination of some of the traditional approaches has allowed for an increased awareness about what works in helping mental health consumers to quit and an appreciation of the significance of quitting for this population in improving health and

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

raising hope.

4.3 The Mental Health Field

Changes in the social, cultural, and political climate in the United States have resulted in significant changes in the mental health field. Yet the two major shifts that have had perhaps the greatest impact on improving the quality of life and sense of well-being for people with mental illnesses in recent decades are (1) the focus on recovery as a result of the 1999 Surgeon General's Report on Mental Health (USDHHS, 1999) which spread the message that people can recover from mental illnesses, and (2) the focus on physical health, wellness, and access to primary care services as a result of the awareness of the 25-year gap in longevity for people with mental illnesses compared to those without these conditions. The first shift, from a focus on symptom management and maintenance to one of recovery, has helped address the intense stigma that has long permeated the mental health field, and has enabled mental health providers to widen their focus to be mindful of mental health consumers' hopes and desires for the future. Simultaneously, the second shift, from a focus exclusively on mental illness to one that focuses on overall physical health needs has enabled an understanding that people with mental illnesses, like people without mental illnesses, can and should strive to lead physically and mentally healthy lives.

Leaders in mental health described how these shifts have created a sense among

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

mental health providers, advocates, family members, and consumers that the person with mental illness is no longer doomed to lead “an eternal life of misery,” but that people can learn to manage their illness, recover, and live a long and fulfilling life. A mental health government official called this new awareness an “important breakthrough” and “an important milestone” because of the sense of freedom and emancipation it produces in the mental health community.

Well, if that’s the case, then this individual is not doomed. And not doomed to live a life that’s on the margins. And you know, that’s part of the rationalization for smoking “well, they’re doomed anyway, so what does it matter anyway because they’re doomed to be suffering from this terrible illness all of their lives.” Well that’s changed now...we no longer look at mental illnesses as the domination for an eternal life of misery but that they are diseases that can be treated successfully and that with proper supports people can live fully a life that they choose. And I think that sense of control and that sense of emancipation from the death sentence of mental illness, which was really the way I looked at it, really helps us to free out the power of the mental health community to say, “We’re not in the business of just maintaining or sustaining people anymore. We’re in the business of helping them to improve their quality of life.” That’s a nice shift.

This shift she describes is, in essence, a change in the social construction of people with mental illnesses and mental illness in general. Mental health consumers have long been rejected by society and considered doomed to endure a lifetime of suffering and misery given the severity of their illnesses and the complexities in treating these conditions. As a result, while people with mental illnesses have long been the objects of intervention and control, there has now been a shift to helping people with mental illnesses to conceive of a life with increasing freedom, possibility, and hope. This also

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

suggests a shift in the social construction of the mental health field and what it means to be a mental health practitioner. Mental health clinicians historically held the role of arbiters of deviance rather than as those that can transform and cure. This shift then holds the potential to disrupt the deeply engrained power dynamic that has long existed between practitioners and clients since clients are now able to conceive of a life in which they are no longer the “other” or perpetually perceived of as “different.”

At the same time, the new focus on physical health, wellness, and access to primary care allows for, and in many ways *calls* for, an integration of the mental health and physical health arenas. One mental health clinician questioned the seemingly arbitrary and artificial division between mental and physical health that has been reinforced throughout the years:

Mental health has been separated from physical health care forever. Psychiatry was the first medical specialty with asylums in the 1830s. We've always had a separate payment system. We have a separate mental health system at the state level where I work. You don't have an arthritis or diabetes department but you have a department of mental health, why? Why aren't we the same as other health care?

Moreover, as this mental health clinician states below, the discovery that the leading causes of death for people with mental illnesses are respiratory and heart diseases rather than suicide (which is typically considered the one cause of death *directly* related to mental illness) serves as a wakeup call to the mental health field that it has misplaced its focus and that new collaborative relationships may be necessary:

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

I think we have data right now that say people with serious mental illness are dying 25 years before they should and respiratory and heart diseases are the two leading causes, not suicide. And once you see that, you ask what's the role of smoking here and what can you do about it? It's not that different from heart disease and lung disease and I think we just haven't partnered that way and we should be.

There has long been “a glaring, unacceptable disparity” (Manderscheid, Druss, & Freeman, 2008, p. 50) in longevity for people with mental illnesses compared to the population overall. But the substantial worsening of this disparity in the last two decades from 15 to 25 years has escalated interest in this area (Colton & Manderscheid, 2006; Lutterman et al., 2003; Parks, Svendsen, Singer, & Foti, 2006). According to a mental health advocate, the awareness of this premature mortality helps to promote wellness as “[as] relevant for a person with severe illnesses as it is for a person who has no health conditions at all” and provides a platform on which to critically examine the multiple ways people with mental illness are unjustly discriminated against.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

The 25 years of premature mortality is a perfect foil to, number one, bring the mental health community together, which has been divided over some issues, because no one is for death, and to get us pointed sort of in a similar direction. From our perspective it also provides this platform that can talk about wellness as being as relevant for a person with severe illnesses as it is for a person who has no health conditions at all. Number two is that a lot of the elements that are involved in promoting wellness overall are also elements that are consistent with things like smoking cessation and the reduction in the use of tobacco in the general population. So the things that promote ordinary general health are often the same things that promote mental health and that the avoidance of harmful behaviors, whether they be addiction to nicotine or overeating or inactivity or all of the things that are thought of as drivers of poor health is a powerful platform to normalize mental health as part of general health. So we think it's a powerful position to come from, that it in fact integrates mental health concerns with general health concerns in a way that normalizes discussions of mental health, which is very helpful for dealing with a poorly understood condition that is discriminated against in several different ways, and that issues of wellness are relevant across a full platform from people with mental illness through people with severe mental illnesses.

The statement that “no one is for death” serves as an astonishing reminder that the mental health field and society at large have long overlooked the disparities in morbidity and mortality that exist for people with mental illness. While “no one is for death,” it must be recognized that there were decades of inactivity and inattentiveness to important health issues that are well-recognized causes of premature death. This statement also suggests that the focus on overall health provides a critical opportunity for collaboration. Finally, this mental health advocate notes that a shift to “normalize” conversations about mental health serves to educate the general public about mental illness and ultimately reduce the stigma associated with it.

The fact that smoking contributes to morbidity and mortality has been recognized

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

for 45 years; nevertheless, the mental health community initially did not identify tobacco cessation as a target of efforts to promote wellness and recovery. Before the development of the Partnership, efforts to address the health disparities for people with mental illnesses centered on weight management including proper nutrition and adequate exercise. The summit that led to the establishment of the National Mental Health Partnership for Wellness and Smoking Cessation allowed smoking cessation advocates to assist mental health leaders in making the connection that tobacco use is both a substantial problem for people with mental illness and a major contributor to these health disparities.

In the interviews, mental health leaders attributed the slow growth of their awareness and actions regarding smoking to the historical acceptance of tobacco use within mental health settings, such as the use of cigarettes as a reward for good behavior. Yet the mental health leaders expressed appreciation and enthusiasm for the Partnership and its members in helping them to become aware of the problem of smoking and the importance of tobacco cessation to the population they serve. In the words of a mental health government official, “that smoking cessation is part of recovery and part of wellness. I wouldn’t have thought about it. It’s a huge change and a huge shift.”

4.4 The National Mental Health Partnership for Wellness and Smoking Cessation

While the social problem definition of smoking among people with mental illness within the smoking cessation field and mental health community is worthy of note, “the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

existence of social problems depends on the continued existence of groups or agencies that define some conditions as a problem and attempt to do something about it” (Kitsuse & Spector, 1973, p. 415). As a collective entity, the National Mental Health Partnership for Wellness and Smoking Cessation, according to its leaders, has played an important, if not essential, role in elevating the issue of smoking among people with mental illnesses to problem status.

Although there existed intense political pressure to stay out of the area of mental health given the deeply engrained cultural and social role tobacco plays among this population, the separation of the mental health field from the rest of health care, and the challenges of working with people with serious mental illness, the SCLC added mental health to its growing list of interests in 2006. The SCLC was motivated to act on this issue because it believed that the statistics and continued high rates of smoking in this population warranted that mental health become a central focus of their work. As mentioned, this interest in working with the mental health community was reinforced by a sizeable grant from the American Legacy Foundation, a foundation committed to tobacco control and smoking cessation efforts and campaigns.

As mentioned, to guide its entry into this unknown territory, the SCLC hired Gail Hutchings, a former chief of staff for SAMHSA who now leads a private consulting firm, to serve as a strategic consultant. The SCLC and Gail decided that a first step was to “have the right players in the room” to talk about tobacco use and mental health and to decide what could be done to address this issue. Gail and the SCLC staff chose leaders in

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

the mental health and smoking cessation arenas, as well as leading organizations that were invited to send a member, based on the leaders'/organizations' visibility within their respective fields and the likelihood of their becoming involved in addressing this issue. These key leaders in mental health and smoking cessation were invited to participate in the initial summit in Virginia in late March 2007 where the National Mental Health Partnership for Wellness and Smoking Cessation was born.

During the interviews, many of the leaders in both mental health and smoking cessation noted that the opportunity for interdisciplinary collaboration was the most unique and noteworthy element of the Partnership given that the mental health field has been considered and has thought of itself as separate from broader health care issues for so long. Given this separation, and the resulting lack of awareness about the issues in other fields, the leaders felt that the Partnership provided them with the necessary credibility and legitimacy to talk about, examine, and address this issue. A smoking cessation advocate, for example, commented that she felt confident in moving forward knowing that she was working in a collaborative arrangement, because if people said, "You don't really understand our issues," she could quickly respond saying, "No, I don't understand your issues, but I am working with people who do."

Overall, the leaders felt that the Partnership itself, as a collective of influential individuals and organizations in mental health and smoking cessation, had not yet created great change in how the issue of smoking among people with mental illnesses is addressed in a broad, systematic way. Yet they felt strongly that individual organizations'

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

initiatives, generated by the Partnership and the support (financial and otherwise) of the SCLC, had created shifts in the way this issue is understood and addressed among particular organizations and provider groups. Leaders also noted that the new resources and support that existed as a result of the Partnership also led to a dramatic increase in discussions and presentations on this topic at local, state, and national conferences and meetings and a proliferation of initiatives, tools, and resources to assist people with mental illnesses, providers, and peers with smoking cessation. Thus, while it seems too early to tell whether these changes will result in a dramatic reduction in the prevalence of smoking in this population and an ultimate increase in the number of lives saved, all of the leaders felt that the Partnership was moving in the right direction.

In order to foster this historic collaboration between the smoking cessation and mental health fields and to quickly achieve buy-in and support from both fields, the Partnership, led by the SCLC, worked to develop unique frames and messages that resonated with the Partnership members (and potential members) and that helped motivate and mobilize the Partnership members (and potential members) to act on this issue as a social problem worthy of their time, attention, and resources. Menashe and Siegel (1998) define a frame as “a way of packaging and positioning an issue so that it conveys a certain meaning” (p. 310), such that framing defines the issue and suggests the solution (Menashe and Siegel, 1998). According to Scheufele (1999), the term “framing” has been used to label similar but different approaches. Scheufele describes how frames can be seen as either dependent (where various extrinsic and intrinsic factors influence

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

the production and selection of news) or independent variables (which have an impact on attitudes, opinions, or individual frames) depending on the study design. The interview and observational data suggest that while the Partnership has been extremely successful in developing numerous messages that resonate with its current and potential constituents, it has not yet been able to develop a single unifying message that successfully frames this issue as important for those individuals and organizations outside the mental health and smoking cessation fields.

4.5 Framing of Messages Focused on Smoking Among People with Mental Illnesses

The Partnership has tried since its inception to develop and/or select simple and effective messages, using the appropriate language and frames, which resonate and have salience with the Partnership members/organizations and other potential constituents, such as mental health consumers and staff. These messages and frames manifest themselves in highly visible and less visible ways. For example, the SCLC has outwardly incorporated some of these messages into a communiqué that is regularly distributed to the Partnership members and others who have expressed an interest in keeping abreast on developments related to mental health and smoking cessation. These messages have also been incorporated into new materials and resources. One message that has been a particularly visible component of the Partnership is “tobacco free for recovery” which is intended to remind mental health consumers, family members of people with mental

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

illnesses, providers, advocates, and government officials that ending tobacco use is a critical factor in achieving recovery from mental illness.

4.6 Message Frames and Challenges in Developing Messages

Yet a recurring theme throughout the interviews and participant observation was the need for “better messaging and messages.” The Partnership and its members, including the SCLC, recognize the importance of these messages in framing smoking among people with mental illness as a social problem and a priority issue. In my research, I uncovered 12 distinct areas around which messages and frames on this issue have been constructed for various target audiences including mental health consumers, family members, providers, and government officials. However, while it is essential to construct messages that have salience for various stakeholders, it appears that the sheer number of messages poses challenges for reaching the broader health field and the general public who must also be aware of the health disparities experienced by people with mental illness if real change in the health, well-being, and social position of mental health consumers is to take place. Given the number of priorities vying for the public’s attention, a single, unifying message may be necessary to engage the broader health field and the general public.

The 12 areas in which messages have been developed (listed here in no particular order) include: (1) making sense of the language and cultural differences between the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

mental health and smoking cessation fields; (2) acknowledging a history of acceptance and endorsement of tobacco use in this population; (3) identifying the numerous and complex factors that leaders have identified as contributing to the high rates of smoking among people with mental illnesses; (4) understanding and incorporating consumers' viewpoints and perspectives; (5) addressing the high rates of smoking among staff, and also addressing provider misconceptions about smoking and the importance of quitting; (6) determining the role of quitlines (toll-free phone numbers that people can call to receive smoking cessation information and support) in helping mental health consumers to quit; (7) challenging and reframing rhetoric around tobacco as legal, tobacco use as a right, and smoking as a choice; (8) recognizing successes of and controversies around smoking bans; (9) understanding the realities of mental health consumer challenges in quitting and the limited number of success stories; (10) discovering ways to sensitively (yet collaboratively) address tobacco use; (11) recognizing failure to address this issue as discrimination, and providers' and advocates' responsibilities to change this; and (12) finding alternatives to smoking.

The analysis below demonstrates what has worked in motivating constituents to care about and take action on this issue, and why these arenas may pose challenges to broader framing and to social movement development. Overall, it is noteworthy that structural and policy issues may be currently overlooked or underplayed by attempts to frame smoking among people with mental illnesses as a social problem.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

4.6.1 Making Sense of the Language and Cultural Differences Between the Mental Health and Smoking Cessation Fields

A formidable challenge in creating an effective message to frame action and engagement with this issue concerns the use of language. The leaders in the smoking cessation field expressed concerns and anxiety about their choice of words. This was based on a recognition that the mental health field is sensitive in regard to the language it uses to describe people with mental illnesses and its understanding that this language is a reflection of the distinctive culture of the mental health community and mental health settings.

For example, this issue of language was evident during the summit when a mental health and smoking cessation researcher and clinician presented her research on the targeting of people with mental illnesses by the tobacco industry. During her talk, she used the word “schizophrenics” and was then subsequently confronted by several mental health leaders for using that term rather than the preferred phrase “people with schizophrenia.” The mental health leaders cautioned that her important work would be criticized or overlooked because she unknowingly used language that was deemed inappropriate by the mental health community. As another example, smoking cessation providers often refer to the person they are assisting in quitting as their “patient.” Yet, as mentioned previously, the word patient is avoided in the mental health community generally in favor of identifiers that are associated with empowerment such as “consumer,” “survivor,” or even “client.”

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

A leader in smoking cessation noted, “I think one of the important lessons you can derive is that there’s a huge language barrier here and that people step in mine fields without knowing that they’re there.” This is because the proper words and phrases to describe the mental health community change frequently and there exist inconsistencies and differing viewpoints about the “right” language to use at any given point in time. While the smoking cessation leaders truly wanted to use the appropriate language to connect with those in mental health, they found it difficult to talk freely about this issue without saying something unintentionally offensive or discriminatory. As a result, concerns over different uses of language, and the language as a reflection of the distinctive culture, permeate the other issues described.

4.6.2 Acknowledging a History of Acceptance and Endorsement of Tobacco Use in Mental Health Settings

Participants noted that tobacco use has historically been, in the words of a mental health advocate, “overtly and covertly” supported within mental health settings as a short-term fix for behavior management, as a reward used to encourage positive behaviors, and as a means for promoting communication and socialization between consumers and providers. In both inpatient and outpatient settings, participants suggested that smoking has been and continues to be endorsed as a meaningful and enjoyable activity and is considered to be one of the “last pleasures” for mental health consumers. In fact, the participants revealed that they were aware of numerous stories of mental health consumers who had first started smoking upon entry to an inpatient psychiatric

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

facility. With this realization of the important historic role of tobacco, the SCLC and the Partnership have been careful to ensure that the framing of this issue does not blame individuals or groups, but instead raises awareness about this unhealthy practice and suggests that changes in cultural practices that denormalize tobacco use are possible.

4.6.3 Identifying the Varied and Complex Factors Resulting in the High Rates of Smoking

One challenge uncovered in framing messages on this “problem” is that individuals and groups hold differing ideas, or what Stone (1989) calls “causal stories,” about the reasons for the high rates of smoking among people with mental illnesses.

While the focus of messages about tobacco use among people with mental illness is not solely on the cause of the high rates of smoking in this population, the conflicting opinions about its cause result in different and sometimes inconsistent solutions for addressing it.

The leaders, many of whom first acknowledged that multiple factors play a role in contributing to the high rates of smoking in this population, focused largely on the social and cultural factors that they believe contribute to the disproportionate rates of smoking in this population during their interviews. The factors cited by the leaders included: provider biases, the perceived effectiveness of cigarettes as a mechanism for managing the stress associated with living with a mental illness, the encouragement of tobacco use by mental health advocacy groups, and the persistent belief that smoking can be beneficial for this population, among others. These social and cultural factors caused

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

people to overlook tobacco use in this population as a “problem.” In some cases, in fact, tobacco was itself seen as a solution. For example, many mental health leaders acknowledged that smoking was an effective means for managing difficult behaviors among people with mental illnesses. Although it was relatively uncommon, it should be noted that some leaders believed there are biological reasons for the high rates of smoking among people with mental illnesses, including biochemical predispositions, neurobiological benefits, genetic vulnerabilities, and tobacco use as a form of self-medication. While the literature and the leaders suggest it is likely that a combination of factors account for the high rates of smoking among people with mental illnesses, the reasons the leaders provided elucidated their own causal stories about this “problem” and the various corresponding solutions available to address it.

4.6.4 Understanding and Incorporating Consumer and Peer Perspectives

Some of the leaders expressed that an increased awareness now exists among mental health consumers about the importance of wellness. This awareness has been demonstrated in an increased demand among mental health consumers to learn about healthy living, to receive information about quitting, and to become more broadly educated about their health-related choices. Mental health consumers themselves bring unique perspectives to the understanding of tobacco use in this population and yet many of the leaders were not aware of what people with mental illness actually think about tobacco. While mental health consumers are in support of the shift to recovery and

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

wellness, bigger questions remain about whether their needs and experiences, as the implicated actors of this initiative, are being clearly understood and incorporated into messages and efforts initiated by the mental health and smoking cessation fields and the Partnership.

Participants also noted the important role of peers in addressing tobacco cessation in the mental health community. As individuals who also have a history of mental illness, the leaders said that peers could provide invaluable support and information based on their own experiences of wellness and recovery that can serve as “medicine for somebody else.” Many participants noted that, while it can be extremely valuable for a practitioner to suggest that a consumer quit smoking, the message is particularly effective when it comes from a peer who has experienced quitting and who “can speak...without the taint of authoritarianism.” Paid roles for peers are becoming increasingly available in mental health settings, and in some states, such as Georgia, Medicaid will pay for services provided by peers who complete a training program and examination (Georgia Certified Peer Specialist Project, n.d.). One participant emphasized that the experience of helping others can also promote continued growth and recovery for peers:

It’s like a win-win situation for both groups. Nothing more clearly represents success than success. And in people who have mastered it and done it themselves, there’s hope and possibility there and if you’re taking on a tough challenge, hope and possibility are a pretty important part of the mix.

Participants mentioned numerous opportunities for mental health consumers to be involved in efforts around tobacco cessation including: encouraging providers to be

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

supportive of and educated about cessation efforts, becoming actively involved in national and local advocacy initiatives to address tobacco use in this population, promoting recovery and wellness within mental health settings, providing information in support of quitting and smoke-free facilities, and in sharing their extremely powerful personal stories.

Consumer advocates speak from a uniquely powerful position because it's kind of "I've walked the walk, I've been there, and are able to talk about," hopefully, the benefits of not smoking, their own fears and what maybe were barriers and how they were able to kind of work through some of that and now are at a different place. I've never smoked but I mean it's a lot harder for me to say, "Gee, I understand. Trust me, you'll be glad in the end," and all that kind of thing. In our office we have two people who are long-term consumers and they're at different stages, the one person has not smoked for seven years after probably smoking for virtually his whole life and the other person is currently once again trying to stop smoking. It's just so powerful to talk with them about what it's like. If I were a consumer and if I were struggling with the same issues I'd go right to them because they can tell it all, their experience with interacting with medication, and it's a very powerful story.

Although it is common for mental health providers to have had the experience of living with a mental illness (this is considered to be "one of the hidden secrets of many mental health care providers, [though] they may not be officially 'out' about it as that themselves"), one leader discussed how mental health providers often try to differentiate themselves from their clients. Peers, on the other hand, make it their goal to relate to one another and to share experiences.

The mental health leaders noted that peers already play an important role in breaking down stereotypes and leading cultural shifts in mental health settings. In the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

words of one participant, peers “are not remote administrators making these abstract policy decisions, they’re human beings who’ve been through this and they’re credible in a very important way...So I think the more they’re involved, I think the more active everybody will be.” While peers have only assisted in supporting smoking cessation in a limited capacity thus far (most notably through the CHOICES program in New Jersey described below), a mental health advocate said:

We’ve found that in recovery in general that people do better with the involvement of peers and certainly the support of family and friends. We have found that we have higher success rates and lower costs, so I think we would have the same thing in regards to smoking cessation when we involve peers...

Overall, the leaders expressed hope that peers might lead the way in efforts to reframe smoking cessation as integral to wellness and recovery. According to a mental health and smoking cessation researcher:

The peer-to-peer culture is understanding that this is killing them. And, you know, there’s been a lot of recent attention among consumer movement groups that this is an issue they need to tackle. I see this locally too. Whether it’s clubhouses, drop-in centers, and so forth, opinion leaders among consumers are changing that flavor of that whole culture right now.

Peer programs developed specifically to help people with mental illness to quit smoking are emerging. An example is Consumers Helping Others Improve their Condition by Ending Smoking (CHOICES) in New Jersey. The CHOICES program employs mental health peer counselors as Consumer Tobacco Advocates who receive intensive training on how to address tobacco use among their peers (CHOICES, n.d.; Williams, 2007). The SCLC also recently collaborated with Rx for Change to create a

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

peer training program, *Tobacco-Free for Recovery: Assisting Mental Health Consumers with Tobacco Cessation* (Rx for Change, 2009).

4.6.5 How Providers are Implicated: Addressing the High Rates of Smoking Among Staff and Also Addressing Provider Misconceptions About Smoking and the Importance of Quitting

The high prevalence of smoking among mental health providers is presented as another challenge and another ground for messaging. The rates of smoking among mental health practitioners and staff are considerably higher, at 30 to 35% (NASMPHD, 2006), than the 20% prevalence in the general population (CDC, 2008) and the prevalence of under 6% found among primary care physicians, emergency physicians, dentists, dental hygienists, and pharmacists (Strouse, Hall, & Kovac, 2004). The high rates of smoking among staff have been attributed to many factors including the cultural role of tobacco in mental health settings, the lower socioeconomic status of some mental health providers, and the fact that many mental health providers and staff also have personal experience with mental illness. Leaders talked about the importance of “flagging this as an issue.” A mental health advocate noted:

I think the clinicians and staff have to recognize the role that they’re in. They have to model similar behavior and they have to understand it takes a toll on them too and their habits take a toll on those they are serving. There’s a symbiotic relationship there.

At the same time, several participants noted that bias (or more appropriately prejudice and discrimination) among mental health providers in regards to people with mental illness continues. Leaders noted that is common for providers to think, “these

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

folks are predisposed to smoking, you can't get them to quit, and there's so much going on in their lives, you shouldn't worry about it," and as a result, providers do not attempt to pursue conversations about tobacco use. Thus messages need to challenge the myths among providers and stress the possibilities for cessation for those they serve, given the increasing availability of new literature and data suggesting that, while they may need additional help to quit, people with mental illness are able to quit smoking.

For instance, many of the leaders who are clinicians mentioned that after merely asking about tobacco use, they were surprised to learn that many mental health consumers "who they never would have dreamed were interested" were actually thinking about or trying to quit. Therefore, a mental health clinician noted that providers may benefit from simply talking with and modifying their expectations for their clients, because "if you expect that somebody can make changes and try to provide opportunities for people to make those changes, you can be surprised in what people decide to do." This demonstrates that provider support in education and quitting and a provider's own construction of the problem can have real implications for how providers approach their clients and disseminate messages about cessation.

4.6.6 Determining the Role of Quitlines in Helping Mental Health Consumers to Quit

Within the smoking cessation field, the SCLC is known for its ability to develop simple, concrete, and doable messages that spread a sense of hope and possibility about people's ability to quit and providers' ability to assist individuals in doing so. The SCLC

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

has incorporated into its messaging the ease with which providers can refer patients to the national toll-free quitline, 1-800-QUIT-NOW, where people who use tobacco can receive free, confidential information on quitting smoking.

Yet the SCLC and the Partnership have been faced with the challenge of determining whether the quitline is a sensitive and appropriate source of referral for people with mental illnesses or whether this message might require some redesign for this population. Leaders expressed both strong and conflicting views about the role of the quitline in helping people with mental illnesses to quit. Research on this issue is currently underway, but at the time of the interviews, it was known that many people who call the quitline have some form of mental illness (often depression), though it remained unclear how appropriate the quitline and the training provided to the quitline staff were for addressing this population. Since completion of the interviews, unpublished data from the California Smokers' Helpline (the state of California's quitline), which will be described below, have demonstrated that people with mental illnesses can and do quit smoking at rates nearly as high as those without mental illnesses.

Some leaders, specifically those in the field of smoking cessation who were more familiar with the specifics of the quitlines, felt that the answer to the question of whether the quitline would work for this population depended on what state the provider and consumer resided in and the degree to which the underlying mental illness was stable versus acute. While there is one national telephone number, callers are immediately routed to the quitline in their state, and there are differences in the resources and level of

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

preparedness of the various state quitlines for handling the needs of diverse populations of smokers (Morris, et al., 2009).

Mental health history is relevant because people with mental illness may require higher doses of nicotine replacement therapies (NRT), longer durations of pharmacotherapy, or the use of combination treatments (Fiore et al, 2008; Morris et al., 2009). Yet people with mental illness are not necessarily aware of the relevance of their mental health status to their smoking and are not likely to present this information unsolicited at the time of the call to the quitline.

While some participants felt that additional training for quitline staff on mental illness could translate to “a whole cadre of individuals to deal with this population over the phone,” others expressed that they would prefer that the information be provided face to face for this population. According to a smoking cessation advocate and provider:

[People with mental illnesses] see a counselor every week. They have a relationship with that person. So my preference for a first line of counseling is to integrate that into their treatment. They’re really familiar with the face-to-face interaction. They know the person. That would be my preference and then to have the quitline as a backup.

Such a protocol would require the continued education of providers and the development of messages that reassure providers that supporting tobacco cessation is an appropriate and effective use of their time and energy.

On the other hand, many of the mental health leaders were only “marginally aware” of the existence of state quitlines and their purpose. In general, the mental health leaders expressed skepticism regarding quitlines’ ability to provide support in quitting for

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

this population, although several leaders recognized that a toll-free suicide prevention hotline that provides support to people in crisis has been effective for this population.

The dominant concern presented by the mental health leaders was that:

Our clients present problems that are beyond the scope of the quitline counselors' repertoire to intervene. Sometimes they are psychotic, sometimes they are paranoid, sometimes they are confused, and sometimes they are terribly terribly depressed. They tend to be on complex psychotropic medication regimens.

While it was acknowledged that many people with mental illness already call the quitline (100% of quitlines take calls from people with mental illnesses) and studies have found that the rate of mental illness among quitline callers ranges from 20% to 33%, (Morris et al., 2009) some leaders felt that calling a quitline may actually be a self-selecting process wherein people who make the call may have higher levels of functioning than those who do not. Therefore, the quitlines may be able to serve the needs of those who are capable of making the call for assistance in quitting, but may be unable to provide the necessary help to those whose disabilities impair their ability to use this service. This framing could alleviate some mental health leaders' concerns about whether the quitline should be promoted among mental health practitioners as a source of referral for people with mental illness who want to quit. Overall, while messages around tobacco use targeted at providers often suggest that the provider, due to time and other constraints, should refer clients to a quitline or other resource, the uncertainties about the appropriateness of the quitline for this population raises important questions for messaging and framing. If not to the quitline, where should busy mental health providers

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

and clinicians refer mental health consumers who want to quit? And if there are no reliable sources of referral for this population, how can the providers themselves get the information they need to be supportive in this process?

In May 2009, approximately 1.5 years after the interviews with leaders in the fields of mental health and smoking cessation were completed, staff from the California Smokers' Helpline reported that they were documenting the numbers of people with mental illnesses who called the state quitline. They found that nearly half (48.9%) of the callers had some form of mental illness (36.9% had depression) based on the question "Do you have any current mental health issues such as: an anxiety disorder? Depression? Bipolar disorder? Schizophrenia? Drug or alcohol problem?" The California Smokers' Helpline found that more people with mental illness who called the quitline (56.4%) actually attempted to quit smoking than those who did not have mental illness (53.1%), and nearly the same percentage of people with mental illness had quit smoking at two months (19%) and compared to those without mental illness (20.8%). They concluded that smokers with mental illness call the quitlines in high numbers and appear to be more motivated than smokers without mental illnesses. They concluded that the motivation and use of treatment by people with mental illnesses seems to compensate for any vulnerability associated with their mental health condition (Tedeschi, 2009).

4.6.7 Challenging and Reframing Rhetoric that Focuses on Tobacco Use as Legal, Tobacco Use as a Human Right, and Tobacco Use as a Choice

Some leaders noted that mental health consumers do not see smoking as a

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

problem because they feel they have the “right” to smoke because tobacco use is legal in the United States. Many leaders expressed strong reactions to this way of thinking. A mental health clinician said:

It’s not a human right to use cocaine. And I know that tobacco is legal. I understand that. But, you know, it kills you. And we’re *health care providers*. I do think we need to try and see if we can look at it in a different way. The right to smoke and its infringing on human rights is an issue.

Many participants also described the ways in which smoking is conceived of as exercising choice among mental health consumers. In the current recovery-oriented system that focuses on person-centered treatment planning, a mental health clinician described the dilemma that providers face in encouraging cessation while also empowering people with mental illnesses to make their own choices. Although this may be an issue for all smokers, it is particularly relevant for people with mental illness who may feel that their options are limited.

As we try to be very much more recovery-oriented, respecting the rights and desires of the consumer, I think that becomes somewhat a two-edged sword when clearly the rights and preferences of the consumer are to not stop smoking. We can’t kind of play it both ways. We can’t say, “You are the master of your treatment plan but we will tell you in this one area that you absolutely have no say.”

This statement by a mental health clinician highlights the need for providers to be careful about not imposing their views or using their authority to make their clients feel as though they have no say. Similarly, a mental health government official explained why the expression of personal liberties and the protection of rights are vital within the mental health community:

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

I think an additional complication is that there has been a historic [pause] problem with authoritarianism in mental health in which people have felt like they're sort of being pushed around, hospitalized against their will, that kind of thing. So there's a certain claim that smoking is a personal liberty and that it shouldn't be taken away from people and it's a matter of personal choice. I think that that argument gets caught up in the symbolism of the previous tendency for mental health professionals and systems to be too authoritarian. So we have to figure out how to disconnect the notion that we're promoting people's health and wellness from the idea that we are, in fact, intruding on people's rights.

Not surprisingly, the tobacco industry has long used complex tactics and strategies to construct tobacco use as a human right, a personal liberty, and a choice (Dreskler & Marks, 2006; Prochaska, Hall, & Bero, 2008). Evidence suggests that the tobacco industry has been instrumental in promoting the legality of cigarettes and smoking as a human right (Smith & Malone, 2007). Thus, while the leaders do express these issues as real barriers to addressing cessation among people with mental illnesses, it must be acknowledged that these ways of thinking about smoking are actually a result of the marketing schemes used by the tobacco industry that have been “sold” to those who smoke as a rationale for their “chosen” behavior.

Several participants suggested that the challenge lies in reframing tobacco cessation rather than tobacco use as the choice to be made. Participants suggested that advocates and providers could offer mental health consumers an outline of their potential choices regarding their tobacco use so that they do have a say and simultaneously “change the system so that people have other options [beyond smoking].” Thus, rather than constructing tobacco as an expression of a human right and personal liberty,

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

messages can be created that emphasize the promotion of health as a mechanism for achieving these values.

4.6.8 Recognizing Successes and the Controversial Nature of Smoking Policies or “Bans”

Smoking policies are developed and enforced with the goals of protecting the health of people with mental illnesses and staff, encouraging cessation, and treating smoking as an addiction. In the words of a mental health advocate:

As it becomes harder and harder and there are fewer and fewer places to participate in this behavior that, in fact, does promote people quitting in a very important way and the social stigmatization can also be a powerful part of that.

Although it was initially expected that these policies banning smoking would increase behavioral problems among people with mental illnesses and would contribute to a greater need for patient seclusion and restraint, the leaders and the literature (el-Guebaly et al., 2002a; Lawn & Pols, 2005) noted that facilities’ transition to becoming smoke-free typically occurred quite smoothly. A mental health and smoking cessation researcher stated that institutional policy changes around smoking have occurred at different rates in different states. In general, though, she notes:

I think that experience of [a psychiatric facility] going smoke-free and seeing that it wasn’t as bad as everybody anticipated helped to change attitudes in the culture. Now we still get patients who come on the unit and are very upset that they can’t smoke.

While the tobacco control field has worked to change normative expectations around tobacco use by framing smoking as risky, unhealthy, and unwise, it is important

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

that promoting cessation does not encourage further social stigmatization among people who may already experience substantial stigma as a result of their mental health conditions.

Some of the leaders expressed disappointment in what they saw as a narrowly focused effort on smoking policies for psychiatric hospitals. As a mental health advocate stated:

We would make the point that the vast, vast, vast majority of people with mental illness are not in public psychiatric hospitals anymore. They used to be, but they aren't anymore. So the issue for us is more of a community issue. People only stay in the hospitals for 5 or 6 days now. Nobody lives in the hospitals, or very few people do. So how do you engage in the community?

Thus, while there has been success in creating smoking bans for psychiatric hospitals, messages also need to focus on ways to discourage tobacco use for mental health consumers who live and receive care in the community. A mental health advocate noted:

When you really lift the veil, I know there are a number of psychiatric hospitals that have gone smoke-free, but the question is how does that translate into peer centers and where people live. We're going into 2008, and that's where the vast number of people with serious mental illness live. If you have people quit in a hospital and then they start smoking as soon as they return to the community, it's like what have you done? It's like taking someone off their medication for five days and then putting them back on. We all agree, I think, in the community that we need to get very serious about getting people access to primary health care and smoking cessation efforts, but the question is how do you build it into the system so that people have ready access?

Finding an answer to the question of how to build a structure that supports cessation for people with mental illness is critical and according to participants, still remains unanswered. For example, another mental health advocate noted that quitting

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

during a hospital stay can be conceived of as a “temporary success but not a permanent one. We need to be looking at these efforts in a much broader way and as a cultural change.” All in all, the questions of how to build a structure and how to engage in culture change to support smoking cessation are critical to lowering the disproportionate rates of tobacco use among people with mental illness.

4.6.9 Understanding the Realities of Mental Health Consumers’ Challenges in Quitting and Highlighting Stories of Success

Another obstacle in creating an effective message is the awareness that people with mental illnesses may have a more challenging time quitting smoking than people without mental illnesses due to many factors such as: a lack of resources (e.g., education, support, access to health care), the side effects common to psychiatric medications, and the stresses associated with managing their mental illness and being prepared for circumstances of poor mental health. Leaders noted that while messages needed to be realistic regarding the real challenge of quitting, they also felt that messages should be positive and should reinforce the important role that smoking cessation can play in recovery, because people with mental illnesses “need to have hope and they need to see this as something they can do.” A smoking cessation advocate noted that there is a division between the negative messages that exist and mental health consumers’ actual personal narratives of health:

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

To begin to, as people are quitting, to really feature more stories and really begin to get a different message out. If the message is we can't possibly do this and it will harm our patients and so on and so forth, we need to have an alternate message in which...the patients or consumers are talking about another story, that this is not about consumers having psychic breaks or acting out or having all of these meltdowns. It's not that story, which is what people are afraid of, but rather the more healthier stories, the more positive stories. So I think it's really trying to get out a different message so that it's not so one-sided.

Some participants reasoned that the lack of real-life tales of mental health consumers who had successfully quit perpetuates the pervasive myths that cessation is impossible in this population. A suggestion that emerged from the interviews was that “success stories” of wellness and recovery through smoking cessation be highlighted to demonstrate the ways in which “quit-friendly environments” and “smoke-free lives” have been successfully developed and fostered. A smoking cessation provider said:

Some of the most miraculous stories that I've had over the years have been the successes of people with mental health diagnoses. I think about one woman in the [smoking cessation support] group who came for years and she was a multiple pack-a-day smoker, three to four packs a day, she had bipolar disease and schizophrenia and she actually quit smoking.

Even the word “actually” in this quote conveys that quitting is seen as an unusual outcome, and yet this provider realizes that real people have quit and that their stories can serve as a motivation for others. Participants felt strongly that these success stories could be effective for mental health consumers, providers, and peers as exemplars in spreading hopeful messages about the possibilities of a smoke-free life among one another and in the media. Given that many people with mental illnesses want to quit smoking, and have historically lacked a strong voice in their own treatment, empowering messages are

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

essential and need to be made more visible so that people can “see” what it is they are working to achieve. These stories, if made visible, could serve as collective action frames in motivating action by mental health consumers and practitioners alike.

4.6.10 Discovering Ways to Sensitively (Yet Collaboratively) Address Tobacco Use

In the interviews with the leaders, another consideration for framing that arose was the need to address tobacco use in a sensitive and empathetic way when working with this population. While leaders in smoking cessation expressed that they have a lot of knowledge and information that they can provide, they also noted that they are outsiders to the mental health culture. Thus, the leaders in smoking cessation and mental health both felt that it was more effective for mental health providers to deliver the message of the importance of smoking cessation and to provide support in quitting to “their population” as members of the same community.

4.6.11 Recognizing Not Addressing Tobacco Use as a Form of Discrimination

Several participants emphasized that not addressing tobacco use in this population further marginalizes people with mental illness by providing unequal opportunities for a healthy and smoke-free life. A representative to a mental health professional group, for example, described how providers familiar with the complex needs of their patients sometimes come from a perspective that:

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Drinking 12 cups of coffee is better than drinking 12 beers. Smoking cigarettes is not as bad as smoking crack. I think we need to begin talking about health and really begin to think about people with mental illnesses as having some potential for health. I don't think that we generally think of that population as a healthy population in general. But we don't do all the things we need to do to promote their health and to prolong their lives, and that kind of thing... We kind of come from a maintenance perspective rather than a health promotion perspective.

Choosing a maintenance perspective rather than a health promotion perspective was discriminatory according to many participants because:

It's basically saying, especially given that startling statistic of 25 years less of life, it's like telling a whole population, "You're really not worth our efforts to treat you." It's probably not going to work and we're just going to feel badly about ourselves because you're going to fail.

Thus, it is important that messages challenge these beliefs and highlight the ways in which these beliefs perpetuate discrimination and stigma. Even the recognition that "we've never taken that approach [addressing smoking cessation] because we've always been so focused on the treatment of the mental illness itself" highlights the pervasive nature of the discriminatory practice of overlooking behaviors that are known to cause early death and disease. These examples of discriminatory ways of thinking have become more apparent since the development of the Partnership.

In fact, it was common for leaders to express feelings of guilt or remorse for not having addressed or considered the problem of tobacco use before they became involved in the Partnership. Once educated, the leaders described a strong motivation to take action on this issue based on a newly recognized feeling of responsibility and potential for leadership. According to a participant, "we have to own up to our

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

responsibilities...Not only did we allow this, but we actually fostered it in many cases. It wasn't purposely designed to harm people, but it was a benign neglect." Many participants said they are now aware of actions they can take individually and/or within their organizations to reverse these discriminatory practices and thoughts by encouraging cessation and promoting the possibilities of a smoke-free life. As a mental health advocate and government official stated, "It's about acknowledging the past, it's not about belaboring it. With this new education comes this responsibility to change."

Attempts to utilize this framing would be considered an injustice frame, where the injustice in the situation is highlighted as a motivation for action (Gamson et al., 1984). Yet what is unique about this framing is that while injustice frames typically draw attention to those who are to blame for the injustice, in this case, those who are to "blame" (most likely the mental health leaders and providers) are also those individuals and organizations that are now working to foster the sense of indignation and outrage. Practitioners have started to own up to the neglect they unwillingly promoted during years of practice working with people with mental illnesses.

4.6.12 Finding Alternatives to Smoking

Perhaps one of the greatest remaining obstacles to addressing the high rates of smoking among people with mental illnesses is the very practical challenge of identifying and normalizing alternatives to smoking that fill the same therapeutic, social, and cultural roles. A mental health clinician stated, "When you're 'in the system' so to speak, there's

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

this whole thing about the smoke break.” Several participants noted that finding replacements for smoking that are pleasurable, promote socialization, and are believed to relieve symptoms of mental illness and the side effects of psychiatric medications and are relatively easy to incorporate and maintain in mental health settings remains a significant challenge, because smoke breaks are the norm, and so much a part of the daily routine in many facilities. Smoke breaks take up what might otherwise be empty time for people with mental illnesses to the extent that one practitioner joked during a conference that the main competition to incorporating health-promoting practices was the daily ritual for many mental health consumers of watching Dr. Phil on television. Further, smoking allows for time outside in a relaxed and unstructured atmosphere, and a time to connect with other mental health consumers and staff. In the words of a mental health clinician:

You have to realize that smoking has served some functions and then you’ve got to figure out alternative ways, more healthy ways and support people through that very difficult transition and know that they may fail periodically but don’t give up on them.

Many leaders saw finding alternatives to smoking as an opportunity to discover other health-promoting ways of rewarding positive behavior and reducing feelings of boredom. A mental health advocate noted:

For years we’ve talked about, as mental health advocates, that there has been a lack of meaningful activity in people’s lives and that so-called day programs have been nothing more than smoking cigarettes and watching television... We’ve been trying to change that culturally within the mental health system and make that an unacceptable practice.

Thus, in essence, efforts to change the culture of mental health settings so that

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

smoking does not play such an integral role requires that leaders grapple with the bigger issue of the lack of “meaningful activities” that people with mental illnesses are able to engage in. While this very notion of meaningful activities is morally charged (What makes an activity *meaningful*? Does what defines a meaningful activity differ for people with and without mental illnesses? Are there other types of activities, such as coffee or tea breaks, gardening, or art classes that can fulfill some or all of the same roles as smoking?), it also raises important questions about what can feasibly and should morally and ethically be incorporated into the cultural and treatment practices in psychiatric settings.

4.7 What Do We Make of All These Messages?

As has been described above, there are many messages and opportunities for framing that can be utilized to help make smoking among people with mental illnesses a recognized problem. It can be argued that the 12 areas of framing outlined above emphasize the micro (individual) and meso (organizational) levels and somewhat overlook opportunities for messaging and culture change on the macro (system and policy) level.

Social movements typically address messages to two groups: (1) power holders and (2) the general public (Snow et al., 1980). While the existence of multiple messages means that the “problem” can be framed as a salient issue for the various groups that have

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

a stake within the mental health community (such as people with mental illnesses, their family and friends, and mental health practitioners and leaders), the large number of messages which lack a concrete overarching theme and the complications and tensions that some of these messages evoke hinder the chances that this problem will gain visibility among the broader public. The next section focuses on the ways in which the media have framed this issue and the impact that this framing may have on the Partnership's efforts.

4.8 The Media

The news media play a critical role in both influencing and reflecting public opinion. The media is a primary means for bringing health-related issues to the attention of the general public (Dorfman, 2003). The mass media can even mobilize societal action to create the conditions for health (Institute of Medicine [IOM], 2003). A frames analysis was conducted as an exploratory attempt to examine how the issue of smoking among people with mental illness or the connection between mental health and smoking are conceptualized, framed, and problematized in recent articles published in leading U.S. newspapers. The central focus of this analysis is on: (1) the “themes” presented and the messages they are intended to convey; (2) the positions that are present or absent; and finally, (3) the language that is used in describing this issue.

The sample selected for this analysis included 46 articles published in the last 10

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

years (1999 to 2009) in six of the most highly circulated U.S. newspapers: the *Chicago Tribune (CT)*, *Los Angeles Times (LAT)*, *New York Times (NYT)*, *USA Today (USAT)*, *Wall Street Journal (WSJ)*, and *Washington Post (WP)* that included the search terms “mental health” or “mental illness” and “tobacco” or “smoking.” As shown previously in Table 5 (section 2.3.4), each of these newspapers published at least four stories on smoking/tobacco and mental illness/mental health, with *The New York Times* leading the way, publishing 11 articles over the 10-year period.

It is noteworthy that while the National Mental Health Partnership for Wellness and Smoking Cessation has been active over the last two years, the majority of the articles that met the selection criteria were published in the early portion of the 10-year period, from 1999-2003. This is interesting in light of the fact that the academic literature on mental health/mental illness and smoking appears to have proliferated in the last several years. See Table 7 below for the distribution of articles by year published.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Table 7 Number of Articles from Six Leading U.S. Newspapers Published Each Year from 1999-2009 on Mental Health/Mental Illness and Smoking/Tobacco

Year	Number of Articles
1999	8
2000	11
2001	3
2002	2
2003	3
2004	0
2005	3
2006	3
2007	5
2008	8
2009*	0
TOTAL	46

*While the table indicates that no articles were retrieved through the search process that were published in 2009, it is important to note that this frames analysis only included articles published in the first two months of that year.

Menashe and Siegel (1998) examined the ways in which the issue of tobacco has been framed in the mass media (front-page newspaper articles from *The New York Times* and *Washington Post* published from 1985 to 1996) in search of clues to why public health efforts to overcome the tobacco industry's influence on public policy and tobacco

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

use may not have been entirely successful. The authors note that there have been several significant shifts in the debates by both tobacco control advocates and the tobacco industry and identified 11 frames for tobacco interest arguments and 10 for tobacco-control arguments. The authors discovered that during the mid- to late 1980s, the dominant tobacco control frames were those based on the argument that tobacco use kills both people who smoke and those who do not (through secondhand smoke), that society is responsible for eliminating tobacco-related deaths, and that tobacco companies should be held accountable for these cases of illness and death. In the 1990s, however, tobacco use was reframed as a health problem not because it kills, but because the tobacco companies manipulate the nicotine levels in cigarettes, deceives the public, and market tobacco towards youth.

Similarly, this portion of the chapter offers an interpretive account of U.S. newspaper coverage of smoking and mental health and smoking among people with mental illnesses over the period from 1999-2009. This analysis focuses on the various framings and representations and the messages they intend to convey to readers. Newspaper editors and journalists construct particular accounts about the connection (if any) that can be drawn between mental health/mental illness and smoking. While the articles do present differing views of the various angles or perspectives for addressing this issue of smoking among people with mental illnesses, very few of the articles problematize smoking among mental health consumers or present information in a way that educates, presents an argument, or motivates action among readers. All in all, the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

results of this frames analysis suggest that if many of the messages the general public receives on a daily basis are from the newspapers (and/or if the newspapers reflect the type of information sought by the public), then people outside of the mental health and smoking cessation fields receive little information that serves to educate or raise their awareness on this issue.

4.9 Themes and Messages Presented in the Media

The 46 articles from the last decade were categorized according to major theme. Seven themes/frames were identified: (1) the plight of people with mental illnesses, or the experience of living with a mental illness as it relates to smoking or tobacco use; (2) general statements about smoking and quitting, including specific information about smoking among people with mental illnesses; (3) smoking policies/bans as they relate to mental health or in psychiatric facilities; (4) research studies about tobacco use and mental illness; (5) the distribution and use of money from the Tobacco Master Settlement Agreement (MSA) in U.S. states; (6) mental health risks associated with the smoking cessation drug Chantix; and (7) the 1999 Surgeon General's Report on Mental Health. As noted in the Table 8 below, nearly one third of the articles meeting the selection criteria for inclusion in this frames analysis presented findings from a research study that had relevance to mental health and smoking.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Table 8 Number of Articles Published in Six Leading U.S. Newspapers from 1999-2009 According to Topic/Theme

Article Topic/Theme	Number of Articles
Plight/Lived Experience	8
General Statements About Smoking	3
Smoking Policies	5
Research Studies	15
Master Settlement Agreement \$	7
Chantix	6
Surgeon General's Report	2
TOTAL	46

First, the analysis will be centered on the use of money from the Master Settlement Agreement (seven articles), Chantix (six articles), and the Surgeon General's Report (two articles). The articles in these thematic areas share many characteristics within each theme. I will then present a more extensive analysis of the 31 articles that fall into the other four thematic areas: the plight of people with mental illnesses (eight articles), general statements about smoking (three articles), smoking policies (five articles), or research studies (15 articles).

4.9.1 Distribution and Use of Tobacco Money

First, six of the seven articles about the distribution and use of Tobacco Master

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Settlement Agreement money were published in the *Los Angeles Times*, and one was published in the *Wall Street Journal*. Given that U.S. states cannot run budget deficits, and there currently exist mounting state budget crises coupled with increasing needs for resources, this money is often used to replace funding for social and health programs that might otherwise be cut or under funded. This money is considered “a great temptation” given that “the needs are so many. And the tobacco windfall is so handy” (Simon, 2001, p. A1). As a result, the health and social service sectors must compete for pieces of the pie for their own “pet cause” (“Taxing the System,” 2005, p. B12).

Several of the articles noted that while the money was intended for health care, less than half of the money provided to the states has been used for that purpose, and only a very small fraction, given the source of the funding (less than five percent according to one article), has been used to “help Americans kick the cigarette habit” by funding for example, smoking cessation programs (Simon, 2001, p. A1). This *Los Angeles Times* article noted that “health care experts” are alarmed by the seemingly haphazard distribution of these funds because “states should be spending three to four times as much on anti-smoking campaigns if they hope to bring future tobacco-related medical costs under control.” The articles note that tobacco control advocates argue that there continue to be deaths that could have been prevented if this money had been better allocated to smoking cessation and tobacco control programs. For example, a *Los Angeles Times* article stated that “anti-smoking activists” have accused others of “raiding money” by using *their* money for other, non-tobacco control/cessation purposes (Saillant, 2002, p.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

B3).

These articles offer specific examples of the ways the states are using these funds, and elucidate the differences in the needs, priorities, and interests within various states including mental health services, housing for people with mental illnesses, helping people with mental illness in crisis, and mental health care for prisoners. The distribution of the funds is complicated in some southern states where the state governments maintain their strong historical ties to the tobacco industry. Although these articles do not say so explicitly, they highlight an interesting and complex relationship between the tobacco control and mental health fields. The mental health arena, which is perpetually lacking needed resources, has benefited from money intended to support smoking cessation and prevention efforts. While this does not appear to have come up in the context of the Partnership's efforts, it is noteworthy, and may underlie some of the perceptions and challenges in establishing and maintaining collaborative efforts between the two fields.

4.9.2 *Chantix*

Six articles (two from the *Los Angeles Times*, two from *The Wall Street Journal*, and two from the *Chicago Tribune*) focus on the warnings associated with the drug varenicline (brand name Chantix), a drug created by Pfizer as the first prescription medication in pill form specifically designed for smoking cessation (bupropion is also a medication in pill form used to help people quit smoking but was originally designed to treat depression and later found to help people stop using tobacco). Chantix promotes cessation by reducing

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

cravings associated with nicotine withdrawal and decreasing the feelings of pleasure associated with smoking. The drug, which has been shown to be effective in helping people to quit smoking, has also been associated with risks of suicidal ideation. The articles, which focused on escalating concerns about the drug, attempt to elicit fear; thus the title of an article in the *Chicago Tribune* warns, “Thoughts of Suicide? It could be the meds you’re taking” (Healy, 2008, p. 4) and from the *Los Angeles Times*: “Daniel Williams hoped Chantix would help him quit smoking and become healthier. Instead, he believes, it nearly killed him” (Alonso-Zaldivar, 2008, p. A20).

The articles present conflicting views from the FDA and Pfizer, with the FDA stating its concerns about Chantix’s safety and Pfizer noting that a very small percentage of people taking the medication had experienced serious side effects and emphasized that quitting smoking itself can evoke mood swings and agitation. The FDA and Pfizer present their differing perspectives based on the results from the same studies. Several articles also noted that the Federal Aviation Administration (FAA) banned the use of Chantix by pilots and air traffic controllers. The articles generally presented information and warnings that were likely to increase anxiety among those currently taking Chantix and among clinicians who may have or were considering prescribing it to patients and clients, particularly people with mental illnesses, who might have a previous history of suicidal thoughts.

None of the articles presented the views of people described as tobacco control or mental health advocates or emphasized the successes of the medication in helping

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

smokers quit. Also noteworthy is that none of the articles examined the high risks of continuing to smoke compared to the risks associated with Chantix. Overall, the articles appeared to express skepticism about Pfizer's motives in denying there were problems associated with the medication and portray the FDA as a hero for creating policies that protected people taking the medication and those considering taking it.

A *Wall Street Journal* article (Beck, 2008, p. D1) focused specifically on the mental health risks associated with taking Chantix and included quotes from a psychologist and a psychiatrist. The article highlighted the connection between mental illness and smoking and noted that nicotine withdrawal can cause depression, especially among those who have experienced depression before. The article cited the Lasser et al. (2000) statistic that 44% of cigarettes in the U.S. are smoked by people with diagnosed mental disorders, including "schizophrenics" and "alcoholics," who may smoke to "self-medicate." This was the only article in which it was mentioned that, although Chantix had received FDA approval, "smokers with psychiatric illnesses weren't included in the pre-marketing trials" (Beck, 2008, p. D1).

More broadly, the larger potential impact of the articles is that the concerns surrounding increased risk of suicide while using Chantix for smoking cessation can contribute to fears about prescribing its use to people with mental illnesses, a sizable segment of current smokers. A possible unintended consequence of this message is that it may make providers hesitant in general to prescribe smoking cessation aids such as NRT for people with mental illnesses who want to quit based on fears about side effects and

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

risks. On July 1, 2009, after this frames analysis was completed, the FDA gave varenicline (Chantix) along with bupropion (Zyban) a black box warning, the agency's strongest safety warning, as a result of increasing evidence of side effects including depression, suicidal thoughts, and suicidal actions after the drugs were closely monitored for two years. With this news, many articles on this topic have been published since February 2009 when all articles for this frames analysis were retrieved.

4.9.3 *Surgeon General's Report on Mental Health*

Two articles in the sample addressed the 1999 release of *Mental Health: A Report of the Surgeon General*, the first report by the Surgeon General that documented the extent of mental health problems in the U.S. and highlighted the scientific advancements in the area of mental health. In one article, Surgeon General David Satcher compared his hopes for the effects of this report to the effects of the first Surgeon General's report *Smoking and Health*, published in 1964, but said that it would be, in his words, "more effective than the smoking report in terms of actually changing how people live" (Kaufman, 1999, p. A3). The relative hopes surrounding the two reports are interesting and provocative, as they broadly illustrate the hopes and possibilities for the two reports. Given the influence of the Surgeon General's Report on Smoking and Health, it is unsurprising that the Surgeon General's Report on Mental Health would strive to achieve the same recognition and impact.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

4.9.4 *Plight or Lived Experience of People with Mental Illnesses*

The articles that were categorized under the theme of “plight” or “lived experiences of people with mental illness” included human-interest stories that highlighted the poor treatment and conditions of people with mental illness. For example, these articles described homes and treatment facilities with significant health and safety problems, a lack of access to necessities and comforts, a lack of meaningful activities, and highlighted the importance of smoke breaks in making life less boring for people with mental illnesses. The articles under this theme are distinct in that they address different issues and provide different perspectives on mental illness.

While the articles discussed smoking and mental health, they tended to emphasize mental health and the experience of mental illness, rather than tobacco use (tobacco use was only peripherally mentioned). While some of the articles appeared to give a glimpse into the experience of mental illness, they fell short by portraying people with mental illnesses as “the other” but also demonstrating the extent of the discrimination mental health consumers experience, such as an article in *The New York Times* titled “For Mentally Ill, Death and Misery” (Levy, 2002, n.p.). These articles also emphasized the differences in the lives of people with mental illnesses, rather than their human qualities, and in some cases portrayed mental health problems as a result of the guilt and shame experienced by those who contract a smoking-related illness (Cook, 2005).

One article notably focused on the health disparities that exist for people with mental illnesses. The article described exercise programs developed to help people with

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

mental illnesses stay physically active and the mental health benefits achieved through these programs; however, the article framed the causes of the health disparities around weight management rather than other behavioral causes such as smoking (Ellin, 2005). This was the only article that provided readers with a sense for the possibilities for wellness and recovery for people with mental illnesses.

4.9.5 *General Statements about Smoking and Mental Health*

Three articles were grouped under the theme of “statements about smoking and quitting.” These articles were framed around tobacco use as a killer, and the challenges of quitting. One article highlighted the work of a former smoker who had “built her career on the psychology of smoking.” The article, published in the *Chicago Tribune*, stated that this person was intrigued by the self-help strategies, including smoking, used by people with schizophrenia to change their brain chemistry, mood, and concentration. The author highlighted the clinician’s work with one of her clients who had a history of depression and noted that a history of depression is “a liability in quitting smoking.” The article provided quitting tips for all smokers, not only people with mental health problems (Lauerman, 2001, p. 1). The article appeared to suggest that expert help is required to quit smoking, portraying smoking cessation as a medicalized process that requires expert intervention.

A 2007 op-ed article in the *Washington Post* by Steven Schroeder, director of the SCLC, highlighted themes that have emerged from the efforts of the SCLC and the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Partnership. The article referred to smoking among people with mental illnesses as “a hidden epidemic.” It offered facts and statistics about smoking and mental illness, including the prevalence of smoking and the 25-year longevity gap. Dr. Schroeder asked, “Why did patient groups, their families, and clinicians do nothing to help smokers quit?” and offered a list of probable reasons. The National Mental Health Partnership for Wellness and Smoking Cessation is mentioned by name and described. Schroeder noted:

It will not be easy to reverse the long alliance of smoking and mental illness. But the fact that mental health clinicians and patient and family advocacy groups have recognized the problem and are willing to address it is an essential first step towards wellness (2007, p. B7).

This article was the only one of the 46 that presented a collective action frame in which the purpose of the article appeared to be to motivate action among readers.

4.9.6 Smoking Policies

Eight articles focused on the initiation, perceptions, and effects of smoking bans or smoke-free policies. Articles around smoking bans framed these policies as either critical to nonsmokers’ rights, an unjust civil liberties issue, or unfair policies that restricted smoking in certain settings while continuing to allow and even endorse the behavior in others. For example, one article noted the types of settings, including mental health facilities, which were excluded in a small town’s implementation of a smoking ban (Little, 2006). However, the article did not offer a reason for why certain environments were excluded from the policy.

Another article described how the new management of a mental health facility

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

backed away from plans to implement a smoking ban in response to mental health consumers who wanted to be able to continue smoking while receiving treatment (Saillant, 2003). This same article framed the issue of a smoking ban as a “quandary” for psychiatric facilities because the hospitals must decide “how to keep work sites smoke-free when many of the people they care for are heavy smokers” (Saillant, 2003, p. B1). It described this quandary from various stakeholder perspectives. This article stated that smoking can help calm patients with major mental disorders, but that for “doctors, tolerance of smoking is clearly a double-edged sword. Although offering temporary relief, the habit may end up killing patients.” The article also presented the perspective of “advocates for the mentally ill” who conveyed that a smoking ban is “too harsh for critically ill patients” (Saillant, 2003, p. B1).

4.9.7 Research Studies

Finally, 15 articles presented the results of research studies on mental health and smoking. In general, the articles provided an overview of the study and typically included direct quotes from the researchers. This analysis is notable as an opportunity to examine which research studies get reported by the popular press and presented to the public. Table 9 provides information about what studies related to mental health/mental illness and tobacco/smoking were published in six U.S. newspapers during the previous 10 years and the frequency at which they were published.

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Table 9 Research Study Findings Related to Mental Health and Smoking Published in Six Leading U.S. Newspapers in 1999-2009

Study Authors Quoted/Mentioned	Main Study Finding	Journal	Date	# Times in Newspaper
Lasser	People with mental illnesses consume 44.3% of U.S. cigarettes	<i>Journal of the American Medical Association</i>	2000	4
Johnson	Teen smoking tied to later anxiety	<i>Journal of the American Medical Association</i>	2000	2
Parks	25-year gap in longevity	Report	2007	1
Goodwin	Pregnant smokers more likely to have depression	<i>Obstetrics & Gynecology</i>	2007	1
Furberg	People with depression more likely to have heart disease	<i>Circulation</i>	2000	1
CDC	Abusive upbringing can lead to smoking	<i>Journal of the American Medical Association</i>	1999	1
Jonas	Anxiety and depression can lead to asthma	<i>J. of Applied Biobehavioral Research</i>	1999	1
CDC	People with disabilities are more likely to smoke	Report	2007	1
Researchers from Rhode Island	History of depression does not necessarily mean a harder time quitting smoking	<i>Nicotine & Tobacco Research</i>	2000	1
Christakis and Fowler, Schroeder	Smokers clustered within social network, there exist social factors for quitting	<i>New England Journal of Medicine</i>	2008	1
Stewart	More than half of Americans who have	<i>Journal of the</i>	2003	1

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Study Authors Quoted/Mentioned	Main Study Finding	Journal	Date	# Times in Newspaper
	depression seek treatment	<i>American Medical Association</i>		

The results of the Lasser et al. study (2000) published in the *Journal of the American Medical Association* which reported that 44.3% of cigarettes are consumed by people with mental illnesses, was cited in four of the six newspapers (*New York Times*, *Chicago Tribune*, *Wall Street Journal*, and *Los Angeles Times*). The fact that the study's findings were cited in two-thirds of the six leading U.S. newspapers is indicative of its influence in raising awareness about the connection between mental illness and smoking. The articles generally provided background information about the sample size of the study, the age range of the participants, and the definition of mental illness (which some articles present as noteworthy given that Lasser et al.'s definition denotes that almost 30% of the U.S. population has a mental illness or substance abuse issue, a high estimate as compared to statistics presented elsewhere).

One article questioned the definition of mental illness used for the study, given that over 28% of Americans fit that definition (this is a higher estimate, even after consideration that it included people with substance use disorders as well, than is suggested in most other places. While this was not addressed among the leaders, clearly the Lasser results must be considered in light of the fact that their definition of mental illness produced a higher prevalence than is typically cited. Only one article of the 46

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

captured the perspectives of a tobacco industry employee (“Mentally ill smoke 44.3%,” 2000). In this article, a R.J. Reynolds vice president was quoted as saying, “to suggest that we target those individuals is crazy.” His use of the word crazy certainly hints of a bias. A *Los Angeles Times* article did note that the author tried to reach representatives for RJR, but that they did not respond to requests for comment (Mestel, 2000). Referring to the idea that people with mental illness consume significantly more cigarettes than might be expected given the size of the population, one article noted that the tobacco industry might have played a role in promoting smoking among this group.

Only one of these four articles discussed the specific risks of smoking for people with mental illnesses, including “serious ailments such as heart disease and lung cancer, but in some cases it can interfere with the effectiveness of medications to treat their disorders” (Mestel, 2000, p. A38). The article stated that although it is harder for people with mental illnesses to quit smoking, a “sizeable number of people with a history of psychiatric disorders” have quit.

The second study that played a prominent role in increasing awareness of this issue among leaders in mental health and smoking cessation was the Lutterman et al. (2003) study which led to other publications including the NASMHPD report (Parks, Svendsen, Singer, & Foti, 2006) and the Colton and Manderscheid (2006) study which concluded that people with mental illness die 25 years earlier, on average, than the general U.S. population. This article was published in *USA Today* on May 3, 2007, more than six months after the study was published (Elias, 2007). The article noted the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

widening gap in longevity for people with mental illness. It first mentioned obesity among people with mental illnesses as “a serious problem,” and portrayed a lack of exercise and the effects of anti-psychotics as contributing to a shorter life span. The article later noted that “mentally ill adults” are more likely to abuse drugs and alcohol and smoke. The article presents the health disparities as a tragedy and a cruelty and quotes a study author who noted that “many struggle for decades to overcome mental illness, and after all that struggle it’s particularly cruel to think that you would die young.”

Finally, an article in *The New York Times* reported on a study by Christakis and Fowler published in the *New England Journal of Medicine* that followed smokers and nonsmokers and their social networks and found that “clusters of smokers were stopping en masse” (Kolata, 2008, n.p.). The article quoted a study researcher who said, “smokers used to be the center of the party, but now they’ve become wallflowers,” and stated that smoking impairs not only physical health but also social health as well as a result of the stigmatization of smoking. The article also quoted SCLC Director Steven Schroeder who authored an accompanying editorial in which he stated that the marginalization of smoking further isolates people with mental illnesses and substance abuse issues who smoke at the highest rates.

In general, while these articles, retrieved by a search of the six leading U.S. newspapers over the last 10 years covered a range of issues relevant to mental health and smoking, they comprised a rather incomplete picture of the issue given its complexity and

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

significance to health. Approximately 20% of the articles presented information in such a way as to create a frame that conveyed the issue as complex or provoking tension.

Instead, most enumerated facts without going into real detail about the varying perspectives and debates such as those around smoke-free policies. The articles about the lives of people with mental illnesses evoked feelings of sympathy and otherness and do not provide an adequate context for understanding the high rates of tobacco use in this population. Furthermore, few of the articles raised hope or educated readers in ways that might motivate action among the general public.

The language used in discussing this topic varied within and between articles. For example, people with mental illness were described as people with “serious psychiatric problems,” “the mentally ill,” “mentally ill people,” “schizophrenics,” and “persons with mental illness,” terms that limited the context for understanding *who* the article was referring to. Mental illness was described loosely as “mental health problems” or in some cases as “severe” or “major mental illness.”

Within the articles, the perspectives that were highlighted included those of professors of psychology or psychiatry, cancer specialists, FDA representatives, mental health experts, executive or medical directors of advocacy organizations, advocates, former patients, a supervisor of an inpatient unit, the medical director of a county mental health department, senators, county representatives/supervisors, representatives from Pfizer, and tobacco control advocates. There was a notable, near-complete absence of some perspectives. For example, only one article included the perspective of people with

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

mental illnesses. This may be due, as mentioned earlier, to the focus of most of the articles, which were on facts and the results of research studies, and not the personal narratives of people affected by the issue. Yet by focusing on the perspectives of researchers who were likely to be disconnected from the implications of their work, the authors missed an opportunity to make a compelling case for the importance of addressing this issue. Another position that was underrepresented was that of the tobacco industry. As mentioned, only one article quoted a tobacco industry representative, which is significant given the evidence that the tobacco industry has promoted smoking in this population. While the public seems to be increasingly aware of the strategies and tactics used by the tobacco industry to lure potential consumers, this perspective is not evident in newspaper articles that included the terms smoking/tobacco and mental health/mental illness.

Dorfman (2003) describes the importance of media advocacy described as “the strategic use of mass media to support community organizing and advance healthy, public policy” (p. S218). Media advocacy targets policymakers, advocates, and community members who may become active in making change through the political process, rather than the people who have “the problem.” Media advocacy views health problems as a lack of power and focuses on the power gap. From a media advocacy perspective, the articles retrieved from leading U.S. newspapers related to mental health and tobacco use do not inspire action by policymakers, advocates, or community members and the articles provided little context for readers to more fully understand the

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

issue. It is possible that other articles on the topic not retrieved using the search terms described may have provided examples of media advocacy, such as letters to the editor.

Instead, the articles analyzed here illustrate that the media may tend to point fingers at individual smokers for their behavior and the history and culture of the mental health community that has been unable or unwilling to regard smoking as a problem even though tobacco use has been framed as a major health problem over the last 45 years.

This analysis demonstrates that media representations of the issue do not fully problematize smoking within this population as a public health or a social justice issue and fail to provide the education and awareness to motivate people to mobilize around the issue. Overall, these articles do not contribute to the notion of smoking among people with mental illness as a social problem. The articles, as a whole, do not define the problem, diagnose causes, make moral judgments, or suggest remedies (Entman, 1993), but instead only provide general statements which serve to provide some education but do not elucidate the connections between smoking and mental illness that are central to efforts to address the high rates of smoking among people with mental illness.

4.10 Conclusions

This chapter examined the creation of the social problem of smoking among people with mental illnesses within the realms of the smoking cessation field, the mental health community, the National Mental Health Partnership for Wellness and Smoking

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

Cessation, and the media. The smoking cessation field has been extremely receptive to the importance of this “problem” and the mental health field, over time and with increased education and awareness, has come to construct tobacco use as a social problem and come to reframe wellness to include tobacco cessation. As a result, the Partnership has been able to successfully weave the framing and messages of these important constituencies into a rationale and a motivation for action that resonates with key leaders in the fields and their organizations. Yet the challenges experienced by the Partnership in developing a singular effective message and the frames analysis of the media’s representation of this problem suggest that the general public is still unaware of the significance of this problem both as a major public health issue and as a broader issue about the ways we treat, interpret, and understand the needs of people with mental illnesses.

In the case of smoking among the general American public, it can be conceived, because of the success of broad public health approaches that have included smoke-free policies, new options and resources for quitting, attacks against the evils of the tobacco industry, and health warnings, that an individual person’s tobacco use has shifted from, in the words of C. Wright Mills, a “personal trouble.” The framing of smoking as integral to the lives of people with mental illnesses as a result of complex social, psychological, physiological, and cultural factors and as being enforced and reinforced by the mental health system and the tobacco industry (as silent partner) have resulted in the construction of smoking among mental health consumers as a personal, professional, and

Chapter 4 | Leader and Media Perspectives on Shifts in the Mental Health and Smoking Cessation Fields and in Framing and Messages About Smoking Among People with Mental Illnesses

broad social issue worthy of increased resources, public attention, and support from the mental health and smoking cessation fields. Yet, the reality is that the mental health community and smoking cessation field must manage and address many “problems” and the media and the general public also have numerous competing concerns. The issue of smoking among people with mental illness may not yet be sufficiently “competitive” in light of the framing and messaging issues described above, to contend with other problems vying for attention in today’s busy, complex, and stressed political, economic, and social climate.

Theories of framing (Benford, 1997; Entman, 1993; Gamson, Benford, & Snow, 2000; Scheufele, 1999) suggest that social movement actors identify problems, define solutions, motivate action, and set action agendas in ways that resonate with the personal experiences, values, and expectations of potential constituents. Thus, framing is significant because the framing process can turn what might otherwise be seen as a personal problem into a social issue (Brown et al., 2004). This analysis is unique in that it is common for theorists and scholars to work backwards from successful mobilization to the methods of framing and frames that activists preferred and then posit on casual linkages between the two (Benford, 1997). Instead, this chapter attempted to examine the frames used and then to highlight the potential strengths and weaknesses in these frames that may create opportunities or barriers to movement mobilization. Efforts and challenges in developing a social movement focused on increasing opportunities for smoking cessation among people with mental illness are described in the next chapter.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

“I think it’s a meet in the middle kind of thing.”

- Smoking Cessation Advocate

5.1 Introduction

Social movements are a major source of social change. The efforts to address smoking among people with mental illness are aimed at creating change in the quality of life for people with mental illnesses and increasing opportunities for wellness and recovery. The framing and processes described in the previous chapter are associated with important shifts in the practices, policies, and treatments available to people with mental illnesses. Yet as these data from focus group interviews presented in Chapter 3 and data from the frames analysis presented in Chapter 4 suggest, challenges remain in raising awareness among mental health consumers and the public about this issue as a social problem.

The shifts described at the beginning of Chapter 4 have enabled issues of wellness and recovery to become central in the field of mental health and have allowed tobacco cessation to become constructed as important to these values and goals. Data presented in this chapter suggest that a social movement specific to the issue of smoking among people with mental illness is not likely to occur given the complex nature of the problem,

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

the historic stigmatization of people with mental illnesses, and the formidable challenges of framing and messaging. Nonetheless, the National Mental Health Partnership for Wellness and Smoking Cessation can and does benefit from the broadening of the mental health and tobacco control movements and can have a profound impact on the health and quality of life of people with mental illnesses by establishing connections with the existing movements in these fields.

This chapter explores the following research questions:

- To what extent do the efforts by the mental health and smoking cessation fields and the Partnership fit the definition of a social movement?
- What theoretical perspectives on social movements can be utilized to understand the formulation, evolution, and effects of the efforts by the mental health and smoking cessation fields and the Partnership?
- What strengths and weaknesses of the mental health community and smoking cessation field can be utilized or might pose barriers to addressing the high rates of smoking among people with mental illnesses?
- What is the role of mental health consumers in efforts to address the high rates of smoking among people with mental illness?
- In what ways does the Partnership benefit from the spillover effects of previous and present social movements around mental health, smoking cessation, and other health and social issues?

For the purposes of this analysis, the Partnership's work is referred to as an "effort" rather than a "movement," based on my contention that the effort has not yet met the definition of a social movement. This chapter begins by examining the ways in which the mental health and smoking cessation fields have begun to branch out and to examine the possibilities for a relationship and a collective effort. Next, it explores the strengths,

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

resources, weaknesses, and challenges of these two fields and of their collective efforts through the Partnership, as well as the ways in which the two arenas differentiate their unique roles in working together. Then the chapter goes on to illustrate the ways in which the Partnership's efforts have found a place at the junction between the current mental health and tobacco-control movements and describes the asymmetries between the mental health and smoking cessation movements/fields.

As mentioned previously, the social movement theories that are the most appropriate fit for understanding efforts to address the high rates of smoking among people with mental illnesses are those from the resource mobilization perspective. Resource mobilization theory posits that movements develop because of long-term changes in group resources, organization, and opportunities for collective action (Brown et al., 2004; Jenkins, 1983). The efforts to raise awareness about this problem and establish the Partnership are a direct result of the influx of financial resources provided to the Smoking Cessation Leadership Center (SCLC) to support mental health-related initiatives. Without these resources, it is very unlikely that efforts to address the disproportionate rates of smoking among people with mental illness would have developed as quickly or with as much enthusiasm as they have today.

These resources were derived from multi-million dollar grants from the American Legacy Foundation, which is “dedicated to building a world where young people reject tobacco and anyone can quit,” and the Robert Wood Johnson Foundation “whose goal is to help Americans lead healthier lives and get the care they need” (American Legacy

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Foundation, n.d.; Robert Wood Johnson Foundation, n.d.). The generous resources from these foundations support SCLC staff time (the SCLC has seven full-time staff members who are all highly skilled at mobilizing individuals and organizations), activities such as the summit that led to the development of the National Mental Health Partnership for Wellness and Smoking Cessation, and mini-grants to professional and advocacy organizations to support work in the area of smoking cessation.

5.2 Branching Out, Collaborating, and Fostering Natural Connections

Given the lack of awareness of the high rates of smoking among people with mental illnesses, a primary goal of the Partnership in its first year and beyond was to convene mental health and smoking cessation experts to facilitate dialogue and develop consensus on how to best address this issue. Increased dialogue and communication were seen as vital to this effort because the mental health community is known to be and was reported by the mental health leaders as being extremely insular. The mental health leaders were extremely familiar with one another and often referred to their propensity to talk among themselves. This is problematic, according to Mechanic (2003), because many decisions about the direction of the field and policies that impact the lives of people with mental illnesses are made outside the mental health arena.

As someone who works both in mental health and more broadly in health policy, I am impressed that mental health advocates too often talk primarily to one another and to those already committed to their positions. Most policies that have the largest effects on the welfare of persons with mental illness are made outside the mental health sector and even outside of health care (Mechanic, 2003, p. 1227).

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

As a result of this separation and insularity, the leaders in the mental health and smoking cessation fields had never communicated with one another or even been formally introduced before the summit that led to the development of the Partnership. As a result, the leaders saw the Partnership as an opportunity for a “historic collaboration” representing the joint efforts of the two fields. The mental health leaders noted that working with the smoking cessation field, which represented for them the broader physical health arena, allowed for capacity building and for establishing new connections between the mental and physical in new and meaningful ways. A mental health clinician described how the “the smoking community is a whole new world to me.”

It’s a whole different world that I never knew existed. The advocacy, the organization, the marketing strategies, the funding, the people, the networks, the partnerships with people we aren’t used to partnering with in the mental health community like the lung association, the department of health, or the heart associations. They are all new potential partners.

The opportunity to meet one another as potential partners and to discuss a problem of significance to both fields allowed many leaders to forge new relationships and, for some, new ways of seeing the work they do.

Several leaders acknowledged that bringing those who work in smoking cessation and mental health together, given the disproportionately high smoking rates among people with mental illnesses, is “such a natural connection, but one...most people don’t make.” That the summit forged and fostered a “natural connection” was evident when this first meeting of leaders in the two fields led to a “public pronouncement” of their joint commitment to address the high rates of smoking among people with mental

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

illnesses and to the development of the National Mental Health Partnership for Wellness and Smoking Cessation.

Yet it was not necessarily love at first sight. While two leaders described the collaboration as analogous to a first date, in which both parties are hoping it will ultimately lead to a romantic relationship, one mental health advocate noted at the time of his interview in December 2007 that “this is not a marriage in any sense yet.” To continue the marriage analogy, the parties (or people) are slow and deliberate in getting to know one another and investigating each other’s motives, interests, strengths, and bad habits before they make a commitment. A smoking cessation advocate said:

I think we just need to have some perspective about this population and be willing to...really look at this as a longer-term relationship and be willing to spend some time at it and slow down a little bit. I think it’s a meet-in-the-middle kind of thing.

Thus, while the initial hope was that the relationship would take off quickly, many participants immediately recognized the benefit of taking a slow approach to coming together and learning more about the “cultural differences on both sides.” The leaders noted that the two fields are distinct in many fundamental ways; they have different ways of seeing the work they do, different emphases, different training, different languages, and different focus populations. Thus, given these asymmetries, participants expressed a worry that there might be a tendency for the fields to go their separate ways once the summit ended; yet many wanted to embrace the Partnership as an opportunity to coordinate efforts based on issues of mutual concern. Leaders from both fields acknowledged that mental health advocates, providers, and government officials have

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

much to learn about tobacco, its risks, and how to help people quit, while the smoking cessation advocates, providers, and researchers needed to learn about the experiences of people with mental illnesses and what information they might need to know about tobacco use and quitting. During and after the summit, the Partnership members purposefully and enthusiastically developed methods for “cross-dissemination,” “cross-fertilization,” and “cross-exposure” to share information and knowledge and to set the stage for continued collaboration.

5.3 Appreciating and Maximizing Strengths and Resources

The mental health and smoking cessation fields have unique strengths and thus may make unique contributions in their united effort to address tobacco use among mental health consumers. Moreover, the Partnership as a whole, based on its collaborative efforts, also has strengths that are significant to the success of a social movement.

5.3.1 Strengths of the Mental Health Community

As described in Chapter 4, shifts in the mental health community have resulted in a realization that overall health and wellness are important and achievable goals for people with mental illnesses. A smoking cessation advocate described the mental health community as:

Very tuned in to their population and all the needs of their population. So when we're trying to find out what's important for this group of people and how to work more effectively with them, they can really answer that question.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Furthermore, in recent years, the mental health field has united to address other important issues, such as seclusion and restraint. Seclusion and restraint was a culturally accepted practice within the mental health community for decades. Ultimately, a federal investigation in the 1990s led to congressional hearings which concluded that “restrained and secluded consumers were traumatized and harmed and that many died as a result of these often violent procedures” (LeBel, 2008, p. 194). Because of these untimely deaths and the realization, based on real-life practice, that seclusion and restraint could be reduced and even eliminated with no increase in staff injuries, the mental health community set a precedent when it mobilized to minimize or discontinue this common practice. The mental health community ultimately realized that seclusion and restraint were inhumane and “impedes our mission of building resilience and facilitating recovery” because people are unable to learn how to manage their illnesses and their lives when they are under external control (Curie, 2006, p. 1139). According to a mental health government official:

People were literally psychologically and physically harmed because they were inappropriately put in seclusion and restraints when it was not a safety issue for hundreds of years. In the last 10 years alone, there has been a dramatic decrease. Some facilities have outright eliminated its use. That makes a big difference for the health and well-being of people. So once we do line up all the stars correctly and decide we’re going after something, it can have a huge impact. And it’s a really proud time to be in the field when things like that happen.

Several of the leaders expressed that they felt confident that they could effectively mobilize around smoking, because they had been successful in ending the long and

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

culturally ingrained practices of seclusion and restraint through a similar process. The move to address the overuse of seclusion and restraint with the goal of complete elimination of these practices began in 1999, when the National Association of State Mental Health Program Directors (NASMHPD) released a position statement declaring that seclusion and restraints must be considered safety interventions of last resort. Then, in 2003, the Substance Abuse Mental Health Services Administration (SAMHSA) convened a National Call to Action to Eliminate the Use of Seclusion and Restraint which led to the development of evidence-based practices and guidelines, training and technical assistance, leadership and partnership development, rights protection, and data collection efforts. Similar to the efforts around smoking cessation, which resulted in an entire issue of the *Journal of the American Psychiatric Nurses Association* in 2009 being devoted to this topic, in 2006 the journal *Psychiatric Services* devoted an issue to the topic of seclusion and restraint in which it recommended specific steps and policy changes. Also similar to the framing of smoking cessation, eliminating the use of seclusion and restraint was framed around the need for culture change. Finally, similar to smoking cessation efforts, there was also an expectation that reducing and then eliminating the use of this practice would require planning and time and that leadership and buy-in by key staff would be essential components (Curie, 2006).

Another strength of the mental health community, according to leaders in both fields, is that mental health care is structured in such a way that allows for the easy integration of tobacco dependence treatment. Mental health providers work intensively

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

with their clients on a regular basis over long periods of time. As a result, practitioners can provide information and support and can address changes in symptoms throughout the quitting process. In the words of a mental health clinician:

The mental health community works intensively with people. That affords us more of an “in” than maybe somebody who goes to their primary care physician every six months or someone who does a group for 10 weeks and then that’s the end of it. We have the ability to do ongoing interactions and interventions with some people.

Furthermore, as several leaders in mental health noted, “behavior change is our business,” and:

There’s already a good knowledge base and experience base in helping people...change addictive behavior and they can apply those principles very nicely to smoking. So it’s not really even like having to adjust a way of working, its more paying attention to when someone also smokes and applying strategies that they already have.

While this comment may downplay the significance of changing practices, even in “small” ways such as identifying clients who smoke, the realization that the mental health community can integrate cessation support into its practice is a step in the right direction.

Moreover, mental health providers are trained in and regularly practice helping people effectively modify their behaviors; they are educated about medication management; and they are knowledgeable about how to work with and treat addictions. The leaders also noted that providers in mental health are flexible and understand that what works for one person or in one setting may not work for another. As part of their day-to-day work, many mental health providers organize and facilitate wellness groups and provide treatment strategies that could incorporate or emphasize smoking cessation.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Moreover, the mental health community, according to many leaders, tends to keep in regular contact, maintains good communication, and foster “reciprocity and collegiality.” According to a smoking cessation advocate this means, “if they can get a shared vision of wellness and being smoke-free, they have a lot more opportunities to implement that.”

And in the words of a mental health advocate:

I think the mental health community has the ability to engage in kind of meaningful internal dialogue to draw on the experiences of many many people who are part of the mental health community and I think learning from people like [a relative] and what their experiences have been and learning from other people who have been abused by the coercive element of the token economy that cigarettes have been a part of.

The understanding of the “coercive element of the token economy” sheds light on the ingrained, culturally bound nature of smoking and the ways in which using cigarettes for behavior modification is a method for making people with mental illness behave “appropriately.”

Finally, the leaders recognized the increasing involvement of mental health consumers in directing their own care and in making changes to the health care system as an important resource. While mental health consumers are often seen as politically and economically powerless in society, they have rich insights into the experience of living with a mental illness and receiving care, insights that are starting to be valued in the transition to a focus on “consumer-driven” care in the mental health community. Mental health consumers have a lengthy history of successful advocacy having long mobilized themselves around various treatment system issues. As the mental health community has come to see people with mental illnesses as powerful resources and has come to

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

appreciate and elicit their insights and perspectives, mental health consumers have become involved in the larger mental health movements themselves by working with the mental health system rather than exclusively against it.

5.3.2 Strengths of the Smoking Cessation Field

The smoking cessation field also has a number of strengths and resources that it contributes to this collaborative effort. First, many leaders suggested that the smoking cessation field has extensive knowledge about evidence-based practices for helping smokers in many different circumstances to quit. Many of the leaders felt that addressing the needs of people with mental illnesses who smoke is “just a matter of taking what we know and translating that into a workable model for this particular population. So all the components are there, it’s just a matter of putting them together.” The leaders further noted that people who work in smoking cessation are highly motivated to help people quit and come from a public health approach where they care deeply for the population’s health. A smoking cessation provider said that her motivation for helping people quit “is that I am aware that stopping smoking is the single most important thing smokers can do to improve their health and the health of anybody around them and their quality of life and their quality of dying.” The strong convictions about the importance of the work they do keeps the smoking cessation providers and advocates passionate about their work and creates a motivation to work quickly to help improve the health of as many people as is possible.

5.4 Understanding Weaknesses and Overcoming Challenges

As a result of their diverse skills and passions, the leaders in mental health and smoking cessation bring unique contributions to their collective efforts. The strengths and resources from each field can potentially be combined to develop an effective strategy for smoking cessation in this population. On the other hand, the differences between the fields can also pose problems for the development of a social movement that is dependent on collaboration and mutual commitment. From here, I describe some of the weaknesses and challenges experienced by the fields on their own and the ways in which these may translate to weaknesses and challenges for the Partnership and the broader movement in addressing the smoking cessation needs of people with mental illnesses.

5.4.1 Challenges for the Mental Health Community

5.4.1.1 The Conviction that the Mental Health Community is Fundamentally “Different”

On the mental health side, leaders mentioned that a weakness in coalescing to focus on this issue is the pervasive attitude that the mental health culture is “different.” This belief was seen as providing permission to the mental health community and society at large to casually and quietly overlook some issues that would never be ignored in the general population, such as smoking. One example is the view that people with mental illnesses need or deserve “small pleasures” like smoking. This “pleasure argument” in support of smoking, which is an argument created and spread by the tobacco industry, suggests that the health of people with mental illness is of less importance than the health

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

of others without mental illnesses, or that it is acceptable to focus on mental health symptoms that are potentially more disruptive to society at the expense of physical health concerns. Arguments and feelings such as these are perpetuated by many groups including mental health providers, advocates, and family members, and are used by people with mental illnesses as a rationale for their continued tobacco use (Smith, 2007; Smith & Malone, 2007).

A historic division also exists between those groups organized and led by mental health consumers and groups comprised of and representing family members of people with mental illnesses. Some visible and active groups for the families of people with mental illnesses initially positioned themselves against smoking cessation initiatives and some continue to express ambivalent or conflicting attitudes about smoking cessation after the development of the Partnership. These attitudes are sometimes expressed as fears that quitting smoking might add to the stress of managing their loved ones' illness (and thus quitting could prove to be burdensome to the family members as well). A leader in one of these family organizations noted several times that his organization would support smoking cessation if "it's done right," (which presumably means they will support it if people are not forced to quit and are given adequate resources to help them in quitting).

5.4.1.2 Tensions About the Benefits and Risks of Tobacco Use

Adding to family members' conflicted feelings about tobacco cessation, according to one mental health advocate, is a sense that "on the surface it seems like this product,

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

tobacco, somehow helps people.” In the focus group interviews and during participant observation, people with mental illnesses noted that although they were educated about the health risks of smoking, they were encouraged to smoke by their family members, friends, and even Alcoholics Anonymous (AA) sponsors when they were stressed or irritable. One person with mental illness mentioned that his family members regularly brought him packs of cigarettes when they came to visit during his six-year stay in a psychiatric hospital and suggested that he smoke when he was feeling bad or down.

There are studies that suggest that tobacco can be calming and can help people with certain symptoms (Dalack et al., 1998; Esterberg & Compton, 2005; Patkar et al., 2002). Moreover, an online survey of nearly 1,000 mental health consumers conducted by the Depression and Bipolar Support Alliance (DBSA) from November 2007 to February 2008 found that over half of current smokers with depression or bipolar disorder report that smoking helps treat their symptoms of mental illness (DBSA, n.d.). At the same time, a study by Prochaska, Hall, and Bero (2008) found that the tobacco industry was instrumental in promoting the positive aspects of tobacco use for people with schizophrenia. The belief that smoking helps people mentally when it also has serious implications for people’s physical health is at the heart of the tensions in addressing this issue. If nicotine does help the symptoms of schizophrenia, for example, some smoking cessation advocates argue that they would support nicotine use by people with mental illnesses in other, less harmful forms, such as NRT.

This is a challenge, then, because family advocacy organizations have a critical

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

influence on the direction of changes in the mental health field. The mental health community has historically listened closely to these groups as valuable collaborators in any reforms to the mental health system. Internal tobacco industry documents illustrate that some of these organizations have received funding from the tobacco industry and the industry has paid for and promoted studies that promote tobacco use among people with mental illnesses (Prochaska, Hall, & Bero, 2008), which may contribute to their attitudes and feelings about smoking.

5.4.1.3 Continued Apathy Regarding Smoking

In some ways, the resistance or apathy toward cessation has weakened among these advocacy groups. Some of these groups now say that they support cessation, but that their new foremost concern is that nicotine replacement therapies (NRT) be readily provided to ease withdrawal symptoms and that other activities be implemented to replace the actual behavior of smoking (suggestions which the smoking cessation providers and advocates fully support for all populations). As matters currently stand, especially given this shift in attitudes, it does not appear, at this point, that the Partnership faces a strong oppositional counter- or resistance movement, although the tobacco control movement more generally has often had to compete against so-called smokers' rights groups and other industry fronts (Apollonio & Bero, 2007). At the same time, though, there remain some chief organizations whose buy-in is central to the movement's ultimate success and who continue to lack the necessary commitment or cohesiveness on this issue.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

5.4.1.4 Feeling Overburdened and the Challenges of Getting Airtime

Another potential weakness noted repeatedly by leaders in mental health is that mental health providers are overburdened by large caseloads and time pressures and are regularly bombarded by demands to keep up with various performance measures. These constraints are often associated with the low levels of resources provided for mental health services and the vast service needs of the population they serve that keep them “busy doing 19 different things.” According to a smoking cessation advocate and researcher: “I think the major weaknesses are just the nature of the healthcare system for this population. It’s severely neglected in terms of resources and training.”

The mental health field faces many unfunded mandates, such as reporting for quality monitoring, wherein they are expected to provide services or provide tasks without adequate funding. As a result, conversations about smoking cessation tend to focus heavily on money, reimbursement rates, and systems for smoking cessation services. The mental health leaders also described their fear of losing the few resources they now have, and noted that the focus on cessation might take them away from opportunities to advocate for additional funds. In the words of one mental health advocate, “We don’t have very much already but there have been assaults against what we do have on the Hill [in Congress].”

The public mental health system has historically not been funded to do this [smoking cessation], they haven’t seen it as their role or responsibility... Many of the old-timers, like me, that were trained ten, fifteen, maybe even five years and probably even three in some cases, three years back to decades back would see this as a medical role not a psychiatric role and that, “Gee, it would be nice if we could get to it but we’ve got to deal with the psychosis. We’ve got somebody who’s acting out or won’t take the

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

meds and why should we try and bite off another responsibility when we aren't funded for it and the feds won't pay for it and da-da-da. So I think one of the challenges is just that we've got to have the mental health community realize the shared benefit of participating in these kinds of initiatives for the people we serve. So that's a challenge when in the past it hasn't been seen as a responsibility nor have people highlighted the cost and benefits to the clientele we serve. We need to be doing a better job of that.

In the words of a representative to a mental health professional organization and a mental health researcher:

There are so many competing demands for the clinical staff and for our clients that it's a real tall order to really get people's attention...and our clients are struggling with those kinds of issues. And they are so often so socially disadvantaged that they are not getting the best of healthcare anyways because they are so disenfranchised so often that it's hard to get airtime on a very busy agenda for clinicians and consumers.

Thus, "getting airtime on a very busy agenda for clinicians and consumers" is an important challenge for this effort, particularly for a population that is "so disenfranchised" that it often has unmet and yet extremely important social, psychological, medical, and financial needs. Even if the entire mental health field were to agree that smoking cessation is a priority, it would still have to compete with other top issues on a lengthy list of priorities and would have to compete for the same resources and training that are already severely lacking.

As a result, mental health leaders and practitioners also have their own hierarchy of important issues given that "their plates are full." Because of the various obstacles and challenges that mental health consumers experience on a regular basis, some people in the mental health community will feel that "taking on smoking is almost trivial in

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

comparison” to other issues such as the needs of veterans coming back from war and “suicide and very delusional patients,” issues which are acute and require immediate and complete attention. Thus, many clinicians feel that people with mental illnesses are predisposed to smoking, that they cannot quit, that there is so much going on in the lives of mental health consumers that they should not worry about it, and that assisting them in quitting is not in their scope of practice because they are not educated to perform this task or reimbursed for their efforts. According to Campion et al. (2008), “some staff may see a conflict between doing the greatest good for the majority through a smoke-free policy, and an attempt to respond to individual need when dealing with distressed, non-comprehending individuals in crisis” (p. 224).

Given these competing priorities, several leaders said that smoking cessation is probably not a “natural priority” and not a number one concern for any of the Partnership members from the mental health field. Below is a list of other priorities mentioned by mental health leaders, beyond smoking cessation, derived from interviews and participant observation.

“Natural” priorities for mental health providers based on interviews with leaders in mental health and participant observation (listed in no particular order):

- Suicide
- Seclusion and restraint
- Veterans’ issues
- Physical activity/weight control
- Medication management
- Homelessness/poverty
- Mental health parity legislation
- Funding/reimbursement

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Of course, this list of natural priorities can and should be problematized. What makes a priority “natural” for the mental health community has to do most generally with funding and identity. Those issues that create additional sources of funding and/or provide mental health providers and advocates with a niche seem most apt to appear on this list, whereas other significant concerns for people with mental illnesses and their families are not necessarily considered within their scope of practice. While over time some mental health providers and advocates started to see a place for smoking cessation on this list, it still remained secondary to their other priorities.

According to a mental health government official, taking on smoking as a priority not only means adding to this list but also means having to listen to others who will ask, “Why is this a priority?”

I guess there are people who will say this is only a slight thing, why are you focusing on smoking? It’s not as important as focusing on better treatments for schizophrenia. There are people who will say, “Why is this a priority?” And then you will have people who will say, you know, I don’t want to stop smoking, so don’t do anything. You’ll have a number of resisters across this system.

At the same time, one mental health advocate expressed hope that the issues brought forward by the Partnership will not be diluted and that tobacco does not become “the soup of the day, the priority of this week and next week it’s something else.” In truth, even the wordy name of the Partnership, which was chosen by its members, suggests that the priority for at least some of the mental health leaders is on wellness first and tobacco cessation second (or third, or fourth...). One of the fundamental issues mentioned in each conversation regarding the need to address other priorities is that

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

people in the mental health field often expressed that if they did not have to constantly fight for the money they deserve for their clients and for providing treatment, they would have more time and energy to devote to the growing list of critical issues.

5.4.1.5 Insularity as a Weakness

Furthermore, two strengths of the mental health community, a strong connection and regular communication, can also become powerful potential weaknesses. It was because no one was talking about smoking cessation that the community as a whole ignored it as an issue for so long. Thus, the fact that the mental health community tends to “talk among themselves,” a common practice in every community, means that someone must be talking about smoking cessation if it is to reach the attention of the broader mental health field. While this has happened with the development of the Partnership, there is a risk that the conversations about smoking will be limited to those organizations that are involved in the Partnership, with little information or knowledge infiltrating other organizations, facilities, or providers who are not yet involved.

Thus, there are significant hindrances to mobilization. Although some participating mental health leaders felt that “our job is to promote health and wellness and that the promotion of health and wellness includes eliminating smoke inhalation and tobacco use,” they suggested that the mental health field requires consistent reminders of the importance of cessation to maintain it among its many priorities. As described in Chapter 4, messaging about the importance of the issue needs to be strategic and resonate with the realities of the various target audiences such as the lived experiences of people

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

with mental illnesses and the competing demands for mental health providers and advocates.

5.4.2 *Weaknesses for the Smoking Cessation Field*

5.4.2.1 Avoiding a Blanket Approach

One of the weaknesses the leaders identified on the smoking cessation side is a sense that smoking cessation providers and advocates may be perceived as insensitive to the special needs of the populations they work with. Mental health leaders said that those working in smoking cessation are perceived of as taking a “blanket approach,” wanting everyone to stop smoking, and are sometimes seen as “a group of people who put no smoking signs everywhere and that’s it.”

Moreover, some of the leaders in both mental health and smoking cessation expressed that smoking cessation providers often focus on the negative aspects of smoking: the risks to health, the costs of smoking, and the risks to loved ones and rarely on the positive aspects of living a smoke-free life. A smoking cessation provider and advocate noted, “I am an old smoker myself. It’s wonderful not to smoke,” and said she felt strongly that the wonderful aspects of not smoking needed to be illuminated to motivate others to quit. She warned:

We need to clean up our own act if we were going to get really involved with mental health consumers because just scaring people doesn’t work and I’m really leery of scaring the hell out of people who are scared anyway and have fewer resources or support.

She worried that the common belief in the smoking cessation and tobacco control field

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

that one should “love the smoker, hate the smoke,” or love the person but dislike and disapprove of the behavior of smoking, does not “go very deeply, especially [among] tobacco people who have been around for a long time.” This is especially true because the person and the “problem” are seen as being deeply intertwined. She suggested that providers and advocates should discuss smoking with people with mental illnesses sensitively, carefully, reassuringly, and without bias or judgment.

Similarly, there was a sense, both among the leaders in smoking cessation and those in mental health that smoking cessation providers often act as though they have all the answers for helping people to quit. The mental health leaders cautioned that quitting might be more complicated for people with mental illnesses. Thus, a smoking cessation provider and advocate suggested that the “tobacco people...be quiet and listen and...have mental health people tell tobacco people about what a complex issue it is for them because it is complicated.” This quote highlights a larger issue: the importance of listening to one another and respecting each other’s concerns. Some leaders felt that they were being pushed into action without having an opportunity to fully appreciate the perspectives and insights of the other field.

Overall, both mental health and smoking cessation leaders felt that smoking cessation providers tend to move at a fast pace and focus on efficiency rather than on the specific patient and his or her unique needs. This weakness relates to the broader issue of pacing which presents problems for collective action by the mental health community and smoking cessation fields and will be addressed in the next section.

5.5 Asymmetries Between the Mental Health and Smoking Cessation Movements/Fields

It is apparent from these discussions about the strengths and weaknesses and similarities and differences between the mental health and smoking cessation fields that asymmetries exist between these two fields and their corresponding movements. For example, leaders noted that the smoking cessation field tends to move quickly, using the science and evidence-based practices that have been developed, tested, and enhanced over the years. They are able to work swiftly by learning from their long history of successes in helping people to quit and because they realize that they must work quickly in order to save people from premature death and disease. With the realization that tobacco use is an epidemic that has been predicted to kill one billion people this century, the larger tobacco control movement must act with great speed if it is to change this startling statistic.

On the other hand, people in the mental health field tend to conduct their work and approach treatment more slowly and deliberately. Mental illness is a chronic condition and is often treated over long periods. While the new hope for recovery has helped speed some treatment efforts in the last decade, the focus remains on maintenance, because there continues to be uncertainty about whether full remission of symptoms will be the ultimate outcome. While the mental health field also utilizes evidence-based practices, people in the mental health field work with the understanding, even in the age of a recovery, that their main role is to manage a chronic disease. A smoking cessation

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

advocate postulated that the slower pacing may also be due to mental health being “a somewhat isolated field and there’s so much stigma, there has been so much stigma apparently attached to people with mental illness that they kind of circle the wagons a bit, at least there’s some mentality around that.” Furthermore, mental health movements have existed for over 100 years, while the tobacco control movement has been in existence less than half as long. As a result, the mental health movement may have activated strategies to maintain its momentum over an extended time period.

The issue of pacing extends to the ways leaders, practitioners, and clients in both fields *expect, plan, and work* to make change happen. Expectations have had to be modified within the context of this collaborative effort. At this point, it is not clear whether the mental health community can speed up its pace of change or if the smoking cessation community is able and/or willing to sustain a long-term, go-slow approach. While there are attempts to understand one another, as indicated in the following statement by a smoking cessation advocate, it may be that the perspectives of individuals and groups in the two fields are fundamentally different in ways that will make continued collaboration unlikely.

I’m not saying it can’t be done, it can. It’s much harder for me to understand my colleagues on the mental health side, and I think it’s much harder for them to understand us too. But they are a bit put upon having been sort of relegated to second-class citizenship, not given parity, fear—a lot of those things over time have contributed to a mentality that is not perfect for moving ahead on a partnership like this.

Challenges also exist related to the language issues discussed in Chapter 4, which hinder the ability of the Partnership and other initiatives to engage in collaborative

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

efforts. As described earlier, the smoking cessation leaders expressed a pervasive fear of offending, insulting, or saying something incorrect that might anger or alienate the mental health leaders because of the cultural differences between them. A smoking cessation advocate said:

So it's easy to kind of offend or to make inaccurate assumptions. The ability to work together becomes somewhat—they're really sensitive to so many different things that you have to proceed with a great deal of caution. And while I think it's really important to be sensitive to the needs of other people, it sometimes makes it really hard [chuckle] to work together to spend all your time trying to figure out how not to offend anybody. So I think there's some hypersensitivity that is—it would help if people in mental health or the people in mental health who are more comfortable reaching out would do more of that.

The smoking cessation leaders felt a need and also expressed a desire to learn and integrate the appropriate terminology so that they could begin to engage in conversations with those in mental health, but they still tended to keep quiet in order to learn or, in many cases, to avoid confrontation. Thus, the distinctive experiences and cultural identities of both fields may pose problems for working together. While the mental health community and smoking cessation field are respectful of these differences and express a desire to learn and work together, these asymmetries pose challenges to the development of a collective cultural identity through which a social movement can be mobilized.

	Mental Health Field	Tobacco Control Movement
Dates back (approx. year)	1845 (modern day consumer movement beginning in 1960s)	1964
Broad focus in 2008	Suicide prevention, veterans issues	Youth smoking prevention
New broadened focus to	Health	Mental health/substance abuse

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Targeted industry	Pharmaceutical industry	Tobacco industry
Led by	Advocates, consumers, activist clinicians	Advocates and providers
Main concern	Treatment	Health
Work to	Fight stigma	Denormalize tobacco use
Pace	Slow and consistent	Fast and efficient

5.6 Maintaining Momentum and Motivation

Overall, it appears that the leaders in smoking cessation have tried to accommodate to this slower approach. With this slower approach comes the challenge of fostering and sustaining the motivation required to maintain the Partnership’s momentum over time. Simply put, “it’s hard for people to stay motivated.” The issue of motivation was framed as a particular issue for mental health clinicians, who may feel discouraged in trying to help people quit. A mental health researcher and representative to a mental health professional organization said that there is a need to take “a long view on this process and [support] clinicians in helping clients get back on the saddle and try to quit again.” These general motivational issues are compounded by the lack of a “critical mass” of success stories that can be, to borrow from the quotation below, “paraded around” for providers, consumers, and advocates to see what life is like for people with mental illnesses who no longer smoke. A mental health clinician described the changes he regularly sees in his clients who have quit, but acknowledged that few people are familiar with these powerful stories.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Their symptoms are less intense, they're taking less medicine, they're functioning better...what people see is just the opposite, people who sit around and smoke all the time. Until there's a critical mass and people can really see what a huge difference it makes in people's lives and how less sick they are. People always think it's going to get worse, it's going to be terrible; they really need this. But the opposite is the case in terms of how much better people are and how much better they feel and how much better they look. But those cases, there's just not a lot of them. A lot of this that's happening is difficult work. I think this is the biggest weakness that becomes a barrier. There aren't enough cases there to parade around to say this is why we're doing this.

Another possible obstacle to maintaining momentum in mobilizing around this issue is that unlike previous partnerships developed by the SCLC, the Partnership's members are "all CEOs." Many of the people in the Partnership hold high-level positions in their organizations. In what might be considered an endorsement of the issue, many executive directors, medical directors, and CEOs of mental health advocacy and government organizations chose to serve as their organizations' representatives at the summit that eventually led to the forming of the Partnership and continue to be the primary contact persons for the Partnership's activities. The SCLC quickly realized that having so many high-level, opinion leader members in the Partnership might ultimately slow the momentum given the other demands on their time. In many of the other partnerships in which the SCLC is involved, a large number of members are management-level professionals who are responsible for daily organizational leadership and operations. These are the "worker-bee types" who can commit large amounts of time to the issue of smoking cessation, and who can carry it forward with day-to-day efforts and can become "champions" through their commitment.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

A smoking cessation advocate and provider suggested that a primary goal of the Partnership might be to create champions who can move the issue onto the broader public's radar screen, based on worries such as one mental health advocate expressed, that "I'm worried that [the SCLC] is one of the few places that's made a full-time commitment to this issue" because they have the financial resources to do so. This opinion illustrates the dire need for people within both the mental health and smoking cessation fields to take leadership roles in carrying out the goals of the Partnership if a social movement is to develop. While the SCLC will not always exist because it relies on funds provided by foundations to be used over a specific time period, the hope is that attention will continue to be directed to this issue well into the future until smoking rates among people with mental illnesses more closely match the overall population.

5.7 "We're Doing This, and They're Doing That": Delineating the Roles of the Mental Health and Smoking Cessation Fields

While the leaders acknowledged the collaborative nature of the Partnership and the importance of a collective effort in creating a broader movement, they clearly differentiated the roles of the mental health community and the smoking cessation field. In general, the leaders felt that the mental health community, as "insiders," need to create policies and change practices and procedures for themselves, instead of relying on the experiences of the smoking cessation communities. Taking the lead would display their commitment to the issue and demonstrate that the mental health community "believe[s] in

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

it.” This is because “it’s very hard to influence this particular world from the outside.”

The main role is in seeing themselves as the people who can make the difference, can make the change. It’s not going to happen from outside...The mental health community needs to take ownership of this as the problem from lots of different perspectives and, again, take ownership of it to develop policies and implement it as a priority.

Thus, given the number of competing priorities for mental health providers, advocates, and policymakers, as mentioned previously, leaders from both fields noted that it is of utmost importance to the effort that the mental health leaders continue to recognize tobacco use as a priority issue and act in ways that exhibit this interest and focus. Yet a smoking cessation advocate and researcher noted the challenges inherent in relying on the mental health community to spearhead this effort: “for so many years we’ve ignored them and they feel that way and now they want to create their own change but this isn’t one that they’ve put on their radar yet.” Addressing tobacco use is still seen as just one more thing that needs to be done, and it is very challenging for outside groups to position it as a priority on their radars.

The mental health community can also serve as role models and leaders in providing education, shifting understanding, supporting informed decision-making, and ultimately changing the culture. “I think first and foremost it’s the duty of the mental health community to suggest to people who are smoking that there may be an alternative for them that they should consider.” A smoking cessation advocate described how people in the mental health field must step up as leaders if this effort is to succeed:

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

I think it's really a matter of a kind of follow-the-leader sort of thing. There's a lot of work to be done in adapting our treatment protocols to work with this population but I think the whole leadership from the advocates to the providers, the administrators, everybody, they need to kind of get on board and point in the same direction and I think it will help move a lot of this forward without huge effort. I mean there needs to be effort on the treatment side but I think getting over this hurdle that it can't be done, there's lots of reasons not to do it, all the pushback, I think, about even trying to do it is really standing in the way. So I think one of the biggest things they can do is to kind of change their minds about it, [chuckle] maybe is a way of putting it, and that will help move a lot of things forward.

There are also many significant roles for the smoking cessation field in this effort.

A mental health clinician stated that “the smoking cessation field is light years ahead of the mental health community in terms of what they can offer in terms of treatment,” although it still remains unclear whether their “canned” approach to cessation is suitable for people with mental illness. The role of the smoking cessation field was described as supporting new research and evidence-based interventions, education and awareness, information, and cutting-edge resources to formulate new ways to help people with mental illnesses quit smoking, or at the least to offer new expectations so that providers can know what does and does not work in supporting and working with this population. The smoking cessation field also has much to teach about effective social marketing, media, messaging, behavior modification for tobacco cessation, and communication. “I think their role is to refine the science and to provide tools to the providers and to consumers. Again, to raise consciousness about the incredible prevalence of smoking.” In general, according to a mental health advocate and government official, “everything they've done for any other population they need to do for people with mental illness.”

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Many participants agreed “if smoking cessation is your top priority, then given the statistics, people with mental illness should be your top priority too.” A smoking cessation advocate and provider said:

We’ve created all kinds of programs to help most individuals quit but I think we’ve missed, by and large, this whole chunk [of people with mental illnesses]. Since the general population of smokers is dropping, then the percentage of co-morbid smokers is going to continue to increase unless we start to address it. So I think we need to become much more proactive in this area.

5.8 Developing and Implementing Strategies for the Partnership

The SCLC developed a two-pronged strategy aimed at fostering the growth of the Partnership as a whole, while simultaneously working with individual members and member organizations that were ready to move forward on smoking cessation initiatives. A mental health advocate called these highly motivated organizations “little Johnny Appleseed sprouts.” This strategy allowed for success to be examined and defined in two ways: within individual organizations and for the Partnership overall. While the leaders felt that there have been some individual initiatives that have taken hold such as the development of toolkits, trainings, and conference talks, the feeling nine months after the summit when the interviews were conducted was that the Partnership as a whole had not “synergistically come together yet.”

Each of the leaders noted during the interviews their own personal goals for the Partnership. These goals illustrate the various ways in which the problem of smoking among people with mental illnesses is socially constructed in ways that create differing goals and unique courses of action for a collaborative effort.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

- Provide needed resources
- Increase awareness of and legitimize the “problem”
- Empower and spread the message that consumers are able to quit
- Identify research priorities and increase evidence-based practices for tobacco cessation for people with mental illnesses
- Identify new initiatives and findings
- Demonstrate in a finite period of time that smoking has decreased among people with mental illness
- Promote education and fluency when talking about this issue
- Determine how the government could and would pay for smoking cessation services for mental health consumers
- Identify sources of funding for peer-to-peer programs
- Develop, advocate for, and make the link to improving access to and quality of physical health services for people with mental illnesses
- Overall, implement a set of strategies that can make these goals a reality

Yet, in general, the question of goals for the Partnership seemed to make many participants uncomfortable about their lack of awareness of the Partnership’s efforts. Some leaders responded apologetically, that they “should have reviewed the action plan” before starting the interview. These types of comments suggested that very few, if any, Partnership members were aware of the specific strategies that had been developed at the time of and immediately following the summit. Some leaders suggested that they would also like to develop more specific goals, such as reducing the prevalence by a certain percentage within a set period of time. The words of one participant, a representative of a mental health professional organization, capture the essence of the members’ feelings about the Partnership at the time of the interviews: “I think the group came together very quickly, but I wasn’t quite sure what this partnership was going to do, how we were

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

going to work together.” There was a sense that the initial emphasis was on coming together, but that the next steps regarding how to actually work collaboratively to reduce the rates of smoking for people with mental illnesses were unknown or vague.

5.9 Evidence of Changes

Overall, the leaders felt that the Partnership was on track in meeting the goal of promoting inter-group collaboration. A smoking cessation advocate stated: “The fact that they were even discussing this topic is important.” A mental health government official said: “I think the initial role was to get together a critical mass of people and organizations that could begin to address this issue within the mental health community. And I think that role has started and is continuing.” Participants commonly expressed that the Partnership’s efforts were bigger than the pieces in which they were personally involved, and people were hesitant to voice any feelings about it, often noting, “I’m sure I’ve only seen a small part of it.”

The leaders expressed optimism regarding the Partnership’s future, suggesting that “there’s no real ceiling to the upside here.” A representative to a mental health professional organization said, “I think people are genuinely energized.” Yet some participants distinguished between what they saw as the theoretically limitless possibilities for the Partnership and the reality of what progress might be made given limited resources and the challenges described above.

Because the Partnership has only been in existence for two and a half years, its

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

influences cannot yet be fully determined. Participants described the changes they had witnessed and been part of, such as incorporating conversations about smoking among people with mental illnesses into their organizations' messaging, and including it in lectures that they presented across the country. The leaders stated that the topic of how to reduce the rates of smoking among people with mental illnesses was now a subject of conversations at influential national conferences. A smoking cessation advocate noted that at the 2007 National Conference on Tobacco or Health, a large national tobacco control conference, there were several well-attended sessions on mental health, whereas sessions on this topic did not even exist a few years ago.

Also, I observed conversations after the 2008 conference of the American Psychiatric Nurses Association, a professional organization for mental health nurses, in which it was noted that the sessions on smoking cessation were extremely popular. APNA ultimately devoted an issue of its journal to this issue and promoted the message that “failure to act equals harm” to encourage psychiatric nurses to do *something* about tobacco use (APNA, n.d.). These examples demonstrate that the issue of mental health and smoking cessation has found a place within the priorities of various target groups.

Further, in the three years since discussion of this issue and planning for the summit began, numerous new resources have been developed, including the NASMHPD toolkit *Tobacco Free Living in Psychiatric Settings* (Parks & Jewell, 2006) and *Morbidity and Mortality Among People with Mental Illness* (Parks, Svendsen, Singer, & Foti, 2006), the *Smoking Cessation for Persons with Mental Illness: A Toolkit for Mental*

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Health Providers (2009), and the Rx for Change Mental Health Peer Curriculum

Tobacco-Free for Recovery: Assisting Mental Health Consumers with Tobacco Cessation

(2008). Articles have also been written, largely within the academic literature, which can be used to raise awareness among practitioners.

According to the leaders, one of the most obvious and perhaps most contentious changes that has taken place since the formation of the Partnership is the increasing number of smoke-free psychiatric facilities. Smoking cessation efforts and tobacco control policies, such as smoking bans in psychiatric facilities, have been framed around protecting and promoting the health and wellness of patients and staff, both those who smoke and those who do not, and also as an attempt to change the mental health culture so that smoking no longer plays such an integral role. Many leaders described NASMHPD's toolkit as effective in helping facilities transition to implementing smoke-free policies. Also, as mentioned in the previous chapter, beginning in 2008, there have been efforts to engage people who manage and provide services for the state toll-free quitlines to develop strategies for better educating and training the quitlines staff about the specific needs of people with mental illnesses. These new advancements and resources stemming from the Partnership are regularly highlighted in the SCLC's electronic communiqué to make all members and interested parties aware of these changes.

Perhaps one of the most influential effects of the Partnership so far has been the collaboration between the SCLC (as a result of the Partnership) with the Substance Abuse

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Mental Health Services Administration (SAMHSA), the government agency in the U.S. Department of Health and Human Services responsible for providing assistance and support in the areas of mental health and substance abuse, regarding both prevention and treatment, so that all people with these disorders can live in the community. The SCLC initiative with SAMSHA, called the 100 Pioneers for Smoking Cessation Virtual Leadership Campaign, provides \$1,000, free technical assistance, and support and education to grantees of 2008 SAMHSA awards who are interested in establishing smoking cessation initiatives within their organizations. This initiative has been met with great enthusiasm. Moreover, as further evidence of the influences of this collaboration, in August 2008, just one month after the SCLC and its partners provided an in-service training to SAMHSA employees on tobacco cessation, SAMSHA officials announced that all meetings and conferences organized by or primarily sponsored by SAMHSA would take place in states, counties, or towns that have adopted a comprehensive smoke-free policy (American Public Health Association, 2008).

5.10 Recognizing Opportunities for Movement Development

The Partnership has just started to take advantage of the many initiatives that can help mobilize a movement or establish a foothold within existing movements. First, many mental health leaders talked with excitement about the opportunity to connect with primary care and “the larger medical community,” including family practice and internal medicine, so that all providers who care for people with mental illnesses would be aware

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

of and could address this issue. Also, several leaders mentioned the opportunity to integrate and streamline care for people with mental illnesses through advancements in electronic medical records and other mechanisms for tracking health conditions and behaviors. These records would enable primary care and mental health providers to work together to offer comprehensive care to their patients.

I think we can get all that information more centralized, and consumers can help build their priorities and get their providers to understand all their priorities. Certainly by integrating mental health and overall health care more effectively so that clinicians, doctors, nurses in the health care system and the specialty mental health system have a chance to address smoking cessation with clients who are clearly defined as having mental health problems.

Another area in which the Partnership has not yet focused great attention is in highlighting the role of the tobacco industry in encouraging people with mental illnesses to smoke and in perpetuating myths about tobacco use in mental health settings.

According to a mental health advocate and government official, mental health advocates have been “as susceptible to some of the tobacco industry’s claims as people with mental illness and staff have been. So some of the work that’s come out we must do a better job of showing the really horrific history.” This could provide a target for a movement, and could align the Partnership’s work with other successful tobacco-control efforts that have made the tobacco industry’s targeting strategies a focus of their work.

While the Partnership’s membership includes peer-run organizations (organizations led by people with mental illnesses), and while some of the people that represent these organizations self-identify as having a mental illness or as having loved

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

ones that have a mental illness, there are always important opportunities to engage additional peer voices to spread the message that cessation is possible. According to a mental health advocate and clinician, it is important to empower people to be “self-managers of their own health.”

Consumer-run organizations are particularly important in this in modeling the behavior that you can be a self-manager and that you can accomplish your goals and be successful. Peers can model that for other peers and can guide them to take care of their health issues, attending to their overall health.

There is a sense among Partnership members and the mental health community more generally, that people with mental illnesses can contribute positively to discussions on how to change the mental health culture. It is important, however, that these efforts truly engage mental health consumers. Most participants mentioned that if peers “did sign onto this, they can be a very, very powerful force,” yet at the same time, if consumer advocates are uninvolved, efforts to encourage smoking cessation would be very difficult to implement and enforce.

With the inclusion of more people with mental illness in roles in the mental health system, there is a risk of people with mental illness being seen as “token” representatives of those with personal experience who are expected merely to be present as decisions are made. Some initiatives want to be recognized as being receptive to the perspectives of people with mental illness, but then give them very little opportunity to voice their opinions and concerns. In other instances, the same people with mental illnesses (often prosumers who take on professional roles because of their experiences with mental

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

illness) make the rounds in representing people with mental illnesses, although the people who fill these professional roles tend to be unique in many ways. The development and increasing use of the Rx for Change Mental Health Peer Curriculum suggests that this curriculum is one tool that can be utilized to educate and engage more peers in providing support to other people with mental illnesses or in sharing their own personal stories to become more involved in efforts to address tobacco use.

A further opportunity exists in that many member organizations of the Partnership, particularly in mental health, are national organizations with hundreds of state and local affiliates. These affiliate programs, which often offer support and educational groups, can also be tapped to spread messages and provide education.

According to a mental health advocate:

To basically understand the power of our networks and map those out in a way so that we could start not only developing and testing technologies in these networks but perhaps linking them up with other resources...in the communities to sort of forge a powerful national movement to try to make a difference in this really important health-related area. So we all at one level or another at least conceptually bring our networks to that table because we have hundreds of community mental health centers, we have fifty state commissioners...a \$28 billion budget if you consider all the state budgets together, and us with our 320 affiliates, NAMI with their thousand support groups, DBSA with all of its support groups. It gets pretty impressive when you start bringing all these people together. If we can get them all pointed in the same direction, I think we can do some pretty spectacular stuff.

Finally, as mentioned, there was a sense among the leaders that it was difficult to gauge progress. In order to determine whether actions to date have “worked,” leaders stated that there was a need and an opportunity to measure progress by gathering data

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

regarding tobacco use in this population over time. While this kind of data collection (e.g., about the percentage of psychiatric facilities that are smoke-free, the percentage of people with mental illness who smoke, the percentage of mental health providers and staff who smoke, etc.) was a core strategy outlined by the initial Partnership members during the 2007 summit, there has been limited measurement of the rates of quitting per se. A mental health government official stated that she hopes there will be a “move toward a public health measure that shows a reduction in smoking among people with mental illnesses.” The development of a system for keeping records of the number of people who have quit, such as a public health measure, could help mobilize people to act by allowing them to see in a concrete way the changes taking place among mental health consumers, staff, and in hospital settings.

5.11 Inadequate Funding as the Key Barrier to Movement Development and “Success”

The SCLC has provided small grants (typically \$25,000 or less) to mental health organizations for smoking-cessation-related projects and initiatives. These initiatives include activities to gather and analyze data, write reports, and create/enhance smoking cessation-related educational campaigns. These grants, often generous by the standards of many mental health grantee organizations, represent a positive gesture toward generating support and commitment.

From a resource mobilization perspective, the grants provide motivation for

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

initiating and sustaining the organizations' efforts. Yet serious concerns remain among the leaders regarding future funding for such initiatives. The major barrier to movement success identified by nearly all of the mental health leaders was a fear of not having enough money to encourage practitioners within the mental health field to engage in smoking cessation efforts and to sustain macro-movement-like initiatives such as the Partnership. Those working in smoking cessation, while sympathetic, expressed discomfort and surprise regarding the constant discussions of money, but attributed this myopic focus to the fact that the mental health field has been severely under-funded for so long.

Leaders in both fields ultimately acknowledged that efforts aimed at “doing something about smoking” could only go so far without adequate funding. According to a mental health advocate and government official, “it’s hard to require something in the system that you don’t pay for.” Most leaders in mental health mentioned fears of another unfunded mandate that would add additional strain to a very stressed system. Questions have arisen about how to change the financing system for mental health, so that smoking cessation can be systematically and fully integrated into the usual care practices. While the SCLC initially tried to move conversations away from funding as the Partnership developed, the SCLC has begun to see these practical financial questions as an indication that the Partnership may have successfully moved beyond raising awareness and must now face the on-the-ground realities related to policy and financing that will help change treatments and cultural practices for the long term.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

5.11.1 The Partnership as a Social Movement Organization (SMO)?

An important question related to whether the “problem” of smoking among people with mental illness has resulted in or will result in a social movement from a resource mobilization perspective is whether the Partnership can be considered a social movement organization (SMO). A SMO is an organization that shares the goals of a social movement and works toward reaching the goals of the movement.

SMOs are defined by their formal structure. Structure is a complicating criterion when it comes to determining whether the Partnership is an SMO because of the somewhat unusual nature and structure of the Partnership. The Partnership was developed using the performance partnership model, a flexible and results-oriented model based on four questions. These four questions are: (1) where are we now? (to develop a baseline); (2) where do we want to be? (to develop a target); (3) how will we get there? (to develop multiple strategies); and (4) how do we know we are getting there (to develop measures). This model is used when a group of partners or potential partners work to address the same issue. The process ultimately develops a baseline, target, process measures, and outcome measures to be addressed by the partners. Partnerships developed under this model are not intended to be “organizations,” but rather efforts that can be sustained and collectively fostered. These partnerships are an attempt to limit the negative influences of bureaucracy and enable and encourage members to shape, direct, and move the effort based on their own strategies and vision.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

It is the SCLC's vision, according to one of its staff, to "keep the Partnership vague and not to turn it into some institutionalized non-profit or something with officers and letterhead because what is never really opened never has to close and it's more sustainable that way." In this way, the Partnership is more like a symbol than an organization. It is self-sustaining and does not rely on outside resources, but instead exists purely as an amorphous entity of committed members and member organizations that strive to reduce the rates of smoking among people with mental illness. There was a sense that, as such an effort, even if the partnering organizations and leaders in these organizations move on to new jobs or to new foci, the Partnership itself could continue to thrive. It is notable, however, that this notion of the Partnership's role stands in contrast to what several participants expected of the Partnership. Many leaders wanted the Partnership to be highly visible and to become a well-known entity in and of itself. The SCLC staff often felt the need to counter the urge to formalize the Partnership and tried to remind members that the goal was not to promote the Partnership but to promote smoking cessation among people with mental illnesses.

Thus, exactly what the Partnership *is* remains a question, and the description of what it is, and its purpose, is likely to vary depending on who is speaking. Regardless of how it is described, it is evident that the SCLC provides the professionalization and controls the resources for the Partnership, filling a common role among modern-day SMOs. While the Partnership is not intended to be an SMO (because it lacks the defining "organization"), it is still possible that the Partnership can be seen as a distinctive form of

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

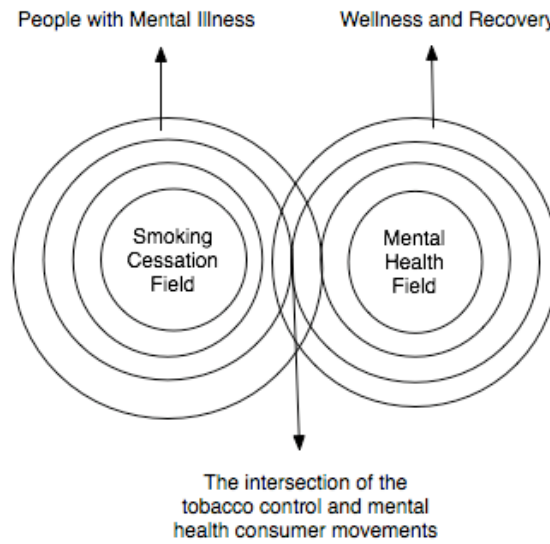
SMO, perhaps a social movement partnership (SMP). This novel form of SMO, which may also exist for efforts led by coalitions, may reflect a new way of stimulating movement activity.

5.12 Filling a Unique Space Within Existing Movements

SMOs often play coordinating roles in movements. It is common for more than one SMO to be a part of a movement and/or for one SMO to take on only one component of a movement's overall mission. Thus, it can be argued that the Partnership has successfully nestled its way into an overlapping space within both the mental health and the tobacco control movements. The National Mental Health Partnership for Wellness and Smoking Cessation, as an SMP, is leading one component of each movement. Within the mental health movement, the Partnership has found its niche among efforts to broaden and reframe opportunities for wellness and recovery for people with mental illnesses. Within the tobacco control movement, the Partnership has become a leading force in broadening opportunities to reach out to underserved populations who continue to experience high rates of tobacco use. Figure 4 below depicts how a broadening of the jurisdiction of the smoking cessation field to work with and treat people with mental illnesses and a broadening of the jurisdiction of the mental health field to deal with issues relevant to wellness and recovery have created a space for the Partnership's initiatives.

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

Figure 4 The Intersection of the Tobacco Control and Mental Health Consumer Movements



5.13 Benefiting from Spillover of Other Social Movements

This Partnership is likely to benefit from social movement spillover from movements beyond those in mental health and smoking cessation as well. For example, these efforts could also connect with and/or benefit from other movements such as those focused on the wars in Iraq and Afghanistan, since so many veterans are returning home as smokers with debilitating mental illnesses like Post Traumatic Stress Disorder (PTSD). Other possible movements from which to benefit from spillover include the environmental movement (smoking bans as promoting environmental equality), civil rights and disability rights movements, antipoverty, and health reform movements. The

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

targeting of people with mental illnesses by the tobacco industry is one way in which to engage these other movements in discussions of the relevance of this issue to their own movement goals. Connecting with other movements is especially important because the tobacco industry has a history of trying to align with various movements. Making smoking *cessation* a component of these established movements could therefore be extremely effective.

5.14 Conclusions

The Partnership's efforts may be best described as a component of the broader health social movements in the mental health and tobacco control arenas. Addressing the needs of people with mental illnesses has long been seen as fitting within the purview of the tobacco control field, a field that is known to have reached out to various movements and to have successfully form alliances with diverse groups toward helping all people quit smoking. On the other hand, smoking was initially disregarded as a key component of the wellness and recovery orientation of the modern mental health movement in favor of other behavioral issues such as physical activity and nutrition. While smoking seems an obvious target for wellness strategies given its high prevalence among people with mental illness, and given that quitting smoking can be the single most important action a person can take for his or her health, the fact that smoking has been an ingrained part of the mental health culture for so long made it easy to overlook. The new recognition among mental health leaders of smoking as a "problem" and the efforts to encourage

Chapter 5 | Mobilization Efforts and the Evolution and Broadening Scope of the Mental Health and Tobacco Control Movements

smoking cessation within the mental health field which are now well underway can undoubtedly have a real impact for mental health consumers when consistently and powerfully linked with this wellness and recovery agenda.

The funding of the SCLC by foundations, which has been used to support essential Partnership-related activities, is significant from a resource mobilization perspective. This funding is critical as it allowed for SCLC staff time to be devoted to the Partnership. Discussions around this issue may have never occurred, or at least not as quickly, if people were not committed to the issue and to making things happen. The development of a unique social movement may not be the most appropriate goal for the Partnership, and working across fields to solve problems does not necessarily require a “movement,” nor does successfully doing so constitute a movement. It is possible that infiltration and culture change through existing movements is more powerful and effective. If the Partnership’s efforts do not move past this initial stage of collaboration, the mutual consciousness-raising that has occurred and the proliferations of new tools and passionate discussions on this topic will have still created new and profound linkages between the once-divided mental health and physical health (smoking cessation) fields.

Chapter 6 | Structural and Policy Considerations and Implications in Addressing Tobacco Use in the Mental Health Community

“I [worked in the mental health field for a long time] and there was not one conversation or one dollar related to smoking among people with mental illness. It’s embarrassing to admit it, but it is the truth. It kind of creeps me out. It makes me think ‘what else did I miss out on that was a big deal.’ I’m sure there is a list of things.”

- Mental Health Advocate and Government Official

6.1 Introduction

The issue at the heart of this dissertation is how to most effectively engage people with mental illness in their attempts to quit smoking. Yet the dialogues (given the newness of efforts in this area), have focused on micro and meso level considerations and have overlooked some significant structural and policy considerations and implications that are critical to this issue.

This discussion explores funding as key to success, the role of the tobacco industry and connections to the pharmaceutical industry, the structural issues influencing the social position and health of people with mental illness, policy changes including mental health parity and other potential changes, the importance of more research and better dissemination of findings, and the ways in which efforts to institutionalize smoking cessation efforts within the mental health community (and a focus on mental health within the broader health care system) can lead to a reduction in the rates of smoking

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

among people with mental illnesses. Broadly, this chapter addresses the following research question:

- What are the health policy, public health, and social justice implications of the Partnership's efforts?

6.2 Funding as the Key to Success

6.2.1 The Role of the Foundation

Funding is critical to addressing the high rates of smoking among people with mental illness. As mentioned, the SCLC receives generous funding from two foundations, the Robert Wood Johnson Foundation (\$10 million) and the American Legacy Foundation (\$3 million). This money is used to support SCLC staff time, provide technical assistance efforts, and to award small grants to organizations, including mental health groups, doing work in the area of smoking cessation. Without this foundation support, the SCLC would not exist and would therefore not be able to provide assistance to initiatives like the Partnership.

Foundations began in the 19th century, coming to fruition as a result of the estate tax structure. Today, there are about 73,000 foundations that provide grants to diverse causes. Foundations have few restrictions on how to distribute their money and are designed to support causes that the founders, their families, or their governing boards consider to be worthy (McCarthy & Zald, 1973; Schlandweiler, 2004). The Robert Wood Johnson Foundation (RWJF) has played an enormous role in combating tobacco use in the United States. When Steven Schroeder interviewed with the RWJF Board of Trustees

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

for the position of President, he mentioned that he would be in favor of expanding the “health” component of the foundation’s “health and health care” mission. He noted that grant making in the area of substance abuse would be one way to do that. Once he was selected, Dr. Schroeder had to persuade other staff that this was a worthy cause for the foundation’s money. In February 1991, Dr. Schroeder brought the Board three proposed new goals for the foundation: (1) reducing harm from substance abuse including tobacco, alcohol, and illicit drugs; (2) improving access to basic health care services; and (3) improving the care of people with chronic conditions. The board quickly approved the second and third goals but shied away from the first because of fears about a backlash from the tobacco and alcohol industries. Ultimately, the compromise was to begin with underage smoking and drinking and then to work from there. By 2006, RWJF had provided nearly a half-billion dollars to tobacco-related initiatives through 522 grants ranging from \$5,000 to \$99 million (Atlantic Philanthropies, 2007; Bornemeir, 2006; Fleishman, 2007).

RWJF’s tobacco programs were recognized as one of 12 high-impact initiatives in Joel L. Fleishman’s (2007) book, *The Foundation: A Great American Secret*, because RWJF “brought to bear the enormous resources of a major funder, and had the courage to tackle a problem that, for political reasons, the federal government had been hesitant to touch” (2007, p. 143). RWJF also has an extensive history of supporting mental health programs (Grob & Goldman, 2006). The other grantor of the SCLC, the American Legacy Foundation (ALF or “Legacy”), received its money from the Master Settlement

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

Agreement. Since its inception, Legacy has focused on tobacco-related causes. The ALF's grant to the SCLC has allowed the ALF to support programs in the mental health community as part of their "priority populations program" which provides funding to populations that are disproportionately targeted by the tobacco industry or who often lack the tools and resources to combat smoking in their communities.

Foundations typically support smaller programs that garner quick success and resolution. Yet there has been a recent shift within foundations to an interest in providing support to macro-level efforts that are focused on broad systems change with the awareness that these types of initiatives may require more time and resources. For example, RWJF led the way in creating a role for foundations in supporting advocacy (Atlantic Philanthropies, 2008). Similar to RWJF, other foundations such as the California Endowment and Atlantic Philanthropies have turned their attention to supporting the development of social movements and other macro-level change efforts (Atlantic Philanthropies, 2008; California Endowment, 2009).

The support to the SCLC may not have been possible without the emphasis on tobacco control and this shift in perspective in foundations' funding priorities. Many of the leaders noted in their interviews that the infusion of resources to the SCLC from RWJF and the American Legacy Foundation was crucial to the development of the Partnership and for elevating smoking cessation among people with mental illnesses to problem and priority status.

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

6.2.2 *Funding for Mental Health and Smoking Cessation*

Nearly every mental health leader stressed the importance of addressing funding issues to further their objectives. Ironically the mental health field has benefited in many ways from the largess of the tobacco industry and the promotion of tobacco use. First, the revenues from tobacco sales have historically provided a valuable source of discretionary income to psychiatric facilities (Parks & Jewell, 2006). Secondly, the tobacco documents provide evidence that mental health programs and organizations have received funding and cigarettes from the tobacco industry (Apollonio & Malone, 2005; Prochaska, Hall, & Bero, 2008). Third, while it was expected that the Master Settlement Agreement (MSA) funding would be used to support tobacco control programs, it has been diverted to other state programs in need, such as mental health services (Houston & Kaufman, 2000, p. 752-753).

Thus, there exists tension in the competing needs for and sources of funding for mental health and smoking cessation. While the funding to the SCLC to support the Partnership and other initiatives has been extremely important for making smoking among people with mental illnesses a priority, concerns about future funding and reimbursement have slowed the progress. A fundamental question that emerged in several interviews is whether resources will continue to be available to support these initiatives after the SCLC's funding ends in the next three years. The time-limited nature of the funding made members of the Partnership worry about the future, acknowledging that resources would be a key to continuing efforts in this area and that it would be difficult to

maintain the present level of activity without funding. The mental health leaders expressed a concern that the mental health field already has too many unfunded mandates that need attention and that the only way to make smoking cessation a formal priority is to ensure that there is financing to support it.

6.3 Recognizing the Role of the Tobacco Industry and the Pharmaceutical Industry

6.3.1 The Role of the Tobacco Industry

A central focus of the tobacco control movement has been to reveal the deceitful actions of the tobacco industry in contributing to smoking in the U.S. and globally. Yet the role of the tobacco industry has not been a focus of the efforts of the Partnership although mental health consumers recognized that the industry perpetuates their need to smoke. The tobacco industry is a prime example of a “manufacturer of illness,” that is, companies that produce material goods and services and “also produce, as an inevitable by-product, widespread morbidity and mortality” (McKinlay, 2005, p. 551). In 1999, the tobacco industry spent nearly \$1 million per hour on marketing its products (Malone, 2009). Greater understanding of the role of the tobacco industry in encouraging tobacco use by people with mental illness may provide motivation for helping mental health consumers to quit.

Although the mental health consumer focus group participants demonstrated a high level of awareness of the tactics used by the tobacco industry in general, they did not

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

recognize that they were perhaps the target of these actions because of their *mental health status*. Yet the tobacco industry's own documents reveal that people who are homeless and those who have mental illnesses and substance abuse issues have been deemed a desirable customer base that is important to the tobacco industry's bottom line (Apollonio & Malone, 2005; Lasser et al., 2000; Prochaska, Hall, & Bero, 2008). Apollonio and Malone (2005) further reveal that the tobacco industry has promoted a culture of tobacco use in mental health settings by targeting, marketing to, and offering free cigarettes to psychiatric facilities. In fact, the document archive includes letters written by psychiatric hospital staff and administrators asking tobacco companies for free products "to be used for patient treatment" (Prochaska, Hall, & Bero, 2008, p. 5).

The documents also expose tobacco industry-sponsored research on the "self-medication" hypothesis, attempting to show that people with schizophrenia are less susceptible to the harms of tobacco. The tobacco industry has funded research on tobacco as a coping mechanism in psychiatric patients, with a "promise to bear fruitful findings," and has promoted smoking in psychiatric patients through direct (distribution, advertising, scientific publications, and meetings) and indirect (policy) strategies (Prochaska, Hall, & Bero, 2008, p. 4). Moreover, there is evidence that the tobacco industry played a role in narrowing the definition of tobacco dependence in the *DSM* (Neuman, Bitton, & Glantz, 2005).

In an article on the role of the tobacco industry in promoting tobacco use among people with schizophrenia, Prochaska, Hall, and Bero (2008) found that the beliefs that

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

individuals with schizophrenia need to smoke as a form of self-medication, that quitting exacerbates their psychiatric symptoms, and that people with schizophrenia cannot and do not want to quit, have been among the greatest barriers to tobacco treatment for people with schizophrenia. Many of the “causal stories” about why people with mental illness smoke including those supported by leaders in the mental health field and family members of those with mental illnesses are stories originally created by the tobacco industry with the intent of increasing profits and market share (Prochaska, Hall, & Bero, 2008). According to a mental health advocate and government official:

We must do a better job of showing the really horrific history [of the tobacco industry’s tactics]. That the research was paid for that said that people with schizophrenia did so much better when they smoked. Because advocates bought that too and still are buying it, whether they smoke or not. So we’ve got a lot of education and course correction to do.

6.3.2 *Concerns About Medications and the Pharmaceutical Industry*

While “a lot of education and course correction” is necessary to make the mental health community more aware of the tobacco industry’s tactics, the mental health community is very aware of similar strategies used by the U.S. pharmaceutical industry. There exist complicated partnerships between the pharmaceutical industry and patients’ groups (Herxheimer 2003). Alarming, Cosgrove, Krimsky, Vijayaraghavan, & Schneider (2006) found that of the 170 panel members responsible for revisions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), 95 of them had one or more financial associations with companies in the pharmaceutical industry. In fact, *all* of

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

the members of the panels on “Mood Disorders” and “Schizophrenia and Other Psychotic Disorders,” conditions where medication is the first line of treatment, had financial ties to drug companies. It is not out of the realm of possibility then, just as some focus group participants noted that they felt that their psychiatric medications made them crave cigarettes, that the tobacco industry might know that the use of certain medications may induce nicotine cravings. Many mental health consumers felt that they would continue to smoke for as long as they were on these medications, presumably for the rest of their life. It is not widely known that when a person stops smoking, medication levels in the blood, including psychiatric medication levels, may rise and cause adverse effects. This reaction can lead a client to return to smoking (Morris et al., 2009).

At the same time, there is a generalized fear and distrust of medications among people with mental illness. The marketing of drugs for mental illnesses has become “an enormous pharmaceutical enterprise” in which the high cost of medication and the serious side effects still pose significant problems for people with mental illnesses (Mechanic, 2008, p. xii). “These drugs have been marketed as perhaps few products ever sold in America have been” (Gittleman, 2008, p. 9).

Over time, though, awareness has increased about the likely effects that psychiatric medications may have on weight gain, diabetes, high cholesterol, insulin resistance, and metabolic syndrome (Roshannaei-Moghaddam & Katon, 2009). However, providers commonly overlook these side effects because the medications successfully help control problematic behaviors (Whitaker, 2002). Yet the side effects can cause

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

mental health consumers to forgo these medications completely.

The general apprehension expressed by the focus group participants about using NRT in quitting efforts may be a consequence of these concerns about medications in general or their feelings about their inability to quit. Interestingly, while several mental health consumers directly linked their smoking to their psychiatric medication use, the leaders (some of whom were psychiatrists) did not mention medication use as a factor contributing to the high rates of smoking in this population. While the literature often mentions smoking as a form of self-medication (Lawn, Pols, & Barber, 2002; Schmitz, Kruse, & Kugler, 2004; Schroeder, 2009; Williams & Ziedonis, 2004; Ziedonis, Williams, & Smelson, 2003), the connection between psychiatric medications and tobacco use has not been fully exposed.

Moreover, concerns about the smoking cessation medication Chantix (varenicline), which has received attention in the media, may have heightened the uncertainty among providers about which smoking cessation medications to prescribe. On July 1, 2009, after three years on the market, Chantix and Zyban (bupropion) received a black box warning, the FDA's most serious caution, on its packaging information due to increased risk of suicidal ideation (Harris & Wilson, 2009). A study by Stapleton et al. (2007) found that most smokers tolerated varenicline and that there was no evidence that it exacerbated mental illness (Stapleton, Watson, Spirling, Smith, Mibrandt, Ratcliffe, & Sutherland, 2007), but concerns about these medications may be warranted and public perception of the fears about Chantix may pose obstacles and

concerns about all types of cessation aids. On a more positive note, the attention to these medications may increase awareness of the high rates of smoking among people with mental illnesses.

6.4 Structural Issues Influencing the Social Position and Health of People with Mental Illness

There are significant political, economic, and social structural issues that exist for people with mental illness that contribute to their smoking and create barriers to their quitting. Many of these structural issues have been discussed previously. In this section, I will examine some further issues that have not yet been addressed.

6.4.1 Social Support, Education, and Income

People with serious mental illness often face challenges in developing and maintaining social relationships (Davidson et al., 2004), and social support can be a key component in successfully quitting smoking (Hanson, Isacson, Janzon, & Lindell, 1990). Mental health consumers' social networks can be considerably smaller than those without serious mental illness, and their support often comes from mental health and social service professionals, family members, and peers (Angell, 2003). Many people with severe mental illness report feeling isolated and lonely (Green et al., 2002).

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

For people with SMI [serious mental illness], perceptions of adequate social support are associated with several psychological benefits, including increased self-esteem, feelings of empowerment, functioning, quality of life, and recovery, while the absence of social support appears related to greater psychiatric symptoms, poorer perceptions of overall health, and reduced potential for full community integration (McCorkle, Rogers, Dunn, Lyass, & Wan, 2008, p. 359).

Furthermore, low levels of education and income are common among both among smokers and people with mental illness (Patkar et al., 2002). Many people in both groups work and receive Supplemental Security Income (SSI) and Social Security Disability (SSDI) to cover their monthly expenses. People with mental illness are 60% more likely than others to report incomes below \$20,000 per year (Glied & Frank, 2009). Because people with mental illness tend to be dependent on limited, fixed incomes, cigarettes can comprise 27-36% of their average monthly budget (Mechanic, Bilder, & McAlpine, 2002; Steinberg, Williams, & Ziedonis, 2004). Although many of the focus group participants stated that they did not find it a challenge to pay for cigarettes, many of the leaders noted that smoking is a “huge problem financially for our patients,” and that although they made sure they had money for cigarettes, other important necessities might be overlooked as a consequence.

For example, although focus group participants were well-educated about the health risks of smoking, they mentioned that “sometimes we don’t get a lot of money to eat like we’d like to and cigarettes stave off hunger.” In a similar qualitative study of smoking and quitting among Australian “psychiatric clients” with schizophrenia, cigarettes were considered a basic core need valued more than food (Lawn, Pols, & Barber, 2002). Furthermore, low levels of income mean that people with mental illnesses

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

often have limited food choices and substandard living environments available to them, factors that can contribute to additional health problems (Everett et al., 2008).

Epidemiological studies in the United States have estimated that patients with schizophrenia consume about \$20 billion worth of cigarettes annually a disproportionately high economic burden for these patients and for society at large, especially considering the low prevalence of schizophrenia in the population (Lohr & Flynn, 1992). Smokers often require higher dosages of psychiatric medications in order to obtain the desired clinical effects; thus the side effects and costs of medication may also be increased (Williams & Ziedonis, 2004).

6.4.2 Employment

As a result of these challenges, people with psychiatric impairments constitute the largest and most rapidly growing subgroup of Social Security Disability Insurance and Supplemental Security Income beneficiaries (Drake et al., 2009). Surveys consistently reveal that fifty to seventy percent of adults with mental illness express a strong desire to work but must often work at reduced wages and in more menial occupations (Drake et al., 2009). People with any mental disorder of working age report employment rates of 48-74% depending on the survey used, while employment among people with serious mental illness is 32- 61% (Mechanic, Bilder, & Alpine, 2002).

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

Despite the evidence that many persons with mental illness with appropriate education hold jobs throughout the occupational structure, most programs and services are oriented to less-educated clients and employment in relatively low status jobs such as janitors, dishwashers, and other low-paying service occupations. This is often the course of least resistance, since the demand for such workers is high and placement involves few barriers. As a result, persons with mental illness often are placed in jobs below their educational background (Mechanic, Bilder, & McAlpine, 2002, p. 251).

Common barriers to employment for people with mental illness include stigmatization by employers, concerned about unpredictable performance, work absenteeism, and disruptions in the workplace (Mechanic, Bilder, & McAlpine, 2002). Yet consistent employment can provide benefits including greater income, access to health insurance coverage, enhanced self-esteem, improvements in quality of life, and reductions in mental health service use (Drake et al., 2009). Additionally, tobacco use can create challenges in securing employment (Schroeder, 2009).

6.4.3 Medicaid and Access to Smoking Cessation Resources

Given that many mental health consumers have low incomes and many do not work, it is common for people with mental illness to receive health care coverage through state Medicaid plans. These plans often create unnecessary barriers to obtaining needed services including NRT and counseling for smoking cessation. In 2006, approximately 35% of adult Medicaid recipients nationally were current smokers compared to 20.8% of the overall population (Pleis & Lethbridge-Cejku, 2006; CDC, 2007). In the same year, eight states did not provide Medicaid coverage for tobacco-dependence treatment, seven states covered all FDA-approved smoking cessation medication and at least one form of

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

counseling for all enrollees, and only one state (Oregon) covered all treatments recommended by the 2000 *Clinical Practice Guideline* (CDC, 2008). Yet, while these plans can undoubtedly be criticized for restricting access to NRT (CDC, 2008) and often not providing coverage to all of those eligible to receive such benefits (Mechanic, 2008), it should be noted that Medicaid, Medicare, and Supplemental Security Income (SSI) have “greatly expanded the resources available to treat mental illness” by providing financial resources and access to health care to those with low socioeconomic status (Frank & Glied, 2006, p. 91). However, there remain significant barriers to accessing mental health and smoking cessation resources for the 45 million in the U.S. under age 65 who lack health insurance (Kaiser Family Foundation, 2008).

6.4.4 *Addressing Health Care System Issues*

Due to a general lack of access to primary care services, the public mental health system is often the de facto health system for many mental health consumers; thus the mental health community has had to take on some of the broader health issues by default. The care of people with mental illnesses has been made separate from the general health care system so that the health concerns of people with mental illnesses are typically seen as psychological treatment issues rather than health care or treatment *system* issues even if they relate to the person’s physical health. The mental health system, with limited resources, must provide support to many people who do not have insurance and who present complicated physical and mental comorbidities.

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

6.4.5 Mental Illness, Smoking Cessation, and the Role of the State

An examination of this topic is not complete without a discussion of the role of the state in creating barriers to health and access to care for people with mental illnesses. People with mental illnesses experience, as the above discussion demonstrates, significant obstacles to achieving adequate levels of social support, education, income and access to employment and health care. I will take a moment to examine some ways in which the state perpetuates these disparities, leading to problems with access to care and the 25 year gap in longevity.

People with mental illnesses, depending on the severity of their illness and many other factors including level of social support and access to resources, often do not have the ability to work. They are therefore not considered “contributing” members of society as defined solely in capitalist economic terms. At the same time, people with mental illnesses often require regular use of health care services (such as visits to a therapist and consistent use of medication) to control the symptoms they may experience as a result of their illness. Thus, not only are people with mental illnesses not able to be “productive” members in helping the state to fulfill its function of creating conditions that are favorable to economic growth, they may also use a disproportionate amount of the state’s limited resources.

The state has created structures that provide support for (or in many cases or in many cases do not support for) the wellness and recovery of people with mental illness. Mental health care, especially without parity, is seen as a commodity and not a right. The

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

notion of people with mental illness as “consumers” is an example of this. Access to and the costs of care and treatment are high and the out of pocket expenses can be huge without the support of government programs.

In the U.S., health care benefits are largely tied to employment. People with mental illnesses, given the challenges experienced with employment, often receive support from Medicaid and SSDI that help them to secure health care and money on which to live. These publicly subsidized benefits help to ensure the legitimacy and operation of social order. The benefits and restrictions on care and personal finances are dictated by those policies set forth by the state. Many of those who have psychiatric disabilities who want to work are discouraged from doing so as it would put these benefits at risk.

Within the organization and social structure under the state, people with mental illnesses are often vulnerable and relatively powerless, creating conditions for mistreatment and discrimination. People with mental illnesses often experience cumulative disadvantage (such as low economic status, minority background, and mental illness) and multiple layers of stigma. This stigma may interfere with the sense of social solidarity that can come with a collective experience, creating challenges to mobilizing against the state. While people with mental illnesses are an example of one of many powerless groups under the state, the sheer power provided to the tobacco industry demonstrates the potential influence of those groups and industries that create profits, even if it is at the risk of human health and life.

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

Thus, when considering the state's inability or unwillingness to fully address the social, political, and economic needs of people with mental illnesses, it may be suggested that the lack of attention to the issues so pertinent to health and quality of life of people with mental illnesses may be an attempt to alleviate the social and economic "burden" or "crisis" of caring for this population. This may also explain why the mental health community so often has to fight for essential resources. The state may "benefit" from denying people with mental illnesses the same rights given to other members of society, such as access to support in quitting smoking given its high correlation to premature disease and death. Yet I attest that the state, mental health consumers, and the mental health community benefit from increased opportunities and resources for wellness and recovery and if this is not fully recognized, considerable challenges for all three will remain.

6.5 Policy Change

6.5.1 Mental Health Parity

Since the passage of the Mental Health Parity and Addiction Equity Act of 2008 in October 2008 as part of the Emergency Economic Stabilization Act of 2008 (H.R. 1424) there is a newly emerging hope regarding the financing for mental health services. The parity bill was included as an attempt to generate legislative support for the bailout package. Under the new law, starting in January 2010, group health insurance companies that offer coverage for mental illness and substance use disorders must provide coverage

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

on the same terms as physical illness, including deductibles, co-payment rates, out-of-pocket expenses, and treatment limitations or service restrictions. The law establishes new coverage requirements for the 113 million Americans enrolled in group health plans, including 82 million people who are protected by state parity laws (Shern, Beronio, & Harbin, 2009). Prior to its passage, group health insurance companies could promote mental health care and addiction coverage in their plans but could institute arbitrary treatment restrictions or decrease reimbursement rates.

While a major milestone, there are some significant exemptions in this plan that raise important questions about it will affect people who need mental health care. While group insurers will soon have to comply with federal parity laws, there are no legal requirements for insurers to provide these services in the first place. Companies with fewer than 50 employees are also exempt. Implementation of the parity bill is now the key issue, in particular, and cost containment in mental health and substance abuse benefits is a major concern (Shern, Beronio, & Harbin, 2009). It has yet to be determined, given increasing health care costs and new coverage requirements, whether states and private insurers will meet these requirements and restructure their plans accordingly. Also, it is unknown how mental health parity will have an effect, if at all, on the treatment of the physical health needs of people with mental illnesses.

Health insurance for mental health services improves access to care and provides protection against the financial costs of treatment (Glied & Frank, 2009). Yet parity alone will not solve the significant issues of access to care. A study published in April 2009

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

found that of 3,400 U.S. primary care physicians, more than two-thirds were unable to obtain outpatient mental health services for their patients. While some barriers were related to issues with health care plans, other important obstacles included a shortage of providers, lack of health insurance, stigmas, and inadequate funding for community-based services. While physicians in states that had enacted mental health parity legislation were slightly less likely to report plan barriers and inadequate coverage compared to states with no parity laws, the author concluded that national mental health parity legislation will reduce some but not all of the barriers to providing quality mental health treatment and that policymakers should focus on ensuring adequate health coverage as well as an adequate supply of providers in local communities (Cunningham, 2009).

6.5.2 Integrating Mental and Physical Health Care

There should be a consideration of opportunities to configure managed care to cover basic health needs such as smoking cessation. Mechanic (2008) notes that managed care is here to stay, but that it is also simply a framework. “What takes place within this framework will continue to be effected by our economic and social philosophies and values and by our conceptions of the nature of mental health and mental illness” (Mechanic, 2008, p. xvi). Furthermore, the establishment and expansion of electronic medical records that will make physical and mental health information more accessible to multiple providers will permit the integration of physical and mental care and make it relatively easy for information about tobacco use to be documented at intake.

6.6 Research and Dissemination

Many of the leaders in mental health and smoking cessation indicated a need for increased research on smoking cessation for people with mental illnesses and faster dissemination and adoption of these findings into the community. Many smoking cessation researchers generally exclude people with mental illnesses as study participants (Fiore et al., 2008). Research on this topic has grown over the last eight years, yet seems to be focused largely within hospital settings, which may or may not translate to the community (Everett et al., 2008). This research can be used clinically, but more information on prevalence rates and predictors of tobacco use among people with mental illnesses could also be useful for service planning and policy initiatives (Morris, Giese, Turnbull, Dickinson, & Johnson-Nagel, 2006).

It was also evident from the interviews with leaders in mental health and smoking cessation that only a handful of articles in the academic literature have garnered the attention of the advocates and providers. This may not be particularly noteworthy, since academic research is often buried behind the walls of academia, but it does suggest that there may be a need to create better channels for disseminating this information to the leaders to maintain and validate the momentum and direction of the Partnership's efforts. It is interesting to note that the same studies and statistics reported by the mental health leaders were those that had been reported in the media.

Furthermore, as we learn more about how to help people with mental illnesses quit smoking, there will always be a need to better understand the potential unique needs

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

of certain subsets of this population. As mentioned in the methods section, the average age of the focus group participants was 62, and many of the participants in the focus groups were likely to be experiencing changes related to aging. For many of these older adults, cigarettes have been part of their life for decades and may have been a primary coping mechanism for their mental illness for a significant length of time.

Currently, very little is known about the needs of older smokers with mental illness. This is likely because there is little concern for smoking among people with mental illnesses in general, because people with severe mental illness have life expectancies 25 years less than the general population, and because ageism and a disregard for the experiences of older people is rampant. Because of this disparity, the smoking rates among older adults are thus the lowest of any age group, at 10.2% (CDC, 2008). Smokers die earlier and people with mental illness die earlier too, so it is unlikely that there will be many people who smoke in the oldest age groups. The leaders in both mental health and smoking cessation expressed that smoking among older adults with mental health problems was likely to be a low priority because of this. Even if this population is small, it has been noted that older smokers are more likely to want to quit than smokers of other ages (CDC, 2002). However, the leaders in smoking cessation have found that there is often a sense of fatalism and resignation among older smokers who are more likely to experience the ill health effects of their long-term cigarette use. Leaders also suggested that older adults with mental illnesses who smoke may experience discrimination from providers who believe it is too late for them quit although research

demonstrates that there are health benefits to quitting at any age (Taylor, Hasselblad, Henley, Thun, & Sloan, 2002).

6.7 A Fundamental Goal is to Institutionalize

6.7.1 Normalizing Smoking Cessation as a Critical Component to Mental Health Treatment

One fundamental goal of the Partnership's efforts is to institutionalize the various practices and policies that support cessation among people with mental illnesses. This means normalizing smoking cessation as a critical component of regular treatment, rather than viewing smoking cessation as an afterthought only. It has been noted that the more clinicians talk with a person about his or her smoking, the more likely the person is to quit (Fiore et al., 2008). Peer programs can supplement providers' support and treatment, and training programs should be expanded to include how better to help peers quit smoking.

6.7.2 Accountability and Incentives

Based on recommendations from my participant observation, it is important that mental health and addiction treatment providers are provided education regarding incorporating tobacco treatment into their daily practice and that they actively advocate for these important services (Ziedonis & Williams, 2003). Providers and organizations should be made more accountable through the development of systems that make it feasible to collect information from all patients and clients about their smoking

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

behaviors. One suggestion mentioned in meetings I witnessed as part of the participant observation is that incentives, including financial motivators, should be institutionalized to ensure that clinicians feel that smoking cessation is within their practice and synonymous with providing good care. Research supports motivation-based treatment, blending mental health and addiction treatment approaches, and integrating tobacco dependence treatment within mental health settings (Ziedonis et al., 2003).

6.7.3 Education

In addition, the literature, participant observation, and interviews with leaders suggest that smoking cessation should be a compulsory component of educational programs for students preparing to enter the mental health field. Likewise, smoking cessation information should be incorporated into continuing education opportunities. All allied health professions should receive information on both smoking and mental illness, and this information should be included on examinations required for basic licensure and advanced practice certification. All of these actions could help smoking cessation to become recognized as a priority issue that disproportionately affects the lives of people with mental illness.

6.7.4 Linking Mental and Physical Health Care Systems Across the Continuum of Care

Overall, physical and mental health care should be provided and linked within the health care delivery system (Colton & Manderscheid, 2006). Information about model states and programs that have successfully created this linkage should be disseminated.

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

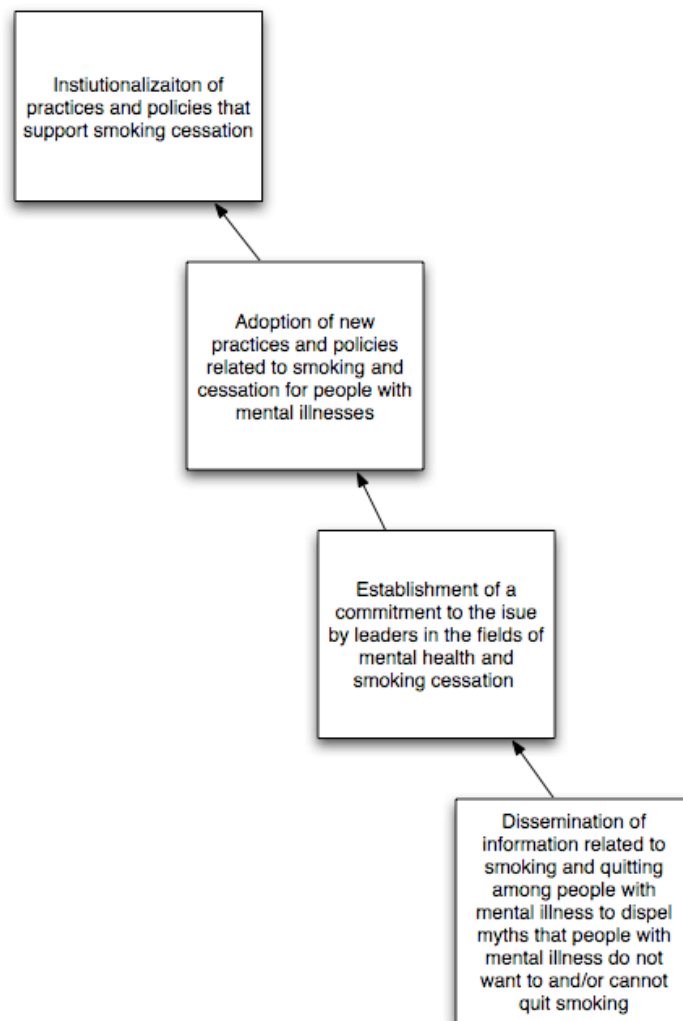
Tobacco dependence treatment like physical health care generally should be seen as a basic service to people with mental illness and a responsibility of all health care practitioners. Support for smoking cessation should follow people from hospitals to the community, including group living environments and drop-in centers.

6.7.5 Institutionalization Processes and the Effects of Institutionalization

Based on Rogers' (1995) theory of diffusion of innovations, the Partnership and other initiatives focused on addressing smoking among people with mental illness could follow the process of institutionalization framework illustrated in the table below.

Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

Figure 5 Processes for Institutionalizing Policies and Practices for Smoking Cessation for People with Mental Illness



Chapter 6 | Structural and Policy Considerations and Implications for Addressing Tobacco Use in the Mental Health Community

Prochaska, Hall, and Bero (2008) questioned, “Might it be that the mentally ill are the largest remaining group of smokers, not because they need to smoke, but rather because they are among the last to be treated?” (p. 8). Institutionalizing policies and practices to remove barriers to cessation treatment and support will finally help give people with mental illnesses the opportunities they desire to quit for good.

6.8 Conclusions

Efforts to address the high rates of smoking among people with mental illnesses were initially focused on problematizing the behavior and its historical cultural acceptance within the mental health community. While there has been some success at creating change on the micro and meso levels, the structural and policy considerations and implications for these efforts have not been fully addressed. This chapter discussed some of these key issues and ultimately suggests that the institutionalization of policies and practices that encourage access to smoking cessation for people with mental illnesses can result in a marked decrease in the prevalence of smoking in this population.

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

“Change is difficult.”

- Mental Health Advocate

7.1 Introduction

This dissertation examined the possibilities for change (including culture change, social change, structural change, and policy change) related to smoking among people with mental illnesses. It tells the story of how the mental health community ignored smoking for decades, but how through the development and efforts of the National Mental Health Partnership for Wellness and Smoking Cessation, tobacco use became a recognized contributor to the growing health disparities for people with mental illnesses. The findings that respiratory and heart disease, not suicide, are the leading causes of death in this population, that people with mental illness want to quit smoking, and the growing awareness of the risks of secondhand smoke exposure have allowed this important issue to be reframed as integral to wellness and recovery. Moreover, the opportunity for collaboration between the mental health and smoking cessation communities quickly became seen as a chance to reenergize discussions about how to integrate the mental health and physical health arenas in new and innovative ways.

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

Through focus group interviews with people with mental illnesses, individual interviews with leaders in the fields of mental health and smoking cessation, participant observation, and a frames analysis of articles from U.S. newspapers, this dissertation demonstrates how the strategic framing and construction of smoking as a problem as well as the broadening scope of tobacco control and mental health movements have paved the way for efforts to support people with mental illnesses in quitting smoking and achieving better overall health.

The perspectives of mental health consumers who are trying to quit and who have quit are critical to these initiatives' ultimate success. While “the mental health system today bears scant resemblance to that of the first half of the twentieth century,” mental illness and its treatment remain largely invisible (Glied & Frank, 2009, p. 1). The mental health consumer movement has initiated important changes in the way we care for and treat people with mental illnesses, and yet the voices of mental health consumers are still not being adequately heard. All in all, research shows that people with mental illnesses want to quit smoking and improve their physical health, but “as citizens frequently relegated to second class, they lack the power to choose needed care” (Manderscheid & Delvecchio, 2008, p. 4). This dissertation attempts to make the perspectives of people with mental illness central to the discussions about smoking cessation because without their input, efforts to help mental health consumers quit smoking may prove futile.

7.2 The Socially Unequal Distribution of Smoking and Stigma

The neglect of smoking highlights deeper tensions regarding the “socially unequal distribution of smoking” and the role and social positioning of people with mental illness in society (Poland et al., 2006, p. 60). The assumptions that mental health consumers do not want to quit smoking, should not concern themselves with quitting because they have other issues to worry about, or should not attempt to quit because tobacco is their “only pleasure,” are biased and discriminatory and only work to increase the stigma and marginalized status of this population.

People with mental illness who smoke may experience a layering of stigma and discrimination that can affect their interpersonal and patient-provider relationships, self-esteem, adherence to treatment regimens, and which may determine whether they receive needed physical and mental health care (Health Foundation of Greater Cincinnati, 2008). People with mental illnesses, given the unequal toll of tobacco on their lives, are disproportionately affected by the negative physical, financial, social, and emotional consequences of smoking, and “if anything, the gap between the health of the general population and the part of our population with mental disabilities is widening” (Everett et al., 2008, p. 9).

Alternatively, quitting smoking may not only alleviate this one stigma, but also has the potential to reduce the stigma associated with mental illness and improve overall health. Smoking can be a barrier to obtaining and keeping a job (Schroeder, 2009; Williams, 2008; Williams & Ziedonis 2004), securing housing (Williams & Ziedonis,

2004), and in establishing relationships with nonsmokers (Christakis & Fowler, 2008).

Thus, quitting smoking may enable mental health consumers to feel and be more connected and may create opportunities to overcome some of the other structural barriers in their lives.

7.3 Collective Efforts to Address the History of Neglect

For decades, smoking within the mental health field was constructed as a treatment modality, a conduit for socialization, and a mechanism for social control as a reward for demonstrating “acceptable” behavior. Overall, both smoking and the resulting health disparities have not been addressed, even when acknowledged. In 2008, two leaders in mental health policy wrote:

Our first impulse is to castigate the members of our field and say, “How could you ever let public mental health consumers die 25 years prematurely? We all know better!” Yet, on second reflection, we are not sure that we were ever fully aware of the severity of the problem. Although this problem was originally recognized as early as 1932 and periodically since then, no one has really talked about it or focused on it for more than a decade. Consumers knew it but were not paid much attention (Mandersheid & Delvecchio, 2008, p. 3).

Where is the outrage? How could this have happened, and how can we ensure that health and wellness are constructed as inalienable rights for people with mental illnesses, just as they are for everyone else? There is a need to eliminate the barriers between mental health and primary care so that a health care system that promotes overall health can be achieved.

In the past, the barriers between mental health and primary-care services seemed to be made of steel. Now, the barrier appears to be made of glass, which at least allows us to see kindred colleagues and consumers on the other side. A telephone call to them to discuss how we can shatter the glass is clearly in order (Manderscheid & Delvecchio, 2008, p. 5).

7.4 The Role of the National Mental Health Partnership for Wellness and Smoking Cessation

Better than a “telephone call,” the National Mental Health Partnership for Wellness and Smoking Cessation has enabled individuals from “both sides of the glass” to sit down, talk with one another, and develop an action plan for collaboration. The National Mental Health Partnership for Wellness and Smoking Cessation encouraged people within the mental health and smoking cessation fields to communicate and work collaboratively and strategically. While there are some asymmetries between the mental health and tobacco control movements that create challenges for collaboration, a connection now exists that all partners hope is strong enough to sustain.

7.5 Addressing Tobacco Use and Smoking Cessation with Sensitivity

Given the historical mistreatment of people with mental illness, including the involuntary institutionalization, the lack of rights, the deeply ingrained stigma, and the power differences that exist between providers and clients that permeate the mental health field, efforts to help people with mental illness to quit smoking need to approach the issue with sensitivity, with an understanding of the reasons for the mistrust of the

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

medical profession, and with an awareness of the needs and interests of the people trying to quit.

Furthermore, as is the case with other health disparate groups, this analysis also points to a need to address the underlying social conditions that are systemic in the lives of people with mental illness, and that may contribute to their poor quality of health, including insufficient access to medical care (including mental health care), low income, and substandard living conditions. “The personal burden of illness represents a significant disparity in health care that must no longer be considered an inevitable de facto outcome of the mental illness experience” (Swarbrick, Hutchinson, & Gill, 2008, p. 70). It is because of these structural conditions that Frank and Glied recognize that while vast improvements in the mental health system have occurred over the last fifty years and the well-being of Americans has improved, the quality of life of those who are most impaired and the poorest has deteriorated. Thus, they conclude that the U.S. mental health system is “not yet well.”

People with mental disorders are among the most vulnerable and disadvantaged members of U.S. society. America’s struggle to address mental illness in its population humanely, efficiently, and fairly has advanced greatly. People with mental illness are much better off than they were just fifty years ago. Nevertheless, we remain limited in our ability to reduce many of the disabling and destructive consequences of mental disorders and we frequently fail to provide circumstances that allow people with mental disorders to live with dignity and meet their basic needs. Our system of care is not yet well (Frank & Glied, 2006, p. xiv).

Tackling the issue of smoking is only one step toward addressing the health disparities and stigma that exist for people with mental illnesses. There continue to be

fundamental issues regarding the care and treatment of people with mental illnesses that must be adequately addressed. The National Alliance on Mental Illness (NAMI) recently gave the nation a grade of “D” in its assessment of services for adults living with serious mental illness (NAMI, 2009). Even with the new parity legislation, the mental health care system continues to be fractured and under-funded. Because of these structural and financial issues, critical opportunities for avoiding or treating preventable health conditions are missed creating unnecessary health disparities for people with mental illness.

7.6 Future Research

It may not be obvious at first glance, but this research topic is a natural fit for a medical sociology dissertation. In *The Birth of the Clinic*, Foucault (1973) demonstrated that medicine is a discourse that can produce its own subjects and showed how medical practice is as open to sociological analysis as any other social institution. This dissertation has sociologically examined the issues around access to and quality of physical health care within the mental health community, and in particular, those needs related to smoking cessation.

Future research should continue to examine this issue both from other perspectives within sociology and outside of it. For example, while the focus of this dissertation was on the social construction of tobacco use in the mental health community, it would be extremely valuable to continue to research this topic, as was

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

started in Chapter 6, from political economy perspectives including a further examination of the state and the role of the medical industrial complex.

While it appears that this topic has gained increased attention within clinical realms such as research in psychiatry, it could benefit from more and deeper examinations on the macro level. Research should continue to examine the social influences of smoking on people with mental illnesses. It still remains unclear to what extent poverty, poor housing, and unemployment are causal factors in the high rates of smoking as compared to the mental illness itself (Phelan, Stradins, & Morrison, 2001). It would also be worthwhile to compare the attitudes and perspectives of those people with and without mental illnesses in similar social situations to explore to what extent mental illness plays a role in these insights as compared to other factors.

Until recently, people with mental illnesses were not included in the clinical trials of the various cessation aids (Fiore et al., 2008). This can only limit our understanding of how NRT can assist people with mental illnesses, one of the largest populations of current smokers. Furthermore, tobacco control studies should examine the role of shifts in policy (such as tax increases) on the smoking behavior of mental health consumers.

Finally, the SCLC has started to develop efforts with the substance abuse community (focused on drug and alcohol abuse and addiction) as an offshoot of the National Mental Health Partnership for Wellness and Smoking Cessation. The substance abuse field, like mental health, has high rates of smoking and a long history of endorsing tobacco use (Fuller et al., 2007; Prochaska, Deluchi, & Hall, 2004). Although these

communities are different, the similarities allow for a co-consideration of the issues experienced by people with mental health and/or substance abuse issues.

7.7 Possibilities for Change: Policy Developments

Recent policy changes and developments in tobacco control and in mental health suggest that there is likely to be a continued focus on these areas in the future. In February 2009, \$75 million was allocated to smoking cessation as part of President Barack Obama's \$885 billion stimulus package. While several sources have attacked this allocation of stimulus funds as unnecessary, there is evidence that this funding may be critical with the downturn in the economy which may threaten vital state tobacco control activities as states must cut valuable health and social service programs to balance their budgets. Moreover, President Obama, who entered the White House as a smoker himself, and his administration have maintained that these programs will reduce health care costs in the long term.

Other new opportunities exist because of the change in leadership and the emergence of new department heads in the administration. Thomas Frieden, a former New York City Health Commissioner and passionate tobacco control advocate who banned smoking in bars in New York City, was tapped to lead the Centers for Disease Control and Prevention. The leader of the Substance Abuse Mental Health Services Administration, which has recently made smoking an important priority issue in its work because of its collaboration with the SCLC, is yet to be named. This change in leadership

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

could help to reenergize government agencies and recommit them to critical health care issues. Furthermore, on April 2, 2009 the U.S. House of Representatives voted to approve legislation (H.R. 1256) that gives the U.S. Food and Drug Administration (FDA) authority to regulate the manufacturing, marketing, and sale of tobacco products. The senate will vote on this legislation in the coming months. While there some concerns about the House's bill, FDA authority has the potential to be a major victory for tobacco control advocates.

Just prior to this approval, on April 1, 2009, a \$0.62 tax increase on every package of cigarettes purchased in the United States took effect, bringing the total federal tobacco tax to \$1.01 per pack. This was the single largest federal tobacco tax increase ever. The tax increase was seen as a way to boost funds for needed health programs (such as the State Children's Health Insurance Program (SCHIP)) while also providing further encouragement for smokers to quit. There is already evidence that this tax increase has changed some smokers' behaviors or made them consider or reconsider quitting. Many state quitlines were overwhelmed with calls from smokers who were motivated to quit in the days prior to the tax increase. In fact, in Michigan, the quitline advertised free nicotine replacement products for those trying to quit as a result of the pending tax increase and had to shut down service completely for nearly three months as the demand (65,000 calls in 5 days) outpaced the available funding (Michigan Department of Community Health, 2009).

On May 19, 2009, California voters were asked to vote on propositions that would

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

determine the future of the California state budget. Proposition 1D would have transferred money from Proposition 10, the tobacco tax, to the general state fund and Proposition 1E would have transferred money from Proposition 63, the Mental Health Services Act, to the general fund. Both Propositions failed as expected. These propositions could have had severe and long-lasting effects on tobacco control and mental health problems, highlighting the very reason that the infusion of funds to support the Partnership was so critical to success. While the voters' decision can be seen as a victory for tobacco control and mental health programs, California's budget crises could severely impact these programs and others as significant cuts are made.

On May 21, 2009, Senator Debbie Stabenow of Michigan introduced the Mental Illness Chronic Care Improvement Act of 2009 (S 1136). This Act would authorize a new \$250 million, 4-year Medicaid demonstration program in up to 10 states that would improve outcomes and satisfaction for individuals with chronic mental illness by improving quality of care and by managing chronic conditions (National Council for Community Behavioral Healthcare, 2009).

Finally, several leaders argued that U.S. health reform efforts, currently underway, are likely to be unsuccessful if they fail to take full account of mental health and substance abuse issues. As an example, failure to treat depression in people with physical health conditions like heart disease, cancer, and diabetes results in higher costs with less successful outcomes (Creed, Morgan, Fiddler, Guthrie, & House, 2002). Moreover, as a result of efforts in tobacco control and smoking cessation, there is now

widespread recognition that tobacco use leads to higher health care costs, and that smoking cessation efforts that overlook the interplay of tobacco with mental health and substance abuse conditions are likely to have only limited success.

7.8 Challenges to Mental Health Policy

In terms of policy changes, Grob and Goldman (2006) argue that:

[The] mix of progress and disappointment derives from the interplay of the work of policy realists and policy idealists. Policy realists have taken advantage of opportunities for incremental change within the realities of an essentially conservative political process. Policy idealists, by contrast, have set out a vision of fundamental change that, though never actually achieved, has served as an objective—a goal or target of those who influence or move the levers of change (p. 181).

The differing worldviews and expectations of realists and idealists have created a “constructive tension in federal mental health policy” that has been resolved in situations where the vision of the realists have been coupled with the creative and strategic activities of the idealists who take advantage of political opportunities to create change (Grob & Goldman, 2006, p.181).

The mental health field continues to struggle with numerous priorities of its own and still remains a separate entity in the broader health care system. As health care reform efforts mobilize, there are likely to be detractors who believe that mental health and substance abuse have already been addressed through the passage of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act in 2008 and through the inclusion of key mental health provisions in the SCHIP Reauthorization in 2009. The

challenge for the mental health community and health reformers is to frame these victories as beginning steps towards the full inclusion of mental health into the mainstream of health policy and the full inclusion of people with mental illnesses into American society.

7.9 Concluding Thoughts

The disparities in morbidity and mortality are widening among people with mental illnesses, and as the single most preventable cause of death, cigarette smoking is a valuable nexus through which to address these health issues. As we have seen, a shift has occurred from historical neglect and in some cases even the full endorsement of tobacco use within mental health settings to a reality in which quitting smoking is now considered integral to wellness and recovery. Tobacco control advocates and providers, with an extensive knowledge on how to help people quit, have served to advance this shift. This offers renewed hope and possibilities for the mental health community, the health care system, and most importantly, for the quality and quantity of life for people with mental illnesses.

With leaders in the fields of mental health and smoking cessation paving the way, important changes have been initiated in how policies and practices encourage tobacco cessation for people with mental illnesses. Yet two years after the establishment of the Partnership, these changes and the reframing of tobacco use as a priority for wellness have yet to deeply influence the day-to-day experiences of people with mental illness. At

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

the same time, the general public remains critically unaware of the disproportionate rates of smoking among mental health consumers.

To some, it may feel like we have “solved” the smoking “problem,” but while smoking appears to be on the wane, it remains prevalent among groups that remain invisible and marginalized in the United States. Efforts to raise public awareness on this social justice issue may not only help mental health consumers to quit smoking, but may help reduce the stigma of mental illness as well. There is also the potential to take hold of the mental health consumer-generated interest that has developed on this topic and at the very least make tobacco cessation an integral part of the next wave of the mental health consumer movement. “As of yet there are no citizen advocacy groups supporting this movement—no race for the cure or brown ribbon—despite tobacco’s heavy toll on the mentally ill” (Schroeder, 2009, p. 71).

Twenty years ago, groups concerned with the AIDS epidemic and premature death of these individuals organized, demonstrated, and sat in. Their actions alerted the media, the public, and elected leaders of the HIV disaster. There was action: Money was, and still is, forthcoming to stem the numbers dying. Now in America, good work is being done to prevent and treat HIV. As a result, the numbers have changed; now more mentally ill die prematurely than people with HIV-AIDS. People with mental illness die primarily due to absence of health care...the public is not informed about what is happening and about the massive number of deaths (Gittleman, 2008, p. 4).

A message disseminated during the 2009 NAMI annual meeting in San Francisco was that rather than stating that people with mental illnesses live 25 fewer years than the population overall, it may be more effective to spread the message that people with mental illnesses living in the United States have a lower life expectancy than those living

Chapter 7 | Promoting Wellness, Creating Change: Conclusions and Future Directions

in Bangladesh. While the 25 year gap is certainly remarkable, NAMI advocates were working to raise the public's consciousness about the injustice inherent in this disparity to elevate public concern on this issue.

In this era of health reform and accountability, maybe it is the appropriate time for smoking cessation and mental health to finally take center stage. Only time will tell whether this issue becomes a leading priority, but in the words of a smoking cessation advocate, “we have launched the blimp. We are on our way.”

APPENDIX A | Interview Protocol for Individual Interviews with National Leaders in Mental Health and Smoking Cessation

Questions for Interviews with Leaders in Mental Health and Smoking Cessation

Introductory questions about you, your organization, and you/your organization's priorities:

1. For which organization do you work and what is your role there? Can you briefly describe your background in the field of mental health and/or smoking cessation and comment on initiatives that you are currently involved in or were previously involved in that relate to smoking cessation and/or mental health?
2. These next questions are about your organization's priorities and also your own priorities in your work.
 - Your organization's priorities:
 - a. How would you rate smoking cessation among your organization's priorities from 1 (a very low priority) to 10 (a very high priority)? _____
 - b. How would you rate mental health among your organization's priorities from 1 (a very low priority) to 10 (a very high priority)? _____
 - c. How would you rate smoking cessation and mental health among your organization's priorities from 1 (a very low priority) to 10 (a very high priority)? _____
 - Your priorities:
 - d. How would you rate smoking cessation among your own priorities in your work from 1 (a very low priority) to 10 (a very high priority)? _____
 - e. How would you rate mental health among your own priorities in your work from 1 (a very low priority) to 10 (a very high priority)? _____
 - f. How would you rate smoking cessation and mental health among your own priorities in your work from 1 (a very low priority) to 10 (a very high priority)? _____

General questions regarding smoking cessation and mental health:

1. What would you suggest is the biggest factor influencing the high rate of smoking among people with mental illness?
2. What do you see as the role of the mental health community (mental health organizations, advocates, consumers, providers, and policymakers) in helping to address the high prevalence of smoking among people with mental illness and those that provide them care?
What do you see as the role of smoking cessation community (educators, researchers, advocates, providers, and policymakers) in helping to address the high prevalence of smoking among people with mental illness and those that

provide them care?

What do you see as your role or the role of your organization in helping to address the high prevalence of smoking among people with mental illness and those that provide them care?

3. Do you think there is enough collaboration between the mental health and smoking cessation communities? If not, what would you suggest could be done to help the mental health and smoking cessation communities work more closely with one another?
4. What three activities/programs/policies would you suggest should be implemented to address smoking cessation among people with mental illness? What about activities/programs/policies that would address smoking cessation among the clinicians and staff that work with people with mental illness? In terms of priorities at this time, do you see the need to address smoking cessation among clinicians and staff in the field of mental health to be more important, equally important, or less important than addressing smoking cessation among people with mental illness?
5. Some people have said that smoking is largely an accepted behavior among people with mental illness and that it is a part of the mental health culture. Do you believe this is true and if so, what, if anything, should be done about this?
6. What do you know about previous efforts either within or outside your organization around smoking cessation and mental health? What happened in these previous efforts? What did you learn from these efforts? What might you do differently?
7. What are the biggest *challenges* for the mental health community/smoking cessation community in addressing the issue of reducing smoking among people with mental illness and the people that provide them care? What are the *strengths* of the mental health community/smoking cessation community that might be helpful in addressing the challenges you just described? What are the *weaknesses* of the mental health community/smoking cessation community that might be barriers to addressing the challenges you just described?

Miscellaneous questions:

1. Do you see a role for consumer advocates (people with mental health problems who are current or former smokers) in helping to increase awareness on the issue of smoking among people with mental illness? If yes, please describe.
2. Do you see any special issues related to aging, mental health, and smoking? If so, do you have any ideas about how to address these issues? How do you feel about reaching out to aging mental health consumers who smoke?

3. These next questions are about the telephone quitline. Have you heard of the telephone quitline?
 - a. Are you familiar with the services that are provided in your state by the quitline?
 - b. Do you think information about the availability of the quitline is being disseminated? If it is not, why not?
 - c. How would you suggest this might be improved?
 - d. What is your confidence in the quitline from 1 (not confident) to 10 (very confident) that the quitline is equipped to address the needs of smokers with mental health problems? _____ Why did you choose that number?
 - e. If a clinician were working with a patient who smoked and had a mental illness and asked who they should refer them to, what would your response be? What do you believe is the feasibility of creating a national resource to help this population (such as a quitline that is specifically designed for people with mental illness where all staff are trained in the specific issues facing people who smoke who also have mental health problems)?

Questions on the National Mental Health Partnership for Wellness and Smoking Cessation (we will skip these questions if you're not actively involved in the Partnership):

1. What do you see as the main role of the National Mental Health Partnership for Wellness and Smoking Cessation?
2. How would you describe the Partnership's progress since the summit (March 2007)? Have there been any changes to your organization in terms of how it deals with issues of smoking cessation/policies around smoking for people with mental illness in the last 9 months?
3. What are your personal goals for the Partnership and what would you pick as the number one goal for you in the upcoming year(s)?
4. On a scale of 1 to 10, how much progress do you think the Partnership can make in addressing this issue from 1 (no progress) to 10 (a lot of progress)? _____ Why did you choose that number?

Final thoughts:

1. Is there anything else you would like to discuss regarding smoking cessation and mental health?
2. If time permits, we would like to do follow-up interviews to see if people's perspectives have changed and to track the development of the partnership. May we contact you again in four to six months for a follow-up interview?

APPENDIX B | Interview Protocol for Focus Groups with Mental Health Consumers

Interview Guides for Focus Groups with People with Mental Illness on Mental Health Consumer Perspectives on Smoking and Smoking Cessation

Thank you very much for coming today. Before we begin, I want to read over the consent form with you and make sure that everyone's questions are answered before we begin. Here is a copy for you. [After reading the information sheet] Do you have any questions?

Questions for all:

1. How do you feel about smoking?
2. What would you suggest is the biggest factor influencing the high rate of smoking among people with mental health problems?
3. Have your doctors or other care providers asked you whether you smoke? Which providers? How did they ask you? If you do smoke (or smoked at the time), what, if anything, did they say or do to help you?
4. Do you think people should be able to smoke here (at the local social service agency), why or why not?
5. How do your friends and family feel about smoking?
6. Are you familiar with telephone quitlines? Have you used one before? What was it like?
7. What, if anything, do you do to promote your mental health? Your physical health?
8. What kinds of information do you think would be helpful in helping people with mental health problems to stop smoking? What types of activities or programs or policies do you think might help people to stop smoking? What about in preventing people from even starting to smoke?
9. What do you see as the role of mental health organizations, advocates, consumers, providers, and policymakers in helping to address the high rates of smoking among people with mental illness?
10. Advocates, providers, and policymakers are working to try and address this issue of high rates of smoking among people with mental illnesses by developing a national partnership through which to come up with appropriate strategies to address this issue. Do you have any suggestions for this group? If so, what are they? What would you suggest this group not do? What should their priorities be? Who should be included? What do you want this partnership to know?

Questions for smokers:

1. When did you start smoking and why?
2. Do you want to quit smoking? Why or why not?
3. How does smoking make you feel?

4. Have you tried quitting smoking?
5. What, if anything, have you tried to help you quit (NRT, quitline, support groups, etc.)?
6. How, if at all, does smoking affect your mental health?
7. How important is it to you that you are mentally healthy before you try to quit?
8. What do you find as the barriers or challenges to quitting?

Questions for people who are trying to quit smoking:

1. Why do you want to quit smoking?
2. What are you doing to help you quit?
3. Leaders in mental health and smoking cessation are working together to try and help people with mental health problems like you who want to quit smoking to be able to do so. What, if anything, do you wish were available to you to help you quit?

Questions for people who have quit smoking (ex-smokers):

1. How did smoking make you feel?
2. How many times did you try to quit smoking?
3. What was helpful to you in quitting smoking?
4. What were the hardest things about quitting?
5. How was your mental health like when you quit?
6. What were your concerns about quitting smoking? Did they happen?
7. What advice, if any, do you have for other people with mental health problems that are trying to quit smoking?
8. Was there anything that quitting smoking allowed you to do that you could not do before?
9. How do you continue to be a nonsmoker? Do you have temptations to smoke? How do you overcome those temptations? What works for you?

Questions for people who have never smoked:

1. Did you experience a lot of temptations to smoke? If yes, what made you not smoke?
2. Do you have a story about a time when you were encouraged to smoke or not to smoke? If so, please share that story with me.
3. Can you talk a little bit about what you see as the reasons for smoking among people with mental health problems?

NOTE: Focus group interviews were semi-structured. Not all questions were asked in every group. Some interviews included other questions or these questions worded in a different way. The order of the questions changed from group to group.

APPENDIX C | Ordered Situational Map

Figure 6 Ordered Situational Map: Mental Health, Mental Illness, the Mental Health Community, and Smoking, Tobacco Control, and the Smoking Cessation Field

Individual Human Elements/Actors

Mental health consumers and peers, leaders in the mental health field, leaders in the smoking cessation field, mental health providers

Nonhuman Elements Actors/Actants

Tobacco, tobacco industry, studies/clinical trials, nicotine replacement therapies (NRT), quitlines, media, psychiatric medications, managed care, mental health system, tobacco control policies

Collective Human Elements/Actors

National Mental Health Partnership for Wellness and Smoking Cessation, Smoking Cessation Leadership Center, Substance Abuse Mental Health Services Administration (SAMHSA), psychiatric hospitals, community mental health centers, peer-run programs, National Institute of Mental Health (NIMH), mental health and smoking cessation professional organizations, National Association of State Mental Health Program Directors (NASMHPD), foundations (Robert Wood Johnson Foundation, American Legacy Foundation)

Implicated/Silent Actors/Actants

People with mental illness who smoke

Discursive Constructions of Individual and/or Collective Human Actors

Mental health consumers as not caring about their physical health, mental health providers and leaders as slow, smoking cessation advocates as insensitive, foundations as all-powerful

Mentalism, discrimination based on ability/disability status, sex/gender stereotypes, class/SES stereotypes, human rights/choice/autonomy

Key Events in Situation

Surgeon General's Report on Smoking and Health (1964), deinstitutionalization in the 1960s/1970s, Surgeon General's Report on Mental Health focuses on possibilities for recovery (1999), Lasser report finds mental health consumers smoke 44% of U.S. cigarettes, NASMHPD report on 25-year mortality gap (2006), summit establishing the

formation of the Partnership (2007).
(For full timeline of events, see Table 2)

Political/Economic Elements

U.S. health care politics and the separation of mental and physical health services, reimbursement policies, concept of individual responsibility for one's own health, distribution of MSA funds, overburdened providers, mental health parity legislation, deinstitutionalization, FDA control over tobacco,

Discursive Constructions of Nonhuman Actants

Concepts of mental health and mental illness as on a continuum, the mental health system as difference and separate, deviance/otherness as bad, strategies for helping smokers to quit (5As, AAR) as simple, tobacco as unhealthy, quitlines as always helpful

Mental health exceptionalism

Sociocultural/Symbolic Elements

Cigarettes, rewards for good behavior, wellness, recovery, peer support, social expectations for those who are deviant

Temporal Elements

Histories of the treatment of people with mental illness and their status in U.S. society, harmful treatments including the use of seclusion and restraints, histories of institutionalization and experimental treatments

Spatial Elements

Institutional, local, regional, and state variations in policies and practices, geographic differences in strength of quitlines to address needs of consumers, differences in MSA funding

Major Issues/Debates (Usually Contested)

Relative importance of smoking cessation (as a top or lesser priority), when to address cessation, who should address cessation, factors influencing the high smoking rates among people with mental illness

Related Discourses (Historical, Narrative, and/or Visual)

Mental health and public health education and discourse/rhetoric, identity politics, victim blaming discourses

Other Kinds of Elements

Other priorities including suicide, veteran's issues, and homelessness

APPENDIX D | Positional Maps

Figure 7 Positional Map of Desire to Quit Among People with Mental Illness

I love my cigarettes and want to die with a cigarette in my hand	<p>I know I could do it if I wanted to do, but I love smoking and just don't want to quit unless I have to.</p> <p><i>*The passionate smoker</i></p>	<p>I really love cigarettes. I love the feelings they bring me and the experience of smoking. All my friends smoke; I smoke when I'm bored. If I wanted to or was told that I needed to quit, I don't know what I would do instead of smoking.</p>	<p>I love to smoke and nothing will ever change my mind. I would never be able to quit because cigarettes bring me so much joy, pleasure, and comfort.</p>
	<p>I just need to be ready, and then I can do it.</p> <p><i>* All about motivation</i></p>	<p>I'm not ready to try to quit, but when I'm ready, I hope I can do it.</p>	<p>I'm not ready to quit and it's because it seems impossible for me to ever imagine not smoking.</p> <p><i>*Trying to avoid feelings of failure</i></p>
I want to quit smoking	<p>I want to quit smoking and I know where I can go for help. I will quit as soon as I am fully motivated.</p>	<p>I've tried a few things and nothing has worked so far. My friends have been able to quit, why can't I?</p>	<p>I have utilized all of the resources I know of to try and quit and I still can't quit smoking.</p> <p><i>*Frustrated and ready to quit ("trying to quit" focus group participant)</i></p>
	I can quit smoking if I want to need/to		I can't quit smoking

NOTE: Many participants moved through these various positions over time. There were times during their lives when smoking was extremely important to them and when they had little desire to quit, and times when they really wished to quit smoking. At the same time, the participants' opinions about whether or not they would be able to quit (and how easy or hard it would be for them) shifted a great deal as well, particularly after hearing quitting stories from family or friends.

Figure 8 Positional Map of Level of Priority of Smoking Cessation in the Mental Health

<p>Thinks smoking cessation will be a top priority for people with mental illnesses</p>	<p>Everyone’s talking about the importance of tobacco. What’s the big deal?</p>	<p>I was not in support of addressing smoking cessation initially, but came to realize, through education and awareness, that it’s an important issue and should be something that people act on.</p>	<p>This is finally the perfect opportunity to do something about tobacco. It’s a killer and it is a main cause of the health disparities among people with mental illnesses. It’s about time!</p>
	<p>We have so many other things going on. Many of these things are more pressing, like suicide, and young people coming back from the war with serious and acute mental health issues.</p>	<p>Many of the mental health leaders/organizations fell in the middle taking a “wait and see” perspective as to what stance to take and what the hopes are for the future</p>	<p>There are enough resources available to make some headway on this issue.</p>
<p>Thinks smoking cessation will not be a top priority for people with mental illnesses</p>	<p>There are other important actions one can engage in to promote wellness. People with mental illness have a hard time quitting and probably don’t want to quit anyway. We should focus on easier behavior changes, like getting people to walk more.</p>	<p>Smoking is an important issues, but we all have full plates and it is not likely to get airtime on our packed agendas.</p>	<p>Though I believe the Partnership and related initiatives are a valiant effort, I am concerned about the future resources and lack of financial support that would certainly hinder the advancement of these smoking cessation initiatives.</p>
	<p>Thinks smoking cessation should not be a top priority for people with mental illnesses</p>		<p>Thinks smoking cessation should be a top priority for people with mental illnesses</p>

NOTE: Again this is a case where all positions are filled because participants’ opinions changed quickly over time. For the leaders, meetings, involvement with other initiatives, and political, economic, and social circumstances caused them to change their opinions quite frequently about whether or not they thought smoking cessation would be a top priority and whether they ultimately wanted it to be.

Figure 9 Relational Map of Smoking Among People with Mental Illness

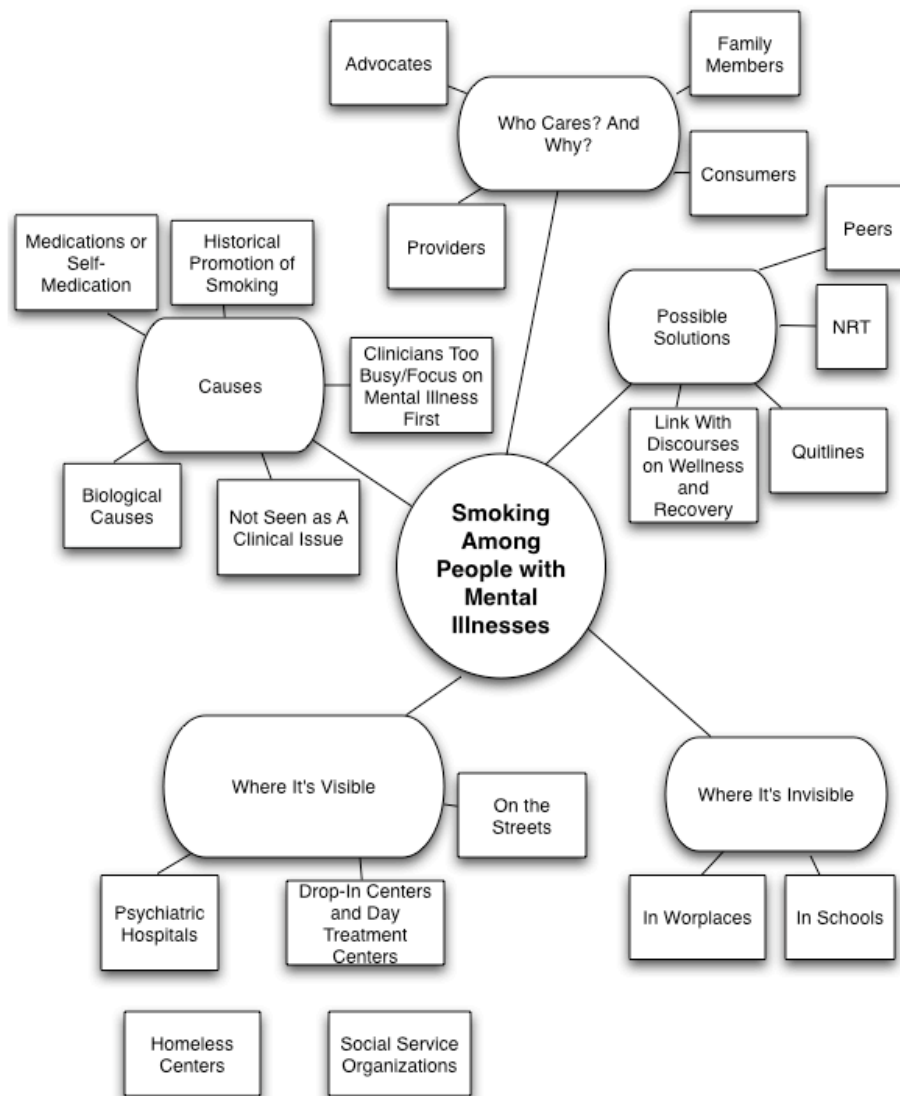
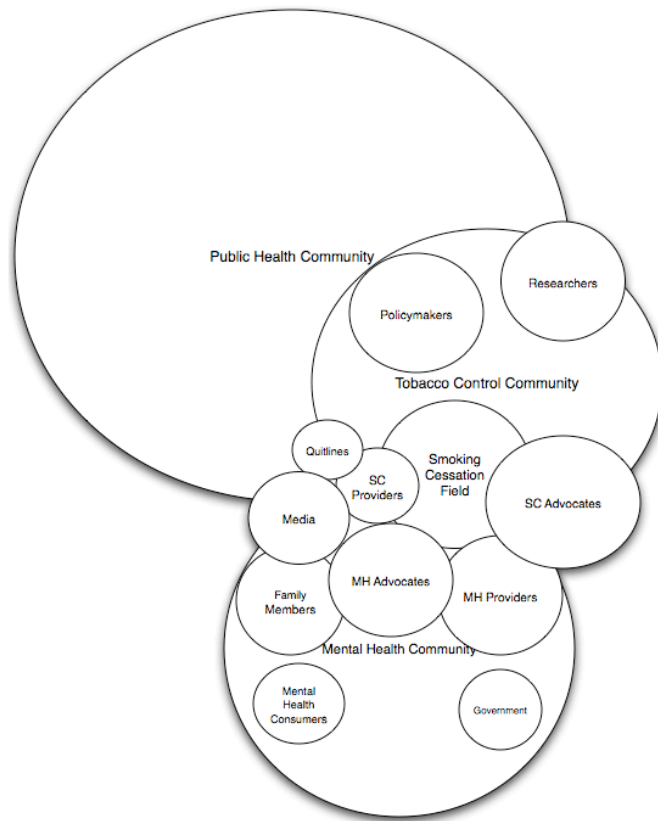


Figure 10 Social Worlds/Arenas Map of the Mental Health Community and Smoking Cessation Field



NOTE: This social worlds/arenas map depicts the social worlds that comprise the mental health community and the smoking cessation field, and the ways in which mental health and smoking cessation fit within the larger arena of public health. The relative size of the circles illustrates the strength of each of the arenas that exist within the social worlds and describes what arenas must be mobilized to address smoking among people with mental illnesses.

APPENDIX G | Articles Used in Frames Analysis

Alonso-Zaldivar, R. (2008, May 25). Drug linked to traffic mishaps; Daniel Williams hoped Chantix would help him quit smoking and become healthier. Instead, he believes it nearly killed him. *LAT*, p. A20.

Alonso-Zaldivar, R. (2008, May 22). FAA bans anti-smoking drug; Chantix is prohibited for pilots and air traffic controllers in response to a new report on risky side effects. *LAT*, p. A11.

Beck, M. (2008, February 19). Puff power: Drug warnings speak to nicotine's sad grip. *WSJ*, p. D1.

Clinton plans cigarette tax boost to cover new spending, aide says. (1999, January 14). *LAT*, p. A20.

Cook, G. (2005, April 12). In a judgmental world, she was ashamed of getting sick. *NYT*, n.p.

Dorak, P. (2008, December 16). Something in the air-When a smoker gets lung cancer, sympathy is stained with blame. *WP*, p. F1.

Duenwald, M. (2003, June 18). More Americans seeking help for depression. *NYT*, n.p.

Eckholm, E. (2006, December 1). Medicaid plan prods patients towards health. *NYT*, n.p.

Elias, M. (2007, May 3). Mental illness linked to shorter life; Anti-psychotics and obesity could be factors. *USAT*, n.p.

Ellin, A. (2005, December 8). Workouts potent medicine for the mentally ill. *NYT*, n.p.

Goode, E. (2003, July 8). Doctors' toughest diagnosis: Own mental health. *NYT*, n.p.

Grady, D. (2000, November 8). Anxiety seen in teenagers who smoke. *NYT*, n.p.

- Grady, D. (2000, November 8). Teen smoking tied to later anxiety study finds a risk of illness soon after starting cigarettes. *CT*, p. 28.
- Graham, J. (1999, December 14). Report profiles mental illness Surgeon General takes on balky insurance companies. *CT*, p. 17.
- Healy, M. (2008, April 29). Thoughts of suicide? It could be the meds you're taking. *CT*, p. 4.
- Kaufman, M. (1999, December 14). Mental illness in America: 50 million people a year; Surgeon General's Report addresses barriers to treatment. *WP*, p. A3.
- Kolata, G. (2008, May 22). Study finds big social factor in quitting smoking. *NYT*, n.p.
- Lauerman, C. (2001, October 14). Unhooked; A onetime pack-a-day veteran smokes out the psychology of addiction and quitting. *CT*, p. 1.
- Little, R. (2006, October 11). Village delays vote on smoking ban. *CT*, p. 6).
- Levy, C. J. (2002, April 28). For mentally ill, death and misery. *The New York Times*, n.p.
- McGahan, J. (2000, March 30). At St. Elizabeth's, a stamp of hope-Patient-run business pays dividend. *WP*, p. J6.
- Meier, B. (1999, December 28). Experiment of privatized mental hospital shows benefits. *NYT*, n.p.
- Mental health report to cover ethnic issues. (2000, October 10). *UST*, p. 6D.
- Mentally ill smoke 43.3% of cigarettes used in the U.S. (2000, November 22). *WSJ*, p. 1.
- Mestel, R. (2000, November 22). Mentally ill twice as likely to be smokers, study finds; Tobacco: Special programs may be needed to encourage patients to quit, give their isolation and tendency to use nicotine to fight depression, experts say. *LAT*, p. A38.

- Murray, S. (2000, March 8). Most states to spend tobacco settlement on improving health care, survey says. *WSJ*, p. 1.
- Nagourney, E. (2000, January 4). Vital signs: Mental health; A healthy move and a possible setback. *NYT*, n.p.
- Naiditch, Z. (1999, September 8). Helping the mentally ill in crisis. *CT*, p. 18.
- Neergaard, L. (2000, November 26). Pregnant smokers may suffer depression.(2007, September 10). *USAT*, n.p.
- Newman, A. (2000, November 26). On sanity and smoking. *NYT*, n.p.
- Payne, J. W. (2007, July 24). In over your head? Ask your body-Persistent stress caused by financial worries can lead to physical and mental problems such as hypertension and eating disorders, say experts. *WP*, p. F1.
- Piccalo, G. (2000, April 26). County lacks beds for mentally ill, study finds. Health: More than 500 are needed to handle patients currently left homeless. Report is expected to help land state and federal funds. *LAT*, p. B1.
- Problems linked to anti-smoking drug. (2008, February 2). *Chicago Tribune*, p. 4.
- Rubin, R. (1999, November 3). Abusive upbringing can lead to smoking. *USAT*, p. 1D.
- Saillant, C. (1999, December 28). Board may use tobacco payout for fiscal woes; Supervisors: Most favor dipping into \$8.3 million in settlement funds to help offset deficit. But Schillo says money should be spent elsewhere. *LAT*, p. B1.
- Saillant, C. (2003, August 18). California: Smoking issue a quandary for psychiatric facilities. *LAT*, p. B1.

- Saillant, C. (2002, October 16). County to spend tobacco money on health system; Supervisors approve a \$5.5 million bailout, angering anti-smoking advocates. *LAT*, p. B3.
- Sanchez, R. (2001, October 28). L.A. may snuff out smoking in city parks-Proposed ban would be tougher than any in U.S. *WP*, p. A3.
- Schroeder, S. A hidden epidemic. (2007, November 18). *WP*. B7.
- Simon, S. (2001, August 26). Little of tobacco money goes to kicking habit; Settlement: Most states spend funds on social projects instead of health care. Experts voice alarm. *LAT*, p. A1.
- Stobbe, M. (2007, October 3). CDC: People with disabilities smoke more. *USAT*, n.p.
- Study says mentally ill are 45% of U.S. cigarette market. (2000, November 24). *CT*, p. 7.
- Taxing the system. (2005, November 30). *LAT*, p. B12.
- Vergano, D. (1999, November 8). Anxiety, depression can lead to asthma. *USAT*, p. 1D.
- Wang, S. S. (2008, December 10). Drug-safety data: Too much information? *WSJ*, n.p.
- Weiss, E. M. (2006, June 14). In harm's way at hospital?-Citing deaths and violence, the Justice Department tells D.C. to improve care at St. Elizabeth's Mental Facility. *WP*, p. B1.

NOTE: Forty-six articles published between 1999 and 2009 were retrieved from the newspapers' website, or from LexisNexis when inaccessible through the respective newspapers' website, using the search terms mental health/mental illness and smoking/tobacco in February 2009.

CT=Chicago Tribune; LAT=Los Angeles Times; NYT=The New York Times; WP=Washington Post; WSJ=The Wall Street Journal; USAT=USA Today

- Acton, G. S., Prochaska, J. J., Kaplan, A. S., Small, T., & Hall, S. M. (2001). Depression and stages of change for smoking in psychiatric outpatients. *Addictive Behaviors*, 26(5), 621-631.
- Alford, R. & Friedland, R. (1975). Political participation and public policy. *Annual Review of Sociology*, 1, 429-479.
- Alonso-Zaldivar, R. (2008, May 25). Drug linked to traffic mishaps; Daniel Williams hoped Chantix would help him quit smoking and become healthier. Instead, he believes it nearly killed him. *Los Angeles Times*, p. A20.
- American Legacy Foundation. (n.d.). Retrieved March 18, 2009 from <http://www.americanlegacy.org/>
- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders*. (4th ed.). Washington, DC: Author.
- American Psychiatric Nurses Association. (n.d.). *Action equals hope*. Retrieved November 2, 2009 from <http://www.apna.org/i4a/pages/index.cfm?pageID=3642>
- American Public Health Association. (November 2008). SAMHSA meetings, conferences to be held in smoke-free jurisdictions. *The Nation's Health*. Retrieved from <http://www.apha.org/NR/rdonlyres/EF6144CB-324B-47B5-A4F6-737C17479989/0/Nov08NationsWeb.pdf>
- Anderson, C. M. & Zhu, S. H. (2007). Tobacco quitlines: Looking back and looking ahead. *Tobacco Control*, 16(Supplement 1), i81-i86.

- Angell, B. (2003). Contexts of social relationship development among assertive community treatment clients. *Mental Health Services Research, 5*(1), 13-25.
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11-23.
- Apollonio, D. E. & Bero, L. A. (2007). The creation of industry front group: The tobacco industry and "Get Government Off Our Back." *American Journal of Public Health, 97, 3*, 419-427.
- Apollonio, D. E. & Malone, R. E. (2005). Marketing to the marginalized: Tobacco industry targeting of the homeless and mentally ill. *Tobacco Control, 14*, 409-415.
- Association of American Medical Colleges (AAMC). (2007). Physician behavior and practice patterns related to smoking cessation. Washington DC: Association of American Medical Colleges. Retrieved from <http://www.aamc.org/workforce/smoking-cessation-summary.pdf>
- Atlantic Philanthropies. (2008). Why Supporting Advocacy Makes Sense for Foundations. Atlantic Reports. Retrieved from http://atlanticphilanthropies.org/news/reports/atlantic_reports_why_supporting_advocacymakes_sense_for_foundations
- Barker, A., Richmond, R., Haile, M., Lewin, T. J., Carr, V. J., Taylor, R. L. et al. (2006). A randomized controlled trial of a smoking cessation intervention among people with a psychotic disorder. *American Journal of Psychiatry, 163*(11), 1934-1942.

- Barreira, P. (1999). Reduced life expectancy and serious mental illness. *Psychiatric Services, 50*(8), 995.
- Bassman, R. (2001). Whose reality is it anyway? Consumers/survivors/ex-patients can speak for themselves. *Journal of Humanistic Psychology, 41*(4), 11-35.
- Bazon Center for Mental Health Law. (2004). *Get it together: How to integrate physical and mental health care for people with serious mental disorders*. Retrieved from <http://www.bazon.org/issues/mentalhealth/publications/getittogether/>
- Beck, M. (2008, February 19). Puff power: Drug warnings speak to nicotine's sad grip. *The Wall Street Journal*, p. D1.
- Becker, H. S. (1966). *Social problems: A modern approach*. New York: John Wiley.
- Beers, C. W. (1908, 2006). *The mind that found itself*. West Valley City, UT: Waking Lion Press.
- Benford, R. D. (1997). An insider's critique of the social movement perspective. *Sociological Inquiry, 67*(4), 409-430.
- Benford, R. D. & Snow, D. A. (2000). Framing processes and social movements: An overview and assessment. *Annual Review of Sociology, 26*, 611-639.
- Berger, P. L. & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Garden City, NY: Anchor Books.
- Berlin, M. T., Fleck, M. P. A., & Shorter, E. (2003). Notes on antipsychiatry. *European Archives of Psychiatry and Clinical Neuroscience, 253*, 61-67.

- Bernstein, S. M. & Stoduto, G. (1999). Adding a choice-based program for tobacco smoking to an abstinence-based addiction treatment program. *Journal of Substance Abuse Treatment, 17*(1-2), 167-173.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley: University of California Press.
- Blumer, H. (1971). Social problems as collective behavior. *Social Problems, 18*(Winter), 298-306.
- Blumer, H. (1978). Social unrest and collective protest. *Studies in Symbolic Interactionism, 1*, 1-54.
- Bogira, S. (2009). Starvation diet: Coping with shrinking budgets in publicly funded mental health services. *Health Affairs, 28*(3), 667-675.
- Bornemeier, J. (2006). Taking on tobacco: The Robert Wood Johnson Foundation's assault on smoking. In K. Warner (Ed.). *Tobacco Control Policy* (pp. 531-550). San Francisco, CA: Jossey-Bass.
- Brandt, A. M. (2007). *The cigarette century: The rise, fall, and deadly persistence of the product that defined America*. New York: Basic Books.
- Breslau, N., Novak, S. P., & Kessler, R. C. (2004). Psychiatric disorders and stages of change. *Biological Psychiatry, 55*, 69-76.
- Brown, P. (1984). The right to refuse treatment and the movement for mental health reform. *Journal of Health Policy, Politics, and Law, 9*, 291-313.
- Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior, 35*(Extra Issue: Forty Years of Medical Sociology: The State of the Art and Directions for the Future), 34-52.

- Brown, P. & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health and Illness*, 26(6), 679-694.
- Brown, P., Zavestocki, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Altman, R. G. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health and Illness*, 26(1), 50-80.
- Brown, R., Kahler, C., Niaura, R., Abrams, D. B., Sales, S. D., Ramsey, S. E. et al. (2001). Cognitive-behavioral treatment for depression in smoking cessation. *Journal of Consulting and Clinical Psychology*, 69(3), 471-480.
- Cadigan, K. & Murray, L. C. (2009). *When medicine got it wrong*. United States: imageReal Pictures.
- California Department of Mental Health. (n.d.). Mental Health Services Act (Proposition 63). Retrieved March 27, 2009 from http://www.dmh.ca.gov/prop_63/MHSA/default.asp.
- Campbell, J. (1997). How consumers/survivors are evaluating the quality of psychiatric care. *Evaluation Review*, 21(3), 357-363.
- Campion, J., Checinski, K., & Nurse, J. (2008). Review of smoking cessation treatments for people with mental illness. *Advances in Psychiatric Treatment*, 14, 208-216.
- Campion, J., Checinski, K., Nurse, J., & McNeill, A. (2008). Smoking by people with mental illness and benefits of smokefree mental health services. *Advances in Psychiatric Treatment*, 14, 217-228.
- Carter-Pokras, O. & Baquet, C. (2002). What is a "health disparity"? *Public Health Reports*, 117, 426-434.

- Cataldo, J. K. (2001). The role of advanced practice psychiatric nurses in treating tobacco use and dependence. *Archives of Psychiatric Nursing*, XV, 107-119.
- Centers for Disease Control and Prevention. (2002, July 26). Cigarette smoking among adults—United States, 2000. *Morbidity and Mortality Weekly Report*, 51(29), 642-645. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5129a3.htm>.
- Centers for Disease Control and Prevention. (2003, September 5). Cigarette smoking-attributable morbidity—United States, 2000. *Morbidity and Mortality Weekly Report*, 52(35), 842-844. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5235a4.htm>.
- Centers for Disease Control and Prevention. (2007, November 9). Cigarette smoking among adults—United States, 2006. *Morbidity and Mortality Weekly Report*, 56(44), 1157-1161. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5644a2.htm>
- Centers for Disease Control and Prevention. (2008, February 8). State Medicaid coverage for tobacco-dependence treatments—United States, 2006. *Morbidity and Mortality Weekly Report*, 57(05), 117-122. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5705a2.htm>.
- Centers for Disease Control and Prevention. (2008, March 21). CDC Urges older adults to improve health, increase longevity, through smoking cessation. Retrieved April 4, 2009 from http://www.chronicdisease.org/files/public/smokingFINAL3_21_08.pdf.
- Centers for Disease Control and Prevention. (2008, November 14). Smoking-attributable mortality, years of potential life lost, and productivity losses—United States, 2000-

2004. *Morbidity and Mortality Weekly Report*, 57(45), 1226-1228. Retrieved March 29, 2009 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5745a3.htm>.
- Centers for Disease Control and Prevention. (2009, March 13). State-specific prevalence and trends in adult cigarette smoking—United States, 1998-22007. *Morbidity and Mortality Weekly Report*, 58(09), 221-226. Retrieved April 17, 2009 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5809a1.htm>.
- Chamberlin, J. (1977). *On our own*. Lawrence, MA: National Empowerment Center.
- Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. *Journal of Mind and Behavior*, 11, 323-336.
- Chamberlin, J. (2005). User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale*, 14(1), 10-14.
- Chapman, S. & Freeman, B. (2008). Markets of the denormalisation of smoking and the tobacco industry. *Tobacco Control*, 17, 25-31.
- Charmaz, K. (2005). Grounded theory in the 21st century: A qualitative method for advancing social justice research In N. Denin & Y. Lincoln (Eds.). *The Sage Handbook of Qualitative Research* (3rd Ed., pp. 507-535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, Sage.
- Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods for the 21st century. In J. Morse, P. N. Stern, J. Cobin, B. Bowers, K. Charamaz, & A. E. Carke (Eds.). *Developing Grounded Theory: The Second Generation* (pp. 127-154). Walnut Creek, CA: Left Coast Press.

- Christakis, N. A. & Fowler, J. H. (2008). The collective dynamics of smoking in a large social network. *New England journal of Medicine*, 358, 2249-2258.
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.
- Clarke, A. E. (2009). From grounded theory to situational analysis: What's new? why? how? In J. Morse, P. N. Stern, J. Cobin, B. Bowers, K. Charamaz, & A. E. Carke (Eds.). *Developing Grounded Theory: The Second Generation* (pp. 194-233). Walnut Creek, CA: Left Coast Press.
- Cohen, J. L. (1985). Strategy or identity: New theoretical paradigms and contemporary social movements. *Social Research*, 52(4), 663-716.
- Collins, P. H. (1990). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. New York: Routledge.
- Colton, C. W. & Manderscheid, R. W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease*, 3(2), Retrieved from http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm
- Conrad, P. (1980). On the medicalization of deviance and social control. In D. Ingleby (Ed.). *Critical psychiatry* (pp. 102-119). New York: Pantheon Books.
- Conrad, P. (1997). Public eyes and private genes: Historical frames, new constructions, and social problems. *Social Problems*, 44(2), 139-154.
- Consumers Helping Others Improve their Condition by Ending Smoking [CHOICES]. (n.d.). Retrieved February 12, 2009 from www.njchoices.org.

- Cook, G. (2005, April 12). In a judgmental world, she was ashamed of getting sick. *The New York Times*, n.p.
- Cook, J. A. & Wright, E. R. (1995). Medical sociology and the study of severe mental illness: Reflections on past accomplishments and directions for future research. *Journal of Health and Social Behavior*, 35(Extra Issue: Forty Years of Medical Sociology: The State of the Art and Directions for the Future), 95-114.
- Cormac, I. & McNally, L. (2008). How to implement a smoke-free policy. *Advances in Psychiatric Treatment*, 14, 198-207.
- Corrigan, P. W. (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice*, 5(2), 201-222.
- Corrigan, P. W. & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765-776.
- Corrigan, P. W., Watson, A. C., Byrne, P., & Davis, K. E. (2005). Mental illness stigma: Problem of public health or social justice? *Social Work*, 50(4), 363-368.
- Cosgrove, L., Krimsky, S., Vijayaraghavan, M., & Schneider, L. (2006). Financial ties between DSM-IV panel members and the pharmaceutical industry. *Psychotherapy and Psychosomatics*, 75, 154-160.
- Creed, F., Morgan, R., Fiddler, M., Guthrie, E., House, A. (2002). Depression and anxiety impair health-related quality of life and are associated with increased costs in general medical inpatients. *Psychosomatics*, 43, 302-309.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. (2nd ed.). Thousand Oaks, CA: Sage Publications.

- Crossley, N. (2002). Mental health, resistance and social movements: The collective-confrontational dimension. *Health Education Journal*, 61, 138-152.
- Crowley, K. & Anthony, W. (2000). *The power of procovery in healing mental illness: Just start anywhere*. Los Angeles, CA: Kennedy Carlisle Publishing.
- Cummins, S. E., Bailey, L., Campbell, S., Koon-Kirby, C., & Zhu, S. H. (2007). Tobacco cessation quitlines in North America: A descriptive study. *Tobacco Control*, 16 (Supplement 1), i9-i15.
- Cunningham, P.J. (2009, April 14). Beyond parity: Primary care physicians' perspectives on access to mental health care. *Health Affairs Web Exclusive*, 28(3). Retrieved from <http://content.healthaffairs.org/cgi/content/full/28/3/w490>
- Curie, C. G. (2005). SAMHSA's commitment to eliminating the use of seclusion and restraint. *Psychiatric Services*, 56, 1139-1140.
- Dalack, W., Healy, D., & Meador-Woodruff, J. H. (1998). Nicotine dependence in schizophrenia: Clinical phenomena and laboratory findings. *American Journal of Psychiatry*, 155, 1490-1501.
- Dani, J. A. & Harrison, R. A. (2005). Nicotine addiction and co-morbidity with alcohol abuse and mental illness. *Nature: Neuroscience*, 8(11), 1465-1470.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York University Press.
- Davidson, L., Shahar, G., Stayner, D. A., Chinman, M. J., Rakfeldt, J., & Tebes, J. K. (2004). Supported socialization for people with psychiatric disabilities: Lessons from a randomized controlled trial. *Journal of Community Psychology*, 32(3), 452-477.

- Davidson, S., Judd, F., Jolley, D., Hocking, B., Thompson, S., & Hyland, B (2001). Cardiovascular risk factors for people with mental illness. *Australian and New Zealand Journal of Psychiatry*, 35, 196-202.
- Daynard, R. A. (2003). Lessons from tobacco control for the obesity control movement. *Journal of Public Health Policy*, 24(3-4), 291-295.
- deBeauvoir, S. (1953). *The second sex*. New York: Penguin.
- de Leon, J. (1996). Smoking and vulnerability for schizophrenia. *Schizophrenia Bulletin*, 22, 405-409.
- de Leon, J., Dadvand, M., Canuso, C., White, A. O., Stanilla, J., & Simpson, G. M. (1995). Schizophrenia and smoking: An epidemiological study in a state hospital. *American Journal of Psychiatry*, 152(3), 453-455.
- de Leon, J. & Diaz, F. J. (2005). A meta-analysis of worldwide studies demonstrates association between schizophrenia and tobacco smoking behaviors. *Schizophrenia Research*, 76, 135-157.
- de Leon, J., Diaz, F. J., Rogers, T. Browne, D., & Dinsmore, L. (2002). Initiation of daily smoking and nicotine dependence in schizophrenia and mood disorders. *Schizophrenia Research*, 5, 47-54.
- de Leon, J., Tracy, J., McCann, E., McGrory, A., & Diaz, F. J. (2002). Schizophrenia and tobacco smoking: A replication study in another U.S. hospital. *Schizophrenia Research*, 56, 55-65.
- Denzin, N. K. & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications.

- Depression and Bipolar Support Alliance. (n.d.). Retrieved April 18, 2009 from http://www.dbsalliance.org/site/PageServer?pagename=empower_smoking
- Desjairlais, R., Eisenberg, L., Good, B., and Kleinman, A. (1995). *World mental health: Problems and priorities in low income countries*. New York: Oxford University Press.
- Dickinson, J. & Russell, B. (1986). *Family, economy, and state: The social reproduction process under capitalism*. Toronto: Garamond Press.
- Diwan, A., Castine, M., Pomerleau, C. S., Meador-Woodruff, J. H. & Dalack, G. W. (1998). Differential prevalence of cigarette smoking in patients with schizophrenic vs. mood disorders. *Schizophrenic Research*, 33, 113-118.
- Dixon, L., Postrado, L., Delahanty, J., Fischer, P., Lehman, A. (1999). The association of medical comorbidity in schizophrenia with poor physical and mental health. *Journal of Nervous and Mental Diseases*, 187, 496-502.
- Dorfman, L. (2003). Studying the news in public health: How content analysis supports media advocacy. *American Journal of Health Behavior*, 27(Supplement 3), S217-S226.
- Dorwart, R. A. & Epstein, S. S. (1993). *Privatization of mental health care: A fragile balance*. Westport, CT: Auburn House.
- Drake, R. E., Skinner, J. S., Bond, G. R., & Goldman, H. H. (2009). Social Security and mental illness: Reducing disability with supported employment. *Health Affairs*, 28(3), 761-770.
- Dreskler, C. & Marks, S. (2006). The emerging human right to tobacco control. *Human Rights Quarterly*, 28, 599-651.

- el-Guebaly, N., Cathcart, J., Currie, S. Brown, D., & Gloster, S. (2002a). Public health and therapeutic aspects of smoking bans in mental health and addiction settings. *Psychiatric Services, 53*(12), 1617-1622.
- el-Guebaly, N., Cathcart, J., Currie, S., Brown, D., & Gloster, S. (2002b). Smoking cessation approaches for persons with mental illness and addictive disorders. *Psychiatric Services, 53*(9), 1166-1170.
- Elias, M. (2007, May 3). Mental illness linked to shorter life; Anti-psychotics and obesity could be factors. *USA Today*, n.p.
- Ellin, A. (2005, December 8). Workouts are potent medicine for the mentally ill. *The New York Times*, n.p.
- Entman, R. M. (Autumn 1993). Framing: Towards clarification of a fractured paradigm. *Journal of Communication, 43*(4), 51-58.
- Esterberg, M. L. & Compton, M. T. (2005). Smoking behavior in persons with a schizophrenia-spectrum disorder: A qualitative investigation. *Social Science and Medicine, 61*(2), 293-303.
- Estes, C. L. (1979). *The aging enterprise: A critical examination of social policies and services for the aged*. San Francisco: Jossey Bass.
- Estes, C. L. (1991). The new political economy of aging: Introduction and critique. In M. Minkler & C. L. Estes (Eds). *Critical perspectives on aging: The political and moral economy of growing old* (pp. 15-36). Amityville, NY: Baywood Publishing Company.
- Estes, C. L. & Associates. (2001). *Social policy and aging: A critical perspective*. Thousand Oaks, CA: Sage Publications.

- Everett, A., Mahler, J., Biblin, J., Gangull, B., & Mauer, B. (Summer 2008). Improving the health of mental health consumers. *International Journal of Mental Health*, 37(2), 8-48.
- Evins, A. E., Cather, C., Deckersbach, T., Feudenreich, O., Culhane, M. A., Olm-Shipman, C. et al. (2005). A double-blind placebo-controlled trial of bupropion sustained-release for smoking cessation in schizophrenia. *Journal of Clinical Psychopharmacology*, 25(3), 218-225.
- Fagan, P. & Rigott, N. A. (2009). Light and intermittent smoking: The road less traveled. *Nicotine and Tobacco Research*, 11, 107-110.
- Farkas, A. J., Gilbpin, E. A., Distefan, J. M. & Pierce, J. P. (1999). The effects of household and workplace smoking restrictions on quitting behaviors. *Tobacco Control*, 8, 261-265.
- Fichtenberg, C. M. & Glantz, S. A. (2002). Effect of smoke-free workplaces on smoking behaviour: Systematic review. *British Medical Journal*, 325(7357), 188-194.
- Fiore M. C., Jaen, C. R., Baker, T. B., Bailey, W. C., Benowitz, N. L., Curry, S. J. et al. (2008). *Treating tobacco use and dependence: 2008 update of the clinical practice guideline*. Rockville, MD: Public Health Service.
- Fisher, W. H., Geller, J. L., & Pandiani, J. A. (2009). The changing role of the state psychiatric hospital. *Health Affairs*, 28(3), 676-684.
- Foley, H. A. & Sharfstein, S. S. (1983). *Madness and government: Who cares for the mentally ill?* Washington DC: American Psychiatric Press.
- Foucault, M. (1961). *Madness and civilization: A history of insanity in the age of reason*. London: Tavistock.

- Frank, R. G. & Glied, S. A. (2006). *Better but not well: Mental health policy in the United States since 1950*. Baltimore: John's Hopkins University Press.
- Frank, R. G., Goldman, H. H., & McGuire, T. G. (2009). Trend in mental health cost growth: An expanded role for management? *Health Affairs*, 28(3) 649-659.
- Frese, F. J. & Davis, W. W. (1997). The consumer-survivor movement, recovery, and consumer professionals. *Professional Psychology: Research and Practice*, 28, 243-245.
- Fuller, B. E., Guydish, J., Tsoh, J., Reid, M. S., Resnick, M., & Zammerilli, L., et al. (2007). Attitudes towards the integration of smoking cessation treatment into drug abuse clinics. *Journal of Substance Abuse Treatment*, 32(1), 53-60.
- Fuller, R. & Myers, R. (1941). Some aspects of a theory of social problems. *American Sociological Review*, 6, 24-32.
- Fuller, R. & Meyers, R. (1941). The natural history of a social problem. *American Sociological Review*, 6(June), 320-328.
- Gamson, W. A. (1975). *The strategies of social protest*. Homewood, IL: Dorsey.
- Gamson, W. A. (1992). The social psychology of collective action. In Morris, A. D. and Mueller, C. M. (Eds.) *Frontiers in Social Movements Theory* (pp. 53-76). New Haven: CT: Yale University Press.
- Geertz, C. (1988). *Work and lives*. Stanford, CA: Stanford University Press.
- George, T. P., Vessicchio, J. C, Termine, A., Bregartner, T. A., Feingold, A., Rounsaville, B. J. et al. (2002). A placebo controlled trial of bupropion for smoking cessation in schizophrenia. *Biological Psychology*, 52(1), 53-61.

- Georgia Certified Peer Specialist Project. (n.d.). Retrieved May 10, 2009 from <http://www.gacps.org/Home.html>
- Gerlach, L. & Hine, V. (1970). *People, power, change*. New York: Bobbs-Merrill.
- Gilbert, D. G. & Gilbert, B. O. (1995). Personality, psychopathology, and nicotine response as mediators of the genetics of smoking. *Behavior Genetics*, 25, 133-147.
- Gittleman, M. (Spring 2008). Why are the mentally ill dying? *International Journal of Mental Health*, 37(1), 3-12.
- Giugni, M.G. (1998). Was it worth the effort? The outcomes and consequences of social movements. *Annual Review of Sociology*, 24, 371-393.
- Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Glassman, A. H. (1993). Cigarette smoking: Implications for psychiatric illness. *American Journal of Psychiatry*, 150, 546-553.
- Glassman, A. H., Helzer, J. E., Covey, L. S., Cottier, L. B., Stetner, F., Tipp, J. E., et al. (1990). Smoking, smoking cessation, and major depression. *Journal of the American Medical Association*, 264, 1546-1549.
- Glied, S. A. & Frank, R. G. (2009). Better but not best: Recent trends in the well-being of the mentally ill. *Health Affairs*, 28(3), 637-648.
- Goff, D. C., Henderson, D. C., & Amico, E. (1992). Cigarette smoking in schizophrenia: Relationship to psychopathology and medication side-effects. *American Journal of Psychiatry*, 149, 1189-1194.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

- Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*.
Boston: Northeastern University Press.
- Goldman, H. H., Frank, R. G., Burnam, M. A., Huskamp, H. A., Ridggely, S., Normand, S-L. T., et al. (2006). Behavioral health insurance parity for federal employees. *The New England Journal of Medicine*, 354(13), 1378-1386.
- Gonzalez-Pinto, A., Gutierrez, M., Ezcurra, J., Aizpuru, F., Mosquera, F., Lopez, P., et al. (1998). Tobacco smoking and bipolar disorder. *Journal of Clinical Psychiatry*, 59, 225-228.
- Goodwin, J. Jasper, J. M, & Polletta, F. (2001). Introduction: Why emotions matter. In J. Goodwin, J. Jasper, & F. Poletta (Eds.). *Passionate politics: Emotions and social movements* (pp. 1-24). Chicago: University of Chicago Press.
- Gordon, B. O. & Rosenblum, K. E. (2001). Bringing disability into the sociological frame: A comparison of disability with race, sex, and sexual orientation statuses. *Disability and Society*, 16(1), 5-19.
- Gordon, L. (1990). *Women, the state, and welfare*. Madison: University of Wisconsin Press.
- Gove, W. (1970). Societal reaction as an explanation of mental illness: An evaluation. *American Sociological Review*, 35, 873-884.
- Granaen, L., Sellers, K., & Brown, L. (October 2008). *Tobacco use, mental health, and Hurricane Katrina*. Poster session presented at the annual meeting of the American Public Health Association, San Diego, CA.
- Greeman, M. & McClellan, T. A. (1991). Negative effects of a smoking ban on an inpatient psychiatry service. *Hospital and Community Psychiatry*, 42, 408-412.

- Green, G., Hayes, C., Dickinson, D., Whitaker, A., & Gilheany, B. (2002). The role and impact of social relationships upon well-being reported by mental health service users: A qualitative study. *Journal of Mental Health, 11*(5), 565-579.
- Grob, G. N. & Goldman, H. H. (2006). *The dilemma of federal mental health policy: Radical reform or incremental change?* New Brunswick, NJ: Rutgers University Press.
- Guindon, G. E. & Boisclair, D. (2003). *Past, current, and future trends in tobacco use.* Washington DC: World Bank. Retrieved from <http://www1.worldbank.org/tobacco/publication.asp>
- Gusfield, J. R. (1989). Constructing the ownership of social problems: Fun and profit in the welfare state. *Social Problems, 36*(5), 431-441.
- Habermas, J. (1973). *Legitimation crisis.* Boston: Beacon Press.
- Hannigan, B. & Cutcliffe, J. (2002). Challenging contemporary mental health policy: Time to assuage the coercion? *Journal of Advanced Nursing, 37*(5), 477-484.
- Hannigan, J. A. (1991). Social movement theory and the sociology of religion: Toward a new synthesis. *Sociological Analysis, 52*(4: Religious Movements and Social Movements), 311-331.
- Hanson, B. S., Isacson, S. O., Janzon, L., & Lindell, S. E. (1990). Social support and quitting smoking for good. Is there an association? Results from the population study, "Men born in 1914," Malmo, Sweden. *Addictive Behavior, 15*(2), 221-233.
- Harris, G. & Wilson, D. (2009 July 1). Suicide warnings for 2 anti-smoking drugs. *The New York Times*, n.p.

- Harris, K. M., Carpenter, C., & Bao, Y. (2006). The effects of state parity laws on the use of mental health care. *Medical Care*, 44(6), 499-505.
- Harris, T., Brown, G. W., & Robinson, R. (1999). Befriending as an intervention for chronic depression among women in an inner city: Randomized controlled trial. *British Journal of Psychiatry*, 174, 219-224.
- Hassmiller, S. & Lumpkin, J. (2007). The role of foundations in improving health. In D. J. Mason, J. K. Leavitt, and W. W. Chaffee (Eds.). *Policy and politics in nursing and health care* (pp. 344-350). St. Louis, MO: Saunders.
- Hatzidimitriadou, E. (2002). Political ideology, helping mechanisms, and empowerment of mental health self-help/mutual aid groups. *Journal of Community and Applied Social Psychology*, 12, 271-285.
- Health Foundation of Greater Cincinnati. (October 2008). Reclaiming 25 Years of Life: Integrating Physical and Mental Health Care to Reduce Health Disparities for People with Severe Mental Illness. Cincinnati: OH. Retrieved from <http://www.healthfoundation.org/publications/order.jsp>
- Healy, M. (2008, April 29). Thoughts of suicide? It could be the meds you're taking. *Chicago Tribune*, p. 4.
- Herrman, H. (2001). The need for mental health promotion. *Australian and New Zealand Journal of Psychiatry*, 35, 709-715.
- Herxheimer, A. (2003). Relationships between the pharmaceutical industry and patients' organizations. *British Medical Journal*, 326, 1208-1210.
- Hierholzer, R. (2007). Views and reviews: Medical classics. A mind that found itself. *British Medical Journal*, 334, 1009.

- Hilgartner, S. & Bosk, C. L. (1988). The rise and fall of social problems: A public arenas model. *American Journal of Sociology*, 94(1), 53-78.
- Himelhoch, S. & Daumit, G. (2003). To whom do psychiatrists offer smoking-cessation counseling? *American Journal of Psychiatry*, 160, 2228-2230.
- Hobson, B. (2003). (Ed.). *Recognition struggles and social movements: Contested identities, agency, and power*. Cambridge: Cambridge University Press.
- hooks, b. (1994). *Teaching to transgress: Education as the practice of freedom*. New York: Routledge.
- Houston, T. & Kaufman, N. J. (2000). Tobacco control in the 21st century: Searching for answers in a sea of change. *Journal of the American Medical Association*, 284(6), 752-753.
- Hubbard, J. C., DeFleur, M. L., & DeFleur, L. B. (1975). Mass media influences on public conceptions of social problems. *Social Problems*, 23(1), 22-34.
- Hughes, J. F., Hatsukamy, D. K., Mitchell, J. E., & Dahlgren, L. A. (1986). Prevalence of smoking among psychiatric outpatients. *American Journal of Psychiatry*, 143, 993-997.
- Hughes, J. R. (1993). Possible effects of smoke-free inpatient units on psychiatric diagnosis and treatment. *Journal of Clinical Psychiatry*, 54, 109-114.
- Hughes, J. R. (1999). Co-morbidity and smoking. *Nicotine and Tobacco Research*, 1, S149-S152.
- Husaini, B. A., Sherkat, D. E., Levine, R., Bragg, R., Holzer, C., Anderson, K. et al. (2002). Race, gender, and health care service utilization and costs among

- Medicare elderly with psychiatric diagnoses. *Journal of Aging and Health*, 14(1), 79-95.
- Institute of Medicine [IOM]. (2003). *The future of public health in the 21st century*. Washington DC: National Academy Press.
- Institute of Medicine [IOM]. (2005). *Improving the quality of health care for mental health and substance use conditions*. Washington DC: National Academy Press.
Retrieved from <http://www.nap.edu/openbook.php?isbn=0309100445>
- Jacobson, P.D. & Banerjee, A. (2005). Social movements and human rights rhetoric in tobacco control. *Tobacco Control*, 14(2), 45-49.
- Jenkins, J. C. (1983). Resource mobilization theory and the study of social movements. *Annual Review of Sociology*, 9, 527-553.
- Jenkins, J. C. & Perrow, C. (1977). Insurgency of the powerless: Farm worker movements (1946-1972). *American Sociological Review*, 42(2), 249-268.
- Jennings, M. K. (1987). Residues of a movement: The aging of the American protest generation. *American Political Science Review*, 81(2), 367-382.
- Jeste, D. V., Gladsjo, J. A., Lindamer, L. A., & Lacro, J. P. (1996). Medical comorbidity in schizophrenia. *Schizophrenia Bulletin*, 22, 413-427.
- Johnson, A. G. (1995). *The Blackwell dictionary of sociology: A user's guide to sociological language*. Malden, MA: Blackwell Publishers.
- Kaiser Family Foundation. (October 2008). The uninsured: A primer. Retrieved from <http://kff.org/uninsured/upload/7451-04.pdf>.

- Kalman, D. (1998). Smoking cessation treatment for substance misusers in early recovery: A review of the literature and recommendations for practice. *Substance Use and Misuse, 33*, 2021-2047.
- Kauffman, R. M., Ferketich, A. K., & Wewers, M. E. (2008). Tobacco policy in American prisons, 2007. *Tobacco Control, 17*(5), 357-360.
- Kaufman, M. (1999, December 14). Mental illness in America: 50 million people a year; Surgeon General's Report addresses barriers to treatment. *Washington Post*, p. A3.
- Kelly, C. & McCreadie, R. G. (1999). Smoking habits, current symptoms, and pre-morbid characteristics of schizophrenic patients in Nithsdale, Scotland. *American Journal of Psychiatry, 156*, 1751-1757.
- Kessler, R. C., Chu, W. T., Demler, O., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of twelve month DSM-IV disorders in the National Comorbidity Survey Replication (NCS-R). *Archives of General Psychiatry, 62*(6), 617-627.
- Kessler, R. C., Herringa, S., Lakoma, M. D., Petukhova, M., Rupp, A. E., Schoenbaum, M., et al. (2008). Individual and societal effects of mental disorders on earnings in the U.S.: Results from the National Comorbidities Survey Replication. *American Journal of Psychiatry, 165*, 703-711.
- Kiesler, C. A. (1980). Mental health policy as a field of inquiry for psychology. *American Psychologist, 35*(12), 1066-1080.

- Kitsuse, J. I. & Spector, M. (1973). Toward a sociology of social problems: Social conditions, value-judgments, and social problems. *Social Problems*, 20(4), 407-419.
- Klandermans, B. (1992). The social construction of protest and multiorganizational fields. In A.D. Morris & C. M. Mueller (Eds). *Frontiers in social movement theory* (pp. 77-103). New Haven: Yale University Press.
- Klandermans, B. & Oegma, D. (1987). Potentials, networks, motivations, and barriers: Steps towards participation in social movements. *American Sociological Review*, 52, 519-531.
- Kolata, G. (2008, May 22). Study finds big social factor in quitting smoking. *The New York Times*, n.p.
- Lamberg, L. (2004). Patients need more help to quit smoking. *Journal of the American Medical Association*, 282, 1286-1290.
- Lasser, K., Boyd, J. W., Woolhandler, S., Himmelstein, D. U., McCormick, D., & Bor, D. H. (2000). Smoking and mental illness: A population-based prevalence study. *Journal of the American Medical Association*, 284(20), 2606-2610.
- Lauerman, C. (2001, October 14). Unhooked; A onetime pack-a-day veteran smokes out the psychology of addiction and quitting. *Chicago Tribune*, p. 1.
- Lawn, S. & Pols, R. (2005). Smoking bans in psychiatric inpatient settings? A review of the literature. *Australian and New Zealand Journal of Psychiatry*, 39, 866-885.
- Lawn, S. L., Pols, R. G., Barber, J. G. (2002). Smoking and quitting: A qualitative study with community-living psychiatric clients. *Social Science and Medicine*, 17, 369-372.

- LeBel, J. (2008). Regulatory change: A pathway to eliminating seclusion and restraint of “regulatory scotoma.” *Psychiatric Services*, 59, 194-196.
- Lester, H., Tritter, J.Q. & Sorohan, H. (2005). Patients’ and health professionals’ views on primary care for people with serious mental illness: Focus group study. *British Medical Journal*, 330, 1122.
- Lester, P. E. & Kohen, I. (2008). Smoking in the nursing home: A case report and literature review. *Journal of the American Medical Directors Association*, 9, 201-203.
- Levy, C. J. (2002, April 28). For mentally ill, death and misery. *The New York Times*, n.p.
- Light, D. W. (2000). Towards a sociologically ideal, justice-based health care system. *Contemporary Sociology*, 29(1), 62-74.
- Link, B. G., Cullen, F. T., Frank, J., & Wozniak, J. F. (1987). The social rejection of former mental patients: Understanding why labels matter. *American Journal of Sociology*, 92(6), 1461-1500.
- Lohr, J. B. & Flynn, K. (1992). Smoking and schizophrenia. *Schizophrenia Research*, 8, 93-102.
- Lucksted, A., Dixon, L. B., & Sembly, J. B. (2000). A focus group pilot study of tobacco smoking among psychosocial rehabilitation clients. *Psychiatric Services*, 5(12), 1544-1548.
- Lucksted, A., McGuire, C., Postrado, L., Kreyenbuhl, J., & Dixon, L. B. (2004). Specifying cigarette smoking and quitting among people with serious mental illness. *American Journal of Addiction*, 13(2), 128-138.

- Lutterman, T., Ganju, V., Schacht, L., Shaw, R., Monihan, K., et al. (2003). Sixteen state study on mental health performance measures. DHHS Publication No. (SMA) 03-3835. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Retrieved from http://www.nri-inc.org/reports_pubs/2003/16StateStudy2003.pdf
- MacArthur Foundation. (n.d.). Retrieved on April 29, 2009 from www.macfound.org.
- Malone, R. E. (2002). Nursing, our public deaths, and the tobacco industry. *American Journal of Critical Care, 11*(2), 102-105.
- Manderscheid, R. & Delvecchio, P. (Summer 2008). Moving toward solutions: Responses to the crisis of premature death. *International Journal of Mental Health, 37*(2), 3-7.
- Manderscheid, R., Druss, B., & Freeman, E. (Summer 2008). Data to manage the mortality crisis. *International Journal of Mental Health, 37*(2), 49-68.
- Mannheim, K. (1936) *Ideology and utopia: An introduction to the sociology of knowledge*. London: Routledge.
- Marx, K. (1867, 1885, 1894/1967). *Capital*. New York: International Publishers.
- Marx, K. & Engels, F. (1848). *The communist manifesto*. New York: International Publishers.
- Mauss, A. L. (1984). The myth of social problems theory. *Social Problems Theory Division Newsletter*. Buffalo, NY: Society for the Study of Social Problems.
- Maynard, D. W. (1988). Interaction, language, and social problems. *Social Problems, 35*(4), 311-334.

- McAdam, D. (1982). *Political process and the development of black insurgency 1930-1970*. Chicago: University of Chicago Press.
- McAdam, D., McCarthy, J. D., & Zald, M. N. (1988). Social movements. In N. J. Smelser (Ed.). *Handbook of sociology* (pp. 695-737). Newbury Park, CA: Sage Publications.
- McAdam, D. & Scott, W. R. (2005). Organizations and movements. In G.F. Davis, D. McAdam, W. R. Scott, & M. N. Zald. (Eds.). *Social Movements and Organization Theory* (pp. 4-40). New York: Cambridge University Press.
- McCarthy, D. (1996). *Knowledge as culture: The new sociology of knowledge*. New York: Routledge.
- McCarthy, J. D., Tarrow, S., & Tilly, C. (2001). *Dynamics of contention*. Cambridge: Cambridge University Press.
- McCarthy, J. D. & Zald, M. N. (1973). *The trend of social movements in America: Professionalization and resource mobilization*. Morristown, NJ: General Learning Press.
- McCarthy, J. D. & Zald, M. N. (1977). Resource mobilization and social movements: A partial theory. *American Journal of Sociology*, 82, 1212-1241.
- McCarthy, J. & Zald, M. N. (1973). *The trend of social movements*. Morristown, NJ: General Learning Press.
- McChargue, D. E., Gulliver, S. B. & Hitsman, B. (2002). Would smokers with schizophrenia benefit from a more flexible approach to smoking treatment? *Addiction*, 97, 785-793.

- McCorkle, B. H., Rogers, E. S., Dunn, E. C., Lyass, A., & Wan, Y. M. (2008). Increasing social support for individuals with serious mental illness: Evaluating the compeer model of intentional friendship. *Community Mental Health Journal, 44*(5), 359-366.
- McKinlay, J. B. (2005). A case of refocusing upstream: The political economy of illness (p.551-564). In P. Conrad (Ed.). *The Sociology of Health and Illness: Critical Perspectives* (7th ed.). New York: Worth Publishers.
- McNally, L., Oyesfeso, A., Annan, J., Perryman, K., Bloor, R., Freeman, S., Wain, B., Andrews, H. et al. (2006). A survey of staff attitudes to smoking-related policy and intervention in psychiatric and general health care settings. *Journal of Public Health, 28*(3), 192-196.
- Mechanic, D. (2003). Policy challenges in improving mental health services: Some lessons form the past. *Psychiatric Services, 54*, 1227-1232.
- Mechanic, D. (2008). *Mental health and social policy: Beyond managed care* (5th ed.). Boston: Pearson.
- Mechanic, D., Bilder, S., & McAlpine, D. D. (2002). Employing persons with serious mental illness. *Health Affairs, 21*, 242-253.
- Melucci, A. (1995). The process of collective identity. In H. Johnson & B. Klandermans (Eds.). *Social Movement and Culture* (pp. 41-63). Minneapolis: University of Minnesota Press.
- Menashe, C. L. & Siegel, M. (1998). The power of a frame: An analysis of newspapers coverage of tobacco issues—United States, 1985-1996. *Journal of Health Communication, 3*, 307-325.

- Mendez, D. Warner, K. E., & Courant, P. N. (1998). Has smoking cessation ceased? Expected trends in the prevalence of smoking in the United States. *American Journal of Epidemiology*, *148*(3), 249-258.
- Mentally ill smoke 43.3% of cigarettes used in the U.S. (2000, November 22). *The Wall Street Journal*, p. 1.
- Merton, R. K. (1971). Social problems and sociological theory. In R.K. Meton & R. Nisbet (Eds.). *Contemporary Social Problems* (pp. 793-845). New York: Harcourt, Brace, and Jovanovich.
- Merton, R. K. & Nisbet, R. A. (1971). *Contemporary social problems revised*. New York: Harcourt, Brace, and Jovanovich.
- Mestel, R. (2000, November 22). Mentally ill twice as likely to be smokers, study finds; Tobacco: Special programs may be needed to encourage patients to quit, give their isolation and tendency to use nicotine to fight depression, experts say. *Los Angeles Times*, p. A38.
- Meyer, D. S. & Staggenborg, S. (1996). Movements, countermovements, and the structure of political opportunity. *The American Journal of Sociology*, *101*(6), 1628-1660.
- Meyer, D. S. & Whittier, N. (1994). Social movement spillover. *Social Problems*, *41*(2), 277-298.
- Michigan Department of Community Health. (2009, June 9). Michigan tobacco quitline to re-open after brief hiatus. Retrieved from <http://www.michigan.gov/mdch/0,1607,7-132--216256--,00.html>
- Mills, C. W. (1959). *The sociological imagination*. Oxford: Oxford University Press.

- Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual causes of deaths in the United States 2000. *Journal of the American Medical Association*, *291*, 1238-1245.
- Morris, C. D., Giese, A. A., Turnbull, J. J., Dickinson, M., Johnson-Nagel, N. (2006). Predictors of tobacco use among persons with mental illnesses in a statewide population. *Psychiatric Services*, *57*, 1035-1038.
- Morris, C. D., Tedeschi, G. J., Waxmonsky, J. A., May, M., Giese, A. A. (2009). Tobacco quitlines and person with mental illnesses: Perspective, practice and direction. *Journal of the American Psychiatric Nurses Association*, *15*(1), 32-40.
- Morris, C. D., Waxmonsky, J., May, M., Giese, A., & Martin, L. (January 2009). *Smoking cessation for persons with mental illness: A toolkit for mental health providers*. Denver, CO: State Tobacco Education and Prevention Partnership.
- Retrieved from http://smokingcessationleadership.ucsf.edu/Downloads/catalogue/MHtoolkitJan_2009.pdf
- Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. E. (Eds.). (2009). *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.
- Murphy, R. F. (1987). *The body silent*. New York: Henry Holt & Co.
- National Alliance on Mental Illness [NAMI]. Retrieved February 22, 2009 from <http://www.nami.org/>.

- National Association of State Mental Health Program Directors. (1999). *Position statement on seclusion and restraint*. Retrieved April 8, 2009 from http://www.nasmhpd.org/general_files/position_statement/posses1.htm.
- National Cancer Institute. (2001). Risks associated with low machine-measured yields of tar and nicotine (NIH Publication No. 02-5074). *Smoking and Tobacco Control Monograph No. 13*. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. Retrieved from <http://cancercontrol.cancer.gov/tcrb/monographs/13/>
- National Institute of Drug Abuse. (2009). *Comorbidity: Addiction and other mental illnesses*. NIDA Research Report Series (NIH Publication No. 08-5771). Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Drug Abuse. Retrieved from <http://www.drugabuse.gov/researchreports/comorbidity/>
- National Institute of Mental Health. (2008). *The numbers count: Mental disorders in America*. Retrieved from <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml>
- Nelson, G. (1994). The development of a mental health coalition: A case study. *American Journal of Community Psychology*, 22(2), 229-255.
- Neugebauer, R. (1999). Mind matters: The importance of mental disorders in public health's 21st century mission. *American Journal of Public Health*, 89(9), 1309-1311.

- Neuman, M. D., Bitton, A., & Glantz, S. A. (2005). Tobacco industry influence on the definition of tobacco related disorders by the American Psychiatric Association. *Tobacco Control, 14*, 328-337.
- North American Quitline Consortium. (n.d.). All quitline facts. Retrieved April 29, 2009 from <http://www.naquitline.org/index.asp?dbsection=map&dbid=2>
- O'Connor, J. (1973). *The fiscal crisis of the state*. New York. St. Martin's Press.
- Office of the Surgeon General. (1964). *Smoking and Health*. Report of the Advisory Committee to the Surgeon General of the Public Health Service. Washington, DC: U.S. Department of Health, Education, and Welfare, Public Health Service, Center for Disease Control. Public Health Service Publication No. 1103. Retrieved from <http://profiles.nlm.nih.gov/NN/B/B/M/Q/>
- Olinicy, A., Young, D. A., & Freedman, R. (1997). Increased levels of the nicotine metabolite nicotine in schizophrenic smokers compared to other smokers. *Biological Psychiatry, 42*, 1-5.
- Omi, M. & Winant, H. (1986). Racial formation. *Racial Formation in the United States: From the 1960s to the 1980s* (pp. 57-69). New York: Routledge.
- Oxman, T. E. & Dietrich, A. (2002). The key role of primary care physicians in mental health care for elders. *Generations, 26*(1), 59-65.
- Parks, J. & Jewell, P. (Eds.). (2006). *Technical report on smoking policy and treatment in state operated psychiatric facilities* (Technical Report 12). Alexandria, VA: National Association of State Mental Health Program Directors Medical Directors Council. Retrieved from http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Oct2006

%20Final%20Report%20on%20Smoking%20Policy%20and%20Treatment%20at
State%20Operated%20Psychiatric%20Facilities.pdf

Parks, J. & Pollack, D. (Eds). (2005). *Integrating behavioral health and primary care services: Opportunities and challenges for state mental health authorities*

(Technical Report 11). Alexandria, VA: National Association of State Mental Health Program Directors Medical Directors Council. Retrieved from

http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Final%20Technical%20Report%20on%20Primary%20Care%20-%20Behavioral%20Health%20Integration.final.pdf

Parks, J., Svendsen, D., Singer, P., & Foti, M. E. (2006). *Morbidity and mortality in people with serious mental illness* (Technical Report 13). Alexandria, VA:

National Association of State Mental Health Program Directors Medical Directors Council. Retrieved September 15, 2008 from

http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf

Pastor, M. & Ortiz, R. (2009). *Making change: How social movements work and how to support them*. Los Angeles: The California Endowment. Retrieved from

http://www.calendow.org/Collection_Publications.aspx?coll_id=62&ItemID=432

Patkar, A. A., Gopalakrishnan, R., Lundy, A., Leone, F. T., Certa, K. M., & Weinstein, S.

P. (2002). Relationship between tobacco smoking and positive and negative symptoms in schizophrenia. *Journal of Nervous and Mental Disease*, 190(9), 604-610.

- Phelan, M., Stradins, L., & Morrison, S. (2001, February 24). Physical health of people with severe mental illness. *British Medical Journal*, 322, 443-444.
- Piven, F. F. & Cloward R. A. (1977). *Poor people's movements: Why they succeed, how they fail*. New York: Pantheon Books.
- Pleis J. R. & Lethbridge-Çejku, M. (2007). Summary health statistics for U.S. adults: National Health Interview Survey, *Vital Health Statistics*, 10(235), 1-135.
- Poland, B., Frohlich, K., Haines, R. J., Mykhalovskiy, E., Rock, M., & Sparks, R. (2006). The social context of smoking: The next frontier in tobacco control? *Tobacco Control*, 15(1), 59-63.
- Polletta, F. & Jasper, J. M. (2001). Collective identity and social movements. *Annual Review of Sociology*, 27, 283-305.
- President's New Freedom Commission on Mental Health [PNFC]. (2003). *Achieving the promise: Transforming mental health care in America*. DHHS Pub. No. SMA-03-3831. Rockville, MD. Retrieved from <http://www.mentalhealthcommission.gov/reports/FinalReport/toc.html>
- Prochaska, J. J., Delucchi, K., & Hall, S. M. (2004). Meta-analysis of smoking cessation interventions with individuals in substance abuse treatment or recovery. *Journal of Counseling and Clinical Psychology*, 72(6), 1144-1156.
- Prochaska, J. J., Fletcher, L., Hall, S. E., & Hall, S. M. (2006). Return to smoking following a smoke-free psychiatric hospitalization. *American Journal of Addictions*, 15, 15-22.

- Prochaska, J. J., Hall, S. M., & Bero, L. A. (2008). Tobacco use among individuals with schizophrenia: What role has the tobacco industry played? *Schizophrenia Bulletin*, 34(3), 555-567.
- Prochaska, J. J., Hall, S. M., Tsoh, J. Y., Eisendrath, S., Rossi, J. S., Redding, C. A., et al. (2007). Treating tobacco dependence in clinically depressed smokers: Effects of smoking cessation on mental health functioning. *American Journal of Public Health*, 57(8), 12-15.
- Prochaska, J. J., Rosi, J. S., Redding, C. A., Rosen, A. B., Tsoh, J. Y., Humfleet, G. L., et al. (2004). Depressed smokers and stage of change: Implications for treatment interventions. *Drug and Alcohol Dependence*, 76, 143-151.
- Prochaska, J. O. & DiClemente, C. C. (1986). Toward a comprehensive model of change. In W.R. Miller and N. Heather (Eds.). *Treating addictive behaviors: Processes of change* (pp. 3-27). New York: Plenum.
- Quadagno, J. (1987). Theories of the welfare state. *Annual Review of Sociology*, 13(1), 109-128.
- Quadagno, J. (2004). Why the United States has no national health insurance: Stakeholder mobilization against the welfare state, 1945-1996. *Journal of Health and Social Behavior*, 45(Extra Issue: Health and Health Care in the United States: Origins and Dynamics), 25-44.
- Redfield Jamison, K. (1995). *An unquiet mind: A memoir of moods and madness*. New York: Random House.

- Reilly, P., Murphy, L., & Alderton, D. (2006). Challenging the smoking culture within a mental health service supportively. *International Journal of Mental Health Nursing, 15*(4), 272-278.
- Robert Wood Johnson Foundation. (n.d.). Retrieved March 18, 2009 from <http://rwjf.org/>
- Rogers, E. M. (1995). *Diffusion of innovations*. (4th ed.). New York: The Free Press.
- Roshannaei-Moghaddam, B. & Katon, W. (2009). Premature mortality from general medical illnesses among persons with bipolar disorder: A review. *Psychiatric Services, 60*(2), 147-156.
- Ross, R. & Staines, G. L. (1972). The politics of analyzing social problems. *Social Problems, 20*(1), 18-40.
- Rx for Change. (2009). Mental health peer curriculum, *Tobacco-Free for Recovery: Assisting Mental Health Consumers with Tobacco Cessation*. Retrieved from <http://rxforchange.ucsf.edu/>
- Saillant, C. (2003, August 18). California: Smoking issue a quandary for psychiatric facilities. *Los Angeles Times*, p. B1.
- Saillant, C. (2002, October 16). County to spend tobacco money on health system; Supervisors approve a \$5.5 million bailout, angering anti-smoking advocates. *Los Angeles Times*, p. B3.
- Sarna, L., Bialous, S. A., Welles, M. J., & Kotlerman, J. (2009). Smoking among psychiatric nurses: Does it hinder tobacco dependence treatment? *American Psychiatric Nurses Association, 15*(1), 59-67.
- Schatzman, L. & Strauss, A. (1966). A sociology of psychiatry: A perspective and some organizing foci. *Social Problems, 14*(1), 3-16.

- Scheff, T. J. (1974). The labeling theory of mental illness. *American Sociological Review*, 39(3), 444-452.
- Scheufele, D. A. (1999). Framing as a theory of media effects. *Journal of Communication*, 49(1), 103-122.
- Schlandweiler, K. (Ed.). (2004). *Foundations fundamentals: A guide for grantseekers* (7th ed.). New York: Foundation Center.
- Schmitz, N., Kruse, J., & Kugler, J. (2003). Disabilities, quality of life, and mental disorders associated with smoking and nicotine dependence. *American Journal of Psychiatry*, 160, 1670-1676.
- Schneider, J. W. (1985). Defining the definitional perspective on social problems. *Social Problems*, 32(3), 232-234.
- Schneider, J. W. (1985). Social problems theory: The constructionist view. *Annual Review of Sociology*, 11, 209-229.
- Schroeder, S. A. (2004). Tobacco control in the wake of the 1998 Master Settlement Agreement. *New England Journal of Medicine*, 350, 293-301.
- Schroeder, S. A. (2005). What to do with a patient who smokes. *Journal of the American Medical Association*, 294(4), 482-487.
- Schroeder, S. A. (2008). Stranded in the periphery—The increasing marginalization of smokers. *New England Journal of Medicine*, 358, 2284-2286.
- Schroeder, S. A. (2009). A 51-year-old woman with bipolar disorder who wants to quit smoking. *Journal of the American Medical Association*, 301(5), 522-531.
- Schroeder, S. A. (2009). Moving forward in smoking cessation: Issues for psychiatric nurses. *Journal of the American Psychiatric Nurses Association*, 15(1), 68-72.

- Schroeder, S. A. (2007, November 18). hidden epidemic. *Washington Post*, p. B7.
- Schroeder, S. A. & Morris, C. D. (Forthcoming). Tobacco use in those with mental illness and substance abuse programs: A neglected epidemic.
- Sherm, D. L., Beronio, K. K., & Harbin, H. T. (2009). After parity—What's next? *Health Affairs*, 28(3), 660-662.
- Simon, B. Loewy, M., Sturmer, S., Weber, U., Freytag, P., Habig, C., et al. (1998). Collective identification and social movement participation. *Journal of Personality and Social Psychology*, 74(3), 646-658.
- Simon, S. (2001, August 26). Little of tobacco money goes to kicking habit; Settlement: Most states spend funds on social projects instead of health care. Experts voice alarm. *Los Angeles Times*, p. A1.
- Sirey, J. A., Bruce, M. L., Alexopoulos, G. S., Perlick, D. A., Friedman, S. J., & Meyers, B. S. (2001). Stigma as a barrier to recovery: Perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric Services*, 52, 1615-1620.
- Slama, K. (2004). Current challenges in tobacco control. *International Journal of Tuberculosis and Lung Disease*, 8(1), 1160-1172.
- Smelser, N. (1963). *Theory of collective behavior*. New York: Free Press.
- Smith, E. A. (2007). 'It's interesting how few people die from smoking': Tobacco industry efforts to minimize risk and discredit health promotion. *European Journal of Public Health*, 17(2), 162-170.

- Smith, E. A. & Malone, R. E. (2007). 'We will speak as the smoker': The tobacco industry's smokers' rights groups. *European Journal of Public Health, 17*(3), 306-313.
- Smoking Cessation Leadership Center (n.d.). Retrieved September 15, 2008 from <http://smokingcessationleadership.ucsf.edu>
- Smoking Cessation Leadership Center (n.d.). The partnership: Mobilizing for change. Retrieved September 1, 2009 from http://smokingcessationleadership.ucsf.edu/MH_Partnership.htm
- Snow, D. A. & Benford, R. D. (1998). Ideology, frame resonance and participant mobilization. *International Social Movement Research, 1*, 197-217.
- Snow, D. A., Rochford, E. B. Jr., Worden, S. K., & Benford, R. D. (1986). Frame alignment processes, micromobilization, and movement participation. *American Sociological Review, 51*, 464-481.
- Snow, D. A., Zurcher, L. A. Jr., & Ekland-Olson, S. (1980). Social networks and social movements: A microstructural approach to differential recruitment. *American Sociological Review, 45*(5), 787-801.
- Sokal, J., Messias, E., Dickerson, F. B., Kreyenbuhl, J., Brown, C. H., Goldberg, R. W., et al. (2004). Comorbidity of medical illnesses among adults with serious mental illness who are receiving community psychiatric services. *Journal of Nervous and Mental Disease, 192*(6), 421-427.
- Solway, E. (2007). "Somebody showed me that mental illness was not a dead end": Insights of older mental health consumer advocates and leaders in mental health and aging. Unpublished manuscript.

- Solway, E. (2009). Windows of opportunity for culture change in mental health settings. *Journal of the American Psychiatric Nurses Association, 15*(1), 41-49.
- Sommer, R. (1990). Family advocacy and the mental healthy system: The recent rise of the alliance for the mentally ill. *Psychiatric Quarterly, 61*(3), 205-221.
- Spector, M. & Kitsuse, J. I. (1973). Social problems: A re-formulation. *Social Problems, 21*(2), 145-159.
- Speed, E. (2006). Patients, consumers, and survivors: A case study of mental health service user discourses. *Social Science and Medicine, 62*(1), 28-38.
- Speer, D. C. & Schneider, M. G. (2003). Mental health needs of older adults and primary care: Opportunity for interdisciplinary geriatric team practice. *Clinical Psychology: Science and Practice, 10*(1), 85-101.
- Stapleton, J. A., Watson, L., Spirling, L. I., Smith, R., Milbrandt, A., Ratcliffe, M., et al. (2007). Varenicline in the routine treatment of tobacco dependence: A pre-post comparison with nicotine replacement therapy and an evaluation in those with mental illness. *Addiction, 103*(1), 146-154.
- Steinberg, M. L., Williams, J. M. & Ziedonia, D. M. (2004). Financial implications of cigarette smoking among individuals with schizophrenia. *Tobacco Control, 13*, 206.
- Stone, D. (1989). Causal stories and the formation of policy agendas. *Political Science Quarterly, 104*(Summer), 281-300.
- Strauss, A., Bucher, R., Ehrlich, D., Sabshin, M., & Schatman, L. (1964). *Psychiatric ideologies and institutions*. New York: Free Press

- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Strouse, R., Hall, J., & Kovac, M. (2004). *Survey of health professionals' knowledge, attitudes, beliefs, and behaviors regarding smoking cessation assistance and counseling*. Princeton, NJ: Mathematica Policy Research, Inc., 1-16.
- Substance Abuse Mental Health Services Administration. (2002). *Report to Congress on the prevention and treatment of co-occurring substance abuse disorders and mental disorders*. Rockville, MD: U.S. Department of Health and Human Services. Retrieved from <http://www.dpt.samhsa.gov/comor/Co-occurring.aspx>.
- Substance Abuse Mental Health Services Administration. (2004). *National consensus statement on mental health recovery*. Retrieved from <http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/>.
- Sutton, J. R. (1991). The political economy of madness: The expansion of the asylum in progressive America. *American Sociological Review*, 56(5), 665-678.
- Swarbrick, P., Hutchinson, D. S. & Gill, K. (Summer 2008). The quest for optimal health. *International Journal of Mental Health*, 37(2), 69-88.
- Szasz, S. (1970). *The manufacture of madness: A comparative study of the inquisition and the mental health movement*. New York: Harper and Row.
- Tarrow, S. (1994). *Power in movement: Social movements and contentious politics*. (2nd Ed.). Cambridge: Cambridge University Press.
- Taylor, D. H., Hasselblad, V., Henley, S. J., Thun, M. J., & Sloan, F. A. (2002). Benefits of smoking cessation for longevity. *American Journal of Public Health*, 92(6), 990-996.

- Tedeschi, G. J. (2009, May). *Mental health and smoking cessation and the California Smokers' Helpline*. Presented at the Mental Health and Smoking Cessation Executive Meeting, San Diego, CA.
- Thorndike, A. N., Stafford, R. S., & Rigotti, N. A. (2001). U.S. physicians' treatment of smoking in outpatients with psychiatric diagnoses. *Nicotine and Tobacco Research*, 3(1), 85-91.
- Tilly, C. (1978). *From mobilization to revolution*. Reading, MA: Addison-Wesley.
- Tilly, C., Tilly, L., & Tilly, R. (1975). *The rebellious century (1830-1930)*. Cambridge: Harvard University Press.
- Torgovnick, K. (December 3, 2008). Why do the mentally ill die younger? *TIME*. Retrieved from <http://www.time.com/time/health/article/0,8599,1863220,00.html>
- Tsoh, J. Y. & Hall, S. M. (2004). Depression and smoking: From the transtheoretical model of change perspective. *Addictive Behavior*, 29(4), 801-805.
- Tsoh, J. Y., Humfleet, G. L. Munoz, R. F., Reus, V. I., Hartz, D. T., & Hall, S. M. (2000). Development of major depression after treatment for smoking cessation. *American Journal of Psychiatry*, 157(3), 386-374.
- Tucker, R. C. (1978). *The Marx-Engels reader*. New York: Norton.
- U.S. Department of Health and Human Services [USDHHS]. (1989). *Reducing the health consequences of smoking: 25 years of progress. A report of the Surgeon General*. DHHS Publication No. 8411. Rockville, MD. Retrieved from <http://profiles.nlm.nih.gov/NN/B/B/X/S/>
- U.S. Department of Health and Human Services [USDHHS]. (1990). *The health benefits of smoking cessation. A report of the Surgeon General*. DHHS Publication NO.

8416. Rockville, MD: Public Health Service, Centers for Disease Control, Office on Smoking and Health. Retrieved from <http://profiles.nlm.nih.gov/NN/B/B/C/T/>
- U.S. Department of Health and Human Services [USDHHS]. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/home.html>
- U.S. Department of Health and Human Services [USDHHS]. (2001). *Mental health: Culture, race, and ethnicity—A Supplement to Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/cre/>
- U.S. Department of Health and Human Services [USDHHS] (2004). *The health consequences of smoking: A report of the Surgeon General*. U.S. Department of Health and Human Services. Office on Smoking and Health. Retrieved from <http://www.surgeongeneral.gov/library/smokingconsequences/>
- Ustun, T. B. (1999). The global burden of mental disorders. *American Journal of Public Health, 89*(9), 1315-1318.
- Warner, K. E. (2006). Tobacco policy research: Insights and contributions to public health policy. In K. E. Warner (Ed.). *Tobacco Control Policy* (pp. 3-86). San Francisco, CA: Jossey-Bass.

- Weiser, M., Richenberg, A., Grotto, I., Yavitzky, R., Rabinowitz, J., Lubin, G., et al. (2004). Higher rates of cigarette smoking in male adolescents before the onset of schizophrenia: A historical-prospective cohort study. *American Journal of Psychiatry, 161*, 1219-1223.
- Whitaker, R. (2002). *Mad in America: Bad science, bad medicine, and the enduring mistreatment of the mentally ill*. Cambridge, MA: Perseus Publishing.
- Williams, J. M. (2008). Eliminating tobacco use in mental health facilities: Patients' rights, public health, and policy issues. *Journal of the American Medical Association, 299*(5), 571-573.
- Williams, J. M., Gandhi, K. K., Steinberg, M. L., Foulds, J., Ziedonis, D. M., & Benowitz, N. L. (2007). Higher nicotine and carbon monoxide levels in menthol cigarette smokers with and without schizophrenia. *Nicotine and Tobacco Research, 9*(8), 873-881.
- Williams, J. M. & Ziedonis, D. (2004). Addressing tobacco among individuals with a mental illness or an addiction. *Addictive Behaviors, 29*, 1067-1083.
- Williams, R. H. (1995). Constructing the public good: Social movements and cultural resources. *Social Problems, 42*(1), 124-144.
- Winett, L. (1995, September). *Advocate's guide to developing framing memos*. Berkeley, CA: Berkeley Media Studies Group.
- Woolgar, S. & Pawluch, D. (1985). Ontological gerrymandering: The anatomy of social problems explanations. *Social Problems, 32*(3), 214-227.
- World Health Organization. (1997). *Tobacco or health: A global status report*. Geneva: World Health Organization. Geneva: Author.

- World Health Organization. (1998). *Guidelines for controlling and monitoring the tobacco epidemic*. Geneva: Author.
- World Health Organization. (2001). *Mental health: New understanding, New hope*. Box 2.3. Geneva: World Health Organization. Retrieved from <http://www.who.int/whr/2001/en/>
- World Health Organization. (2002). Quantifying selected major risks to health. *World Health Report*. Geneva: World Health Organization. Retrieved from <http://www.who.int/whr/2002/chapter4/en/index.html>
- World Health Organization. (2004). World health report 2003: Changing history, Annex Table 3: Burden of DALYs by causes, sex, and mortality stratum in WHO regions. Estimates for 2002. *World Health Report*. Geneva: Author. Retrieved from <http://www.who.int/whr/2003/en/index.html>
- World Health Organization. (2007). *Mental health: Strengthening mental health promotion*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs220/en/>.
- World Health Organization. (n.d.). *WHO framework convention on tobacco control*. Retrieved April 9, 2009 from <http://www.who.int/fctc/en/>.
- Zald, M. N. & Ash, R. (1966). Social movement organizations: Growth, Decay and change. *Social Forces*, 44(3), 327-341.
- Zald, M. N. & Berger, M. A. (1978). Social movements in organizations: Coup d'Etat, insurgency, and mass movements. *American Journal of Sociology*, 83(4), 823-861.
- Zald, J. D. & McCarthy, M. N. (1977). Resource mobilization and social movements: A partial theory. *American Journal of Sociology*, 82(6), 1212-1241.

- Zhu, S-H., Anderson, C. M., Tedeschi, G. J., Rosbrooke, B., Johnson, C. E., Byrd, M., et al. (2002). Evidence of real world effectiveness of a telephone quitline for smokers. *New England Journal of Medicine*, *347*, 1087-1093.
- Ziedonis, D., Williams, J. M., & Smelson, D. (2003). Serious mental illness and tobacco addiction: A model program to address this common but neglected issue. *American Journal of the Medical Sciences*, *326*(4), 223-230.
- Ziedonis, D. M. & George, T. P. (1997). Schizophrenia and nicotine use: Report of a pilot smoking cessation program and review of neurobiological and clinical issues. *Schizophrenia Bulletin*, *23*, 247-254.
- Ziedonis, D. M., Kosten, T. R., Glazer, W. M., & Frances, R. J. (1994). Nicotine dependence and schizophrenia. *Hospital & Community Psychiatry*, *45*, 204-206.
- Ziedonis, D. M. & Williams, J. M. (2003). Management of smoking in people with psychiatric disorders. *Current Opinion in Psychiatry*, *16*, 305-315.

UCSF Library Release Form

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sign the following statement:

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Eva Ungersboeck
Author Signature

September 8, 2009
Date