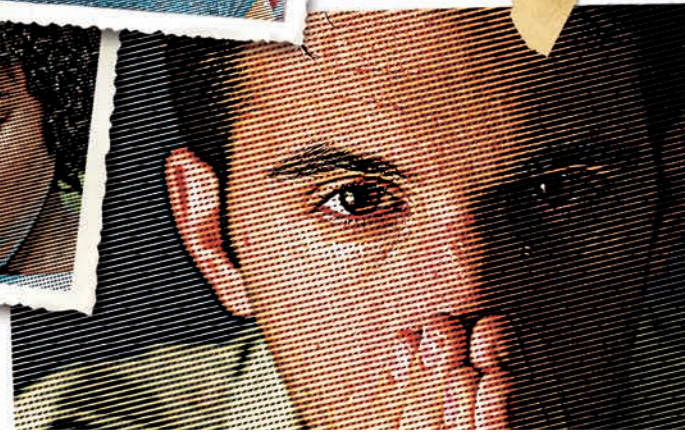


*A Hidden Epidemic:*

# Tobacco Use and Mental Illness





A Hidden Epidemic:  
**Tobacco Use and Mental Illness**



June 2011

## Legacy's Commitment to Dissemination

Legacy® is a national non-profit committed to helping Americans live longer, healthier lives. Its mission is to build a world where young people reject tobacco and anyone can quit. To further this mission, Legacy has engaged in a comprehensive dissemination effort to share lessons learned from the replicable, sustainable tobacco control projects that were implemented across the nation with the assistance of past Legacy funding. In response to the recent financial downturn and to maximize the impact of limited funds, Legacy has shifted its efforts to focus mostly on population-based strategies and suspended its competitive grant-making programs. Legacy no longer solicits or accepts competitive funding requests and all existing grants will be phased out by 2012.

*A Hidden Epidemic: Tobacco Use and Mental Illness* is the tenth publication in Legacy's dissemination series. This publication seeks to call attention to the issue of the high prevalence of tobacco use and nicotine dependence among people with mental illnesses and to highlight barriers to effective tobacco-cessation efforts to help people with mental illnesses quit. This publication also features examples of five projects that demonstrate how organizations across America are addressing tobacco-related disparities faced by people with mental illnesses. These examples represent a broad range of tobacco prevention and cessation projects implemented by past Legacy grantees to deal with the issue of tobacco use in this population.

This publication may include certain grantee activities beyond the scope of Legacy's grants. Some of the grantees' tobacco control activities have multiple funders, and it is essential to examine the full range of program activities to explore various ways organizations are addressing the issue of tobacco use among persons with mental illnesses. No Legacy funds were used for lobbying or other political activities.

[Legacy recognizes and honors the fact that tobacco has a sacred cultural place in American Indian life in parts of North America. Many Native American tribes use tobacco for spiritual, ceremonial, and traditional healing purposes. Legacy, therefore, distinguishes traditional, ceremonial and spiritual use of tobacco from its commercial use. Legacy promotes tobacco control efforts that are not geared toward targeting traditional tobacco. Legacy only supports programs and activities designed to address the issue of manufactured, commercial tobacco use in communities, including Native American Indian communities in the United States.]



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# A Hidden Epidemic: Tobacco Use and Mental Illness



This Legacy publication is designed to highlight the issue of the high prevalence of tobacco use among people with mental illnesses. People with mental illnesses smoke at

rates almost twice as high as the general population (41 percent versus 22.5 percent, respectively). Nearly half the cigarettes smoked in the United States (44-46 percent) are consumed by people with co-occurring psychiatric or addictive disorders. The smoking prevalence rates are even higher (60-80 percent) for those who are diagnosed with depression, bipolar disorder, or schizophrenia.

The report takes a close look at the disproportionate rates of tobacco use and its staggering effects on the health and well-being of persons with mental disorders. It also examines the issue of how tobacco prevention and cessation is not fully integrated into the mental health treatment community in the United States. Various studies have shown that providing smoking cessation to people with mental illnesses is not a high priority for many mental health care providers. Moreover, many mental health care facilities still support the use of tobacco by their patients and staff.

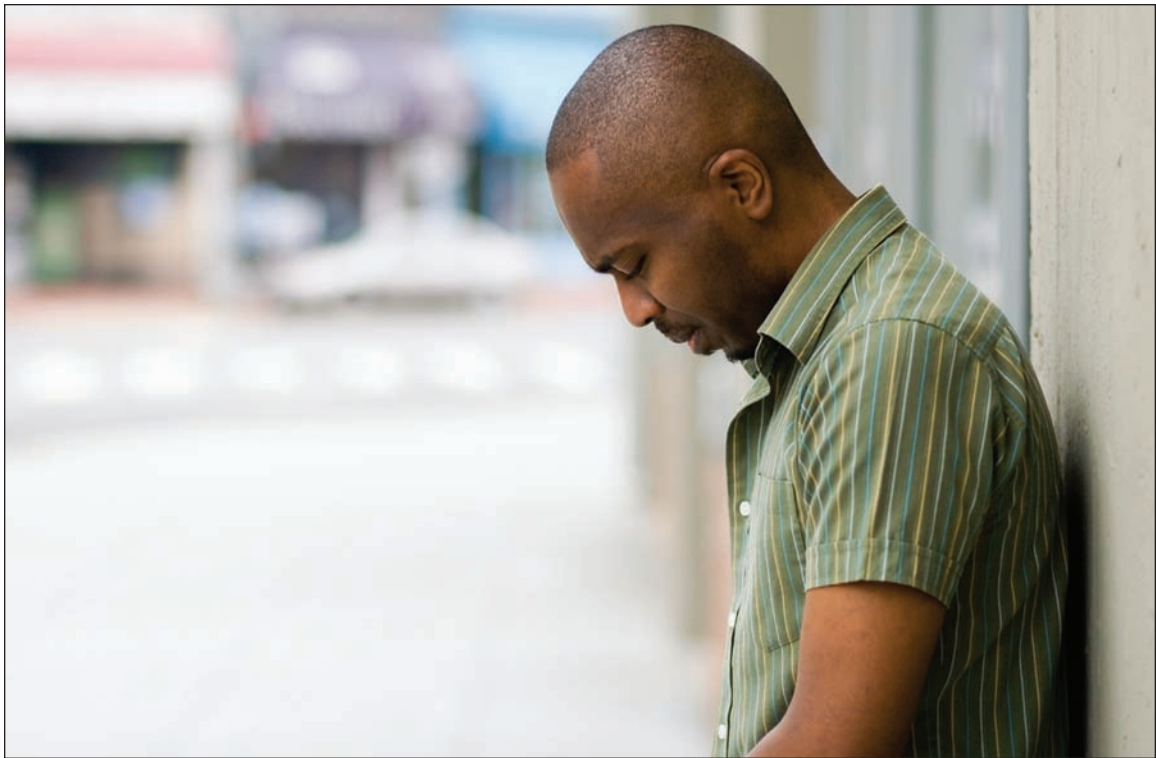
This publication explores some of the complex issues inherent to this public health issue and outlines some of the barriers to the full integration of tobacco control into mental health systems. The publication examines:

- Tobacco-related disparities facing individuals with mental disorders;
- Motivation among people with mental illnesses to quit tobacco use;
- Education and training among mental health providers in evidence-based tobacco cessation;
- Integration of tobacco prevention and cessation into mental health care;

- Research on various aspects of co-morbidity of tobacco use with psychiatric disorders; and
- Key strategies to address the high prevalence of tobacco use among people with mental illnesses.

This publication also features five case studies of different Legacy-funded programs that demonstrate promising ways organizations and coalitions are addressing this issue of co-morbidity. These projects have focused on raising awareness and knowledge about the issue among mental health professionals and have worked toward transforming policies and systems to integrate tobacco prevention and cessation into mental health care settings. They exemplify ways of providing smoking cessation as part of a goal to achieve overall, holistic recovery and wellness for people with mental illnesses. These are examples of projects that expanded beyond the traditional, clinical psychiatric treatment model for tobacco cessation. Most created innovative premises of facilitating and empowering mental health consumers to make their own decisions and work in partnership with their health care providers toward better health and recovery. Collectively, these projects have contributed greatly to changing the overall culture and perception of smoking and smoking cessation in mental health.

In the first case study, we discuss how the Smoking Cessation Leadership Center (SCLC) based at the University of California, San Francisco brought diverse national stakeholders together to establish and promote a national tobacco control agenda for mental health. SCLC formed the National Mental Health Partnership for Wellness and Smoking Cessation, a coalition representing 48 leaders from a variety of governmental, consumer, advocacy, academic, and provider organizations. SCLC offered training and technical assistance to organizations to develop and implement tobacco control initiatives. SCLC also partnered with national organizations such as the Substance Abuse and Mental Health Services Administration,



the American Psychiatric Nurses Association, and the National Association of State Mental Health Program Directors to implement a wide range of projects to advance tobacco control in behavioral and mental health settings.

The second case study looks at the need for a knowledge and resource base to enhance the capacity of state programs to implement tobacco-free policies and cessation programs in mental and behavioral health contexts. This case study examines how the Tobacco Cessation Leadership Network (TCLN) collaborated with its members to develop and refine knowledge of integrating comprehensive tobacco cessation with mental health care at the state level. Based on the input and expertise provided by its members, TCLN created a resource guide and training toolkit called *Bringing Everyone Along*. The resource guide outlines six recommendations for integrating tobacco control into mental health care and addiction treatment. Those recommendations are: 1) Change existing beliefs; 2) Provide tailored treatment services; 3) Use results from comprehensive assessment to help tailor services; 4) Provide cessation pharmacotherapy and monitor psychiatric medications concurrently; 5) Tailor behavioral treatment; and 6) Increase training and supervision for counseling staff.

The third case study examines a project known as CHOICES (Consumers Helping Others Improve their Condition by Ending Smoking), which uses a peer-to-peer education and counseling approach to help mental health care consumers quit tobacco. CHOICES is a model project developed by the Division of Addiction Psychiatry at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey (UMDNJ). CHOICES hires nonsmoking mental health care consumers, called Consumer Tobacco Advocates (CTAs), to educate and reach out to their peers about tobacco use and cessation. CTAs travel to mental health clinics, day programs, psychiatric hospitals, and residential facilities statewide to provide information about tobacco and offer individual feedback sessions to interested consumers about the health effects and financial implications of tobacco use. To address the gap between demand and available cessation services for mental health care consumers, the project team at UMDNJ has also developed a continuing-education workshop for psychiatrists and advance-practice nurses to provide training on integrating tobacco cessation into mental health care.

The fourth case study in this publication discusses how the Genesis Club, in partnership with the Department of Psychiatry at the University of

Massachusetts, adapted the CHOICES program for use in a Clubhouse, a psychological rehabilitation center that focuses on empowering the people it serves and offers opportunities for them to share responsibility and ownership for their overall health and recovery. In this model, Clubhouse members (people with mental illnesses) and staff work together using a consensus model in all aspects of the program's operation and activities. Following the CHOICES model, the Genesis Club identified and trained peer tobacco-cessation leaders to encourage the Clubhouse members who smoked to quit as part of their healthy lifestyle decisions. The case study highlights how the Genesis Club created an organizational change to integrate tobacco cessation and prevention into its Clubhouse activities through a leadership team representing its staff and members. The leadership team received training on developing peer leaders, screening for interest in tobacco cessation among members, and integrating tobacco cessation into the overall rehabilitation plan (goals plans) set by members and their staff advisors. As a result of this project the Genesis Club has begun to see some cultural change around tobacco use among

members at the Clubhouse.

The fifth and final case study looks at a project implemented by Counseling Services, Inc. (CSI). By collaborating with and gathering input from heavy smokers in its client population, CSI developed and implemented a smoking cessation and wellness model tailored to low-income individuals with mental health and substance abuse disorders. Based on recommendations from the clients, CSI concluded that support from peers was essential to help overcome the feelings of worthlessness and isolation that were causing people with mental illnesses to disregard their own health. This led to the formation of peer support groups, co-led by clients and CSI staff members, that discussed health and wellness in the group and encouraged people to identify alternative healthy activities such as swimming, bike-riding, exercise, and more. With the help of these peer support groups, clients helped each other not only to cut down on their smoking and quit but also to work on their overall health and wellness.



## Tobacco Use and Mental Illness



### Introduction

Smoking rates are significantly higher in people with mental illnesses than in the general population.<sup>1</sup> People with psychiatric disorders such as schizophrenia, anxiety disorders, bipolar disorder, and depression are smoking at shocking levels.<sup>2,3</sup> It is a hidden epidemic with serious consequences for the physical, psychological, and financial health of this already vulnerable population. It is also an epidemic that has yet to be addressed on a wide scale within the mental health treatment community.

One study, which examined data from the early 1990s, shows that people with psychiatric disorders smoke at rates almost twice as high as the general population (41 percent versus 22.5 percent, respectively).<sup>4</sup> Almost half the cigarettes smoked in the United States (44-46 percent) are consumed by people with co-occurring psychiatric or addictive disorders.<sup>5,6</sup>

The prevalence rates are extremely high: 60 percent of people with lifetime depression are

either current or former smokers; as many as 70 percent of people with bipolar disorder smoke; and up to 88 percent of people with schizophrenia are current smokers.<sup>8,9,10,11,12,13</sup>

The effects of this rampant tobacco use are staggering. Persons with serious mental illness (SMI) are now dying a full 25 years earlier than the general population.<sup>14,15,16</sup> As compared to the general population, for example, people diagnosed with schizophrenia face double the risk of death due to cardiovascular problems and triple the risk of respiratory disease and lung cancer.<sup>17,18,19,20</sup> To be sure, it is a vulnerable population, but this increased morbidity and mortality is due in large part to treatable medical conditions associated with modifiable risk factors such as smoking, obesity, substance abuse, and inadequate access to medical care.<sup>21</sup> In addition, there is a general disregard among mental health care providers for making tobacco cessation a priority.<sup>22</sup>

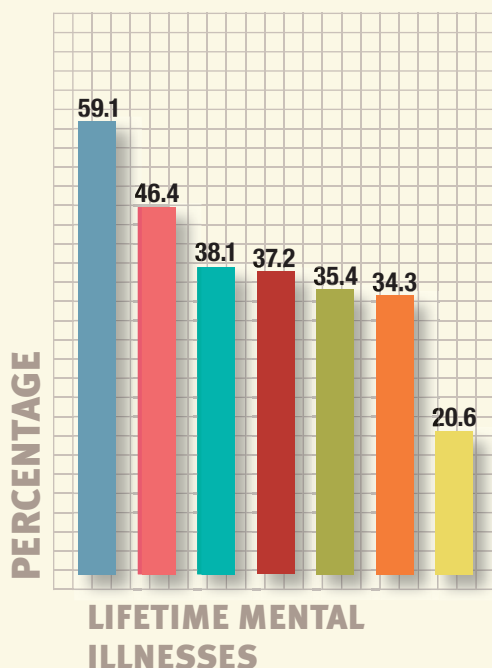
## Smoking Prevalence among Adults by Lifetime Mental Illnesses Compared to General Population<sup>23</sup>

Schizophrenia	59.1%
Bipolar Disorder	46.4%
Serious Psychological Distress	38.1%
Attention Deficit Disorder	37.2%
Dementia	35.4%
Phobias or Fears	34.3%
General Population	20.6% <sup>24</sup>

Source: Annette K. McClave et al., "Smoking Characteristics of Adults With Selected Lifetime Mental Illnesses: Results From the 2007 National Health Interview Survey," *American Journal of Public Health* 100:12 (2010).

FIGURE 1

## Smoking Prevalence among Adults by Lifetime Mental Illnesses Compared to General Population



Source: Annette K. McClave et al., "Smoking Characteristics of Adults With Selected Lifetime Mental Illnesses: Results From the 2007 National Health Interview Survey," *American Journal of Public Health* 100:12 (2010).

Graphic prepared by Legacy

There are financial consequences as well. People with mental illness often rely on fixed incomes, and the high prevalence of tobacco use among this population has a deep economic impact.<sup>25,26</sup> Smokers with schizophrenia spend as much as a quarter of their income on cigarettes.<sup>27</sup>

This outpouring of limited resources benefits the tobacco industry. In a landscape in which tobacco companies are losing their foothold with the general public, selling cigarettes to people with SMI represents a huge market. The 175 billion cigarettes sold each year to people with psychiatric disorders earn tobacco companies approximately \$39 billion dollars annually.<sup>28,29,30,31.</sup>

Despite these sobering statistics, tobacco control is not a priority within the mental health treatment community. Studies of both outpatient and hospital-based care of persons with psychiatric disorders show that "less than a quarter of outpatients with psychiatric diagnosis receive counseling from their physicians aimed at smoking cessation, and in hospitals, only 1 percent of psychiatric inpatient smokers were assessed for smoking; none of the treatment plans for these patients addressed tobacco use."<sup>32</sup>

**"In terms of lives saved, quality of life, and cost efficacy, treating smoking is considered to be one of the most important activities a clinician can do."**<sup>33,34</sup>

In the following chapters, this publication explores some of the complex issues inherent to this tobacco epidemic, outlines some of the barriers that have historically stood in the way of integrating tobacco control into mental health treatment efforts, and highlights some current promising efforts designed to begin bridging the gap.

### Disparity at a Glance

Nicotine dependence and mental illness present a complex playing field, involving multiple variables. A combination of neurobiological and psychosocial factors is at play, and people with SMI often have co-occurring disorders. In fact, psychiatric disorders and substance abuse often go hand in hand.

In addition, there is a strong relationship between a consumer's history of trauma and abuse, especially adverse experiences in childhood, and a risk for mental

health issues and concomitant tobacco and other substance use later in life.<sup>35,36</sup> The connection between trauma, mental health, and tobacco prevalence are discussed in the fifth case study in this report.

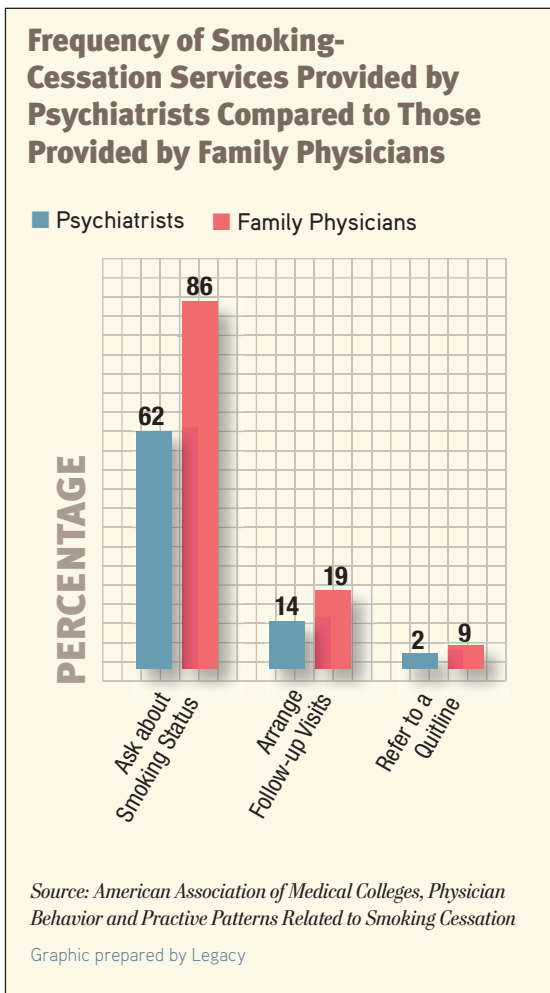
As presented in Figure 2 to the right, smoking cessation is not a priority for many mental health care providers. According to a 2007 study conducted by the Association of American Medical Colleges with Legacy’s funding support, 62 percent of psychiatrists ask patients about their smoking status and only 14 percent arrange for follow-up visits, while 2 percent refer patients to a quit line.<sup>37</sup> Based on the same study, 86 percent of physicians in family medicine ask patients about their smoking status, 19 percent arrange for follow-up visits, and 9 percent refer patients to a quit line.<sup>38</sup>

**Psychiatrists were less likely to ask about smoking status, to advise patients who smoke to quit, or to assess patient willingness to quit than other physicians. Some of the differences may be related to the fact that they are more likely to report that “Patients have more immediate problems to address.” Psychiatrists were more likely than other physicians to want additional information on asking patients whether they smoke, providing social support to smokers trying to quit, and treating smokers with psychiatric or chemical-dependency disorders.**<sup>39</sup>

Association of American Medical Colleges, 2007

A lack of training of mental health care providers in cessation techniques and strategies plays a central role in the disparity. A 2005 survey of psychiatric residents assessing their knowledge about and preparation for implementing evidence-based tobacco-cessation strategies with patients highlights this training deficit. The study reports, “The majority of respondents reported receiving none or inadequate training on tobacco-related interventions

FIGURE 2



in medical school or residency training.”<sup>40</sup> The need for training in smoking cessation exists in various medical practices beyond psychiatry. A national survey of U.S. health professionals, conducted in 2003-2004, determined there is lack of training in smoking cessation among doctors across multiple disciplines. For example, 26.3 percent of professionals in the field of psychiatry had cessation training compared to 33.8 percent in the field of primary care, 19.1 percent in emergency medicine, and 21.3 percent in dentistry.<sup>41</sup> More discussion on this topic will take place later in the report.

In addition to limited training opportunities, there is a strong belief system among mental health providers that often stands directly in the way of integrating tobacco cessation into patients’ overall recovery plans. Case Studies 3, 4, and 5 featured in this report demonstrate how mental health practitioners can work in partnership with patients to incorporate cessation into their individual plans for recovery and wellness. The beliefs or perspectives among mental health providers, some

## Schizophrenia and Smoking

Addiction to nicotine is the most common form of substance abuse in people with schizophrenia. They are addicted to nicotine at three times the rate of the general population.

... The relationship between smoking and schizophrenia is complex. People with schizophrenia seem to be driven to smoke, and researchers are exploring whether there is a biological basis for this need. In addition to its known health hazards, several studies have found that smoking may make antipsychotic drugs less effective.

Quitting smoking may be very difficult for people with schizophrenia because nicotine withdrawal may cause their psychotic symptoms to get worse for a while. Quitting strategies that include nicotine replacement methods may be easier for patients to handle. Doctors who treat people with schizophrenia should watch their patients' response to antipsychotic medication carefully if the patient decides to start or stop smoking.<sup>46</sup>

—NATIONAL INSTITUTE OF MENTAL HEALTH, 2009

of which merit further study, include the following:

- Individuals with mental illnesses are not motivated to quit;
- Tobacco use is a form of self-medication and helps patients control their symptoms;
- Quitting smoking will exacerbate symptoms and lead to a relapse of the psychiatric disorder;
- Tobacco use is an individual right of patients; and
- Use of cigarettes is an effective reward system in institutions and psychiatric hospitals.<sup>42,43,44,45</sup>

Further complicating matters is the belief among many practitioners that restricting or banning tobacco use in psychiatric hospitals can lead to increased levels of coercion and violence. However, there is a growing body of evidence that points to a decrease in coercion and violence in facilities that have banned smoking.<sup>47,48</sup>

Finally, although extensive research has been conducted on the effects of tobacco use in the general population, and resources have been devoted to developing and testing evidence-based strategies aimed at helping people overcome nicotine addiction, few studies have focused specifically on issues surrounding tobacco cessation and individuals with mental illnesses. The research conducted thus far in this population is based on limited data, derived from small sample sizes, focused on just a few psychiatric disorders. More studies that 1) evaluate smoking-cessation treatments in multi-treatment settings and 2) cover a broad range of psychiatric disorders are needed.<sup>49</sup>

**“Developing strategies that address tobacco use in those with psychiatric disorders not only improves the long-term health of those with co-morbid mental disorders, but also provides improved cessation methods that may be applicable to other populations and furthers our understanding of the mechanisms contributing to both tobacco dependence and psychiatric disorders.”<sup>50</sup>**

### Motivation to Quit

One of the biggest assumptions made by mental health care providers and family members of individuals with mental illnesses is that people with SMI are simply not motivated to quit.

As researchers Sharon M. Hall and Judith J. Prochaska acknowledge, this is a logical, if flawed, assumption. “There are plausible reasons to believe that smokers who are mentally ill and who abuse substances might not be motivated to quit smoking. For example, smokers in treatment for substance abuse often have a chaotic lifestyle, and one might assume the resultant lack of stability and stress would drain energy from health-maintenance behaviors, such as quitting smoking. Similarly, smokers with mental health problems might be too amotivated or disorganized to quit smoking. For the

most part, however, recent data do not support these beliefs.”<sup>51</sup>

What the recent data do show is that approximately 70 percent of mentally ill smokers want to quit.<sup>52,53,54,55,56</sup>

In fact, a study conducted by Siru et al. showed that people with mental illness are as motivated to quit smoking as the general population. “The recent data suggest that both people served in inpatient environments and outpatient environments, with a variety of diagnoses, are as ready to quit smoking as is the general population.”<sup>58</sup>

A 2006 study examined smoking behaviors and motivations to quit among people served in inpatient environments in a smoke-free psychiatric hospital. Although all participants in the study returned to smoking after discharge, 87 percent willingly participated in the study while hospitalized. “They are interested in and have attempted to quit smoking, but are rarely advised to do so by their mental healthcare providers.” As opposed to a lack of patient motivation to quit, it was the lack of follow-up support and intensive counseling that were cited as contributing to the high rates of post-discharge relapse.<sup>59</sup>

### **Educating Providers**

If motivation to quit is not an impediment, then what else accounts for the huge disparity in providing individuals with mental illnesses with proven, evidence-based strategies to help them reach this goal?

The American Psychiatric Association (APA) guidelines recommend that psychiatrists assess their patients’ smoking status and history, as well as advise their patients about cessation strategies.<sup>60</sup>

Are psychiatrists adequately prepared to implement this recommendation? The literature suggests that they are not. A study published in 2006 showed that only half of psychiatry residency programs offer any kind of training in tobacco use and cessation, and among those that did, training only lasted for approximately one hour.<sup>61</sup> In addition, a survey of eight trials focused on the efficacy of training health care professionals in basic evidence-based cessation practices found that not one trial was conducted with mental health providers.<sup>62</sup>

A survey published in 2005 looking specifically at a psychiatric training in five residency programs in Northern California found that 74 percent of the respondents had little or no tobacco cessation training in medical school, and that 79 percent had

### **Depression and Smoking**

Persons with depression were more likely to be current smokers than persons without depression. Almost one-half of adults under age 55 with current depression were current smokers, while less than a quarter of people in this age group without depression were smokers.

The proportion of adults who were current smokers tended to increase with an increase in depression severity. Even persons with mild depressive symptoms below the threshold for the diagnosis of depression were more likely to be smokers than people with no depressive symptoms.

Adults with depression were more likely to smoke over a pack a day and smoke their first cigarette within 5 minutes of waking than were adults without depression. Both of these are indicators of heavy smoking. Heavy smoking is highly correlated with inability to quit.

—LAURA A. PRATT AND DEBRA J. BRODY,  
“DEPRESSION AND SMOKING IN THE U.S. HOUSEHOLD  
POPULATION AGED 2 AND OVER 2005–2008,” *National  
Center for Health Statistics Data Brief 34* (2010).

little or no tobacco cessation training in the course of their psychiatric residency.<sup>63</sup> This lack of training was not due to lack of interest, however; the survey showed that 94 percent of the residents would be interested in receiving training if it were available.<sup>64</sup>

Training clinicians in evidence-based cessation strategies has proven to be effective. A randomized clinical trial in an outpatient Veteran’s Administration (VA) clinic for veterans suffering from chronic Posttraumatic Stress Disorder (PTSD) trained mental health providers to integrate these strategies into mental health recovery and wellness plans for their consumers. The VA is the largest health care system in the country, and “this study demonstrated the feasibility of training mental health providers to integrate guideline-based smoking-cessation treatment into mental health care for veterans with PTSD. PTSD clinic prescribers readily incorporated the delivery of tobacco-cessation medications into their clinical practice.”<sup>65</sup>

In their review of integrating cessation strategies into the mental health care, Hall and Prochaska state, “Dissemination of an evidence-based cigarette smoking treatment curriculum has the potential of

**“The high rates of tobacco use among individuals with mental illnesses and the resulting negative health, social, financial, and treatment consequences cannot be ignored. Without clinical intervention, however, levels of tobacco use are unlikely to change. A focus on training the next generation of psychiatrists may help ensure that changes in clinical practice are achieved and that tobacco interventions are delivered to this high risk group of smokers.”<sup>68</sup>**

dramatically increasing the proportion of smokers with mental illness who receive assistance with quitting.<sup>66</sup>

To achieve this goal, Dr. Judith Prochaska and colleagues at the University of California, San Francisco developed the Psychiatry Rx for Change, a four-hour tobacco control curriculum tailored specifically to train psychiatry residents how to integrate tobacco cessation strategies into mental health recovery plans for their consumers.<sup>67</sup>

### **Integrating Cessation Strategies into Psychiatric Treatment**

For people served in inpatient environments, hospitalization can be an opportunity to quit smoking. Due to a hospital standard requiring a ban of smoking in all U.S. hospitals since 1993,<sup>70</sup> many people served in inpatient environments are forced to quit while hospitalized. Although “mental health and addiction treatment settings are among the only remaining sites with exemptions to permit continued tobacco use,”<sup>71</sup> Prochaska et al. observe, “For some patients, hospitalization may provide one of the few experiences with not smoking for an extended period of time.”<sup>72</sup>

However, just stopping cold turkey doesn’t mean that patients will stay quit. In fact, 80-90 percent start smoking again soon after they’re released.<sup>73,74</sup>

Part of the problem is the lack of tobacco-cessation strategies made available to patients. In the case of Nicotine Replacement Therapy (NRT), the APA guidelines recommend prescribing it only when withdrawal symptoms are present.<sup>75</sup> Symptoms associated with nicotine withdrawal, such as agitation, inability to concentrate, irritability, etc. can mimic symptoms of psychiatric disorders like depression, making it difficult for providers to distinguish between the two.<sup>76</sup>

### **Smoking Cessation by Specialty<sup>69</sup>**

<b>Percent of Physicians Who “Usually”</b>	<b>Family Medicine</b>	<b>Internal Medicine</b>	<b>OB/GYN</b>	<b>Psychiatry</b>
Advise patients to stop smoking	87%	93%	90%	62%
Ask about smoking status	86%	89%	89%	62%
Discuss pharmacotherapies	77%	71%	52%	61%
Assess patient willingness to quit	60%	73%	65%	44%
Discuss counseling options	39%	36%	35%	37%
Recommend nicotine replacement therapy	30%	39%	23%	23%
Discuss enlisting support for quitting	30%	30%	29%	24%
Monitor patient progress in attempting to quit	30%	30%	10%	28%
Prescribe other medications	26%	30%	17%	20%
Provide brochures/self-help materials	25%	24%	30%	13%
Arrange follow-up visits with patient to address smoking	19%	19%	7%	14%
Refer patients who smoke to others for appropriate cessation treatment	10%	15%	14%	11%
Refer patient to a quitline	9%	7%	7%	2%

*Source: Association of American Medical Colleges, Physician Behavior and Practice Patterns Related to Smoking Cessation, 2007.*



Starting and stopping smoking can also affect the way that antidepressants and antipsychotic medications are metabolized, which can adversely affect dosage and effectiveness.<sup>77</sup> However, the degrees to which such an interaction between smoking status and the effectiveness of psychiatric medications occur vary depending upon specific medication.<sup>78,79</sup> Moreover, contrary to the general misperception among many mental health clinicians, not all psychiatric medications have such an interaction with smoking status. Only some antipsychotics and antidepressants interact with smoking.<sup>80,81</sup> More research is needed to better understand such interactions. In the words of Douglas Ziedonis et al. “Limited data indicate that certain psychiatric medications have an effect on smoking behavior and cessation. These effects should be explored further, along with how smoking cessation treatments and long-term abstinence may affect psychiatric symptoms and functioning.”<sup>82</sup>

Clinicians need to keep track of any such interactions in their patients who are trying to quit.<sup>83</sup> The following table presents a list of psychiatric and other medications with possible interactions related to smoking status and cessation:

### **Medications Known or Suspected to Have Their Levels Affected by Smoking and Smoking Cessation**

#### **Antipsychotics**

Chlorpromazine (Thorazine), Olanzapine (Zyprexa), Clozapine (Clozaril), Thiothixene (Navane), Fluphenazine (Permitil), Trifluoperazine (Stelazine), Haloperidol (Haldol), Ziprasidone (Geodon), and Mesoridazine (Serentil)

#### **Antidepressants**

Amitriptyline (Elavil), Fluvoxamine (Luvox), Clomipramine (Anafranil), Imipramine (Tofranil), Desipramine (Norpramin), Mirtazapine (Remeron), Doxepin (Sinequan), Nortriptyline (Pamelor), Duloxetine (Cymbalta), and Trazodone (Desyrel)

#### **Mood Stabilizers**

Carbamazepine (Tegreto)

#### **Anxiolytics**

Alprazolam (Xanax), Lorazepam (Ativan), Diazepam (Valium), and Oxazepam (Serax)

#### **Others**

Acetaminophen Riluzole (Rilutek), Caffeine Ropinirole (Requip), Heparin Tacrine Insulin Warfarin, Rasagiline (Azilect), Riluzole (Rilutek), Ropinirole (Requip), Tacrine, and Warfarin

*Adapted from Chad Morris et al., “Smoking Cessation for Persons with Mental Illnesses: A Toolkit for Mental Health Providers,” University of Colorado, Department of Psychiatry, Behavioral Health and Wellness Program, January 2009.*



Further research is warranted to determine the extent of the relationship between tobacco use and various psychiatric medications. However, mental health caregivers already have the psychological and pharmacological training needed both to monitor patients for adverse drug reactions, and to provide support for continued abstinence.<sup>84</sup> As Judith Prochaska states in a 2010 paper, “The evidence indicates that individuals with psychiatric disorders can be aided in quitting smoking without threat to their mental health recovery. Fear of decompensation should not be used as an excuse to overlook patients’ tobacco use in clinical practice. Integration of smoking cessation treatment within psychiatric care is encouraged so that clinicians can identify and address nicotine withdrawal and any changes in psychiatric symptoms during the quit attempt.”<sup>85</sup>

In fact, there is a range of mental health settings that can create opportunities for mental health care professionals to provide cessation services to people with mental illnesses. Hospitalization may be one of those opportunities to reach individuals with mental illnesses on issues of tobacco control. But it is important to note that for many mental health care consumers, hospitalization may not be a positive environment in which to think about and work on quitting.

Compulsory smoking bans can give mental health care providers a unique opportunity to address nicotine dependence with a population that they might not otherwise reach.<sup>86</sup> As the *Tobacco-Free Living in Psychiatric Settings* toolkit, produced by the National Association of State Mental Health Program Directors (NASMHPD), states: “At any given time, approximately 50,000 consumers are housed in the 235 state public psychiatric facilities in the U.S. Roughly 200,000 pass through the facilities each year. With comprehensive programs to curb tobacco use, we have the potential to help them choose to quit and learn new ways to live longer, healthier lives.”<sup>87,88</sup>

While progress is being made in the effort to change norms in inpatient facilities, a cultural shift in attitudes is still necessary. Psychiatric facilities continue to use cigarettes as a form of currency used to encourage patient behavior. According to an article by Steven A. Schroeder, MD, “... many hospitals responded that gaining access or permission to smoke was a motivator for patients to comply with staff. Family members and staff often viewed smoking as one of the patients’ few pleasures and were reluctant to eliminate it.”<sup>89</sup>

Smoking by patients and staff is still allowed in many mental health care facilities. For example, results from a 2008 survey conducted by the



**“Revenue from the sales of tobacco provides discretionary income for facilities. Smoke breaks for staff and patients have become an ‘entitlement,’ deserved and protected, and one of the only times consumers can practice relating to each other and staff in a ‘normalized’ way. When, what, and how much to smoke are often the only choices consumers make as people served in inpatient environments, reinforcing cigarette use by virtue of the autonomy it appears to allow. More troubling, cigarettes are used as positive/negative reinforcement by staff to control consumer behavior. While taking seriously and treating illicit drug use by those with mental illness for some time, a substance far more deadly and pervasive, and used disproportionately by this population, has largely been ignored.”<sup>95,96</sup>**

NASMHPD Research Institute (NRI) showed that 49 percent of 164 state psychiatric facilities that responded to the survey had a smoke-free policy.<sup>90</sup> Continuing to permit smoking takes time that could be used for tobacco control. Presently, in units where smoking is openly permitted, mental health staff spend an average of 15 minutes per shift managing patient smoking, and up to four hours a day when patients are allowed off-unit smoke breaks.<sup>91,92,93</sup> These treatment facilities should explore meaningful opportunities for offering a broad range of healthy activities such as yoga, meditation, music therapy, dance classes, etc. to their patients as alternatives to tobacco use.

As discussed in Case Studies 3, 4, and 5 featured in this report, it is important for mental health professionals to make available various tobacco-

cessation tools to their patients, offer healthy activities for stress and boredom relief, and create empowering and respectful environments and opportunities for people with mental illness to participate in their overall health and recovery.

In addition, in settings where smoke-free bans are enforced but cessation support is not provided, “patients may perceive the ban as punitive, their smoking habit as a non-medical issue, and themselves as unworthy of receiving intervention on this deadly addiction.”<sup>94</sup>

The National Association of State Mental Health Program Directors, under the leadership of Dr. Robert W. Glover, has promoted tobacco-free policies and tobacco cessation across public mental health service delivery systems and state-operated psychiatric facilities. As a result of Dr. Glover’s persistent leadership efforts, NASMHPD has established consensus among its members (representing state public health systems) on a position statement for creating tobacco-free facilities and providing cessation services to people with mental illnesses in those facilities.<sup>97</sup>

## **Research**

The National Institute of Mental Health (NIMH) Expert Panel on Smoking in People with Psychiatric Disorders states that “the reasons for the low rates of assessment and treatment may include health professionals’ acceptance of smoking by psychiatric patients as a matter of individual rights and as a means of self-medication aimed at relieving symptoms.” The report goes on to note, however, that research on smoking in this population needs to explore other potential explanations for tobacco use besides self-medication.”<sup>98</sup>

In fact, there is evidence that much of the research supporting the self-medication hypothesis may have been funded with tobacco-industry support.<sup>99</sup> Even so, there is some validity to self-medication hypotheses.

For example, nicotine affects cognitive processes in some people with schizophrenia. The stimulant effect of nicotine might counter some of the sedative effects of antipsychotic medications.<sup>100,101</sup> There is also evidence that hypothalamic-pituitary-adrenal (HPA) axis activation and nicotine addiction in PTSD and anxiety-disorder patients may be related. Furthermore, it is possible that the genes that affect dopamine production might influence the likelihood that a person with depression will smoke.<sup>102</sup>

Clearly, there are many unanswered questions. The NIMH panel concluded its report by identifying the following issues that will be important for future research across these disorders:<sup>103</sup>

- *“Better precision is needed in defining the specific psychiatric disorders of interest in a given study. “Depression,” for example, is used in reference to a number of different conditions. Similarly, clearer definitions of smoking behavior and patterns and progression of use are needed.*
- *Longitudinal studies can provide more complete information on the relative risk, incidence, and course of smoking and various mental disorders.*
- *More focus is needed on exploring the potential causal links between tobacco use and psychiatric disorders, including possible genetic, neurobiological, psychological, or social factors. The extent to which smoking is used as a form of self-regulation needs to be explored.*
- *More information is needed on how smoking and other health-related factors such as stress, obesity, and limited physical activity contribute to the illness and mortality seen in people with mental disorders.*
- *The report had a number of recommendations related to smoking cessation in this population. The report noted the need for adequate sample sizes in cessation trials, greater emphasis on adapting cessation treatment to various psychiatric populations and in different treatment settings, and research on how tobacco-control policies affect psychiatric populations.”*

However, even though more research is needed, Hall et al. assert that cessation strategies developed for the general population are effective, and should be used with mental health care consumers.<sup>104</sup> There is no reason to wait.

### **Key Strategies**

- Training mental health care providers in evidence-based tobacco cessation strategies;
- Integrating evidence-based cessation strategies into mental health treatment plans;
- Enforcing smoke-free policies at psychiatric hospitals and clinics;

- Assessing smoking status of all people served in psychiatric inpatient and outpatient environments;
- Supporting further research to identify the most effective cessation strategies for individuals with mental illnesses;
- Supporting further research on the use of antidepressants in tobacco cessation, and the effects of withdrawal on medication dosage and effectiveness;
- Conducting further research on the appropriate timing of the use of NRT in people with serious mental illness; and
- Focusing on tobacco prevention and early education among youth, particularly in programs and facilities that provide mental health services to youth with mental health care needs.

### **Case Studies**

In the following sections are five case studies of different Legacy-funded programs that address the public health issue of tobacco use among people with mental illnesses. These case studies include a broad range of tobacco-prevention and cessation programs implemented by Legacy’s past grantees.

**Case Study 1, *Smoking Cessation Leadership Center: Getting Tobacco Control on the Mental Health and Recovery Agenda*** outlines the efforts of the Smoking Cessation Leadership Center at the University of California, San Francisco to initiate a series of collaborations and partnerships aimed at integrating tobacco control into national behavioral health initiatives and programs.

**Case Study 2, *Bringing Everyone Along: A Resource Guide for Providers*** looks at the strategies that led the Tobacco Cessation Leadership Network to develop a resource guide to help state-level mental health and substance use providers integrate tobacco control into their individual programs and services.

**Case Study 3, *Building Blocks: A Multipronged Approach to Tobacco Control for Mental Health Care Consumers in New Jersey*** focuses on two initiatives developed by Dr. Jill Williams and her team at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey. The first program, CHOICES (Consumers Helping Others Improve their Condition by Ending Smoking), addresses tobacco use, and increases the demand for cessation services, by using mental

health care consumers to educate and reach out to their peers. The second program focuses on a Continuing Medical Education course designed to train mental health and substance abuse providers in tobacco-cessation strategies designed specifically for the populations they serve.

**Case Study 4, The Power of Teamwork: *Changing the Culture of the Clubhouse*** adapts the CHOICES program for use in Clubhouses, a model in which Clubhouse members and staff work together using a consensus model in all aspects of the operation and activities of a day program for people with mental illness. Members and staff also worked together to tailor the Learning about Healthy Living toolkit for use in the Clubhouse model.

**Case Study 5, Nurturing Connection: *A Tobacco-Cessation Model for Low-Income Smokers with Mental Illness*** also utilizes a peer model in educating and reaching out to low-income, heavy smoking people with serious mental illness and substance use disorders. In this case study, health-focused mutual aid groups were created using input from the clients to direct and guide the goals and activities of the groups.

# Smoking Cessation Leadership Center:

Getting Tobacco Control on Mental Health and Recovery Agenda



(Left to right) Jonathan E. Fielding, MD, MPH, Director Health Officer, Los Angeles County Department of Public Health and Current Treasurer; Legacy Board of Directors; Steven A. Schroeder, MD, Director of SCLC and Former Chair, Legacy Board of Directors; and Yvonne Brathwaite Burke, Los Angeles County Board of Supervisors at an “It’s Quitting Time L.A.!” press conference on August 2, 2006.

## Project Overview

**T**he Smoking Cessation Leadership Center (SCLC) is a national program office of the Robert Wood Johnson Foundation that aims to increase smoking-cessation rates and increase the number of health professionals who help smokers quit. Founded in 2003 and housed at the University of California, San Francisco, the SCLC is a relatively small organization with an increasingly large footprint in the world of tobacco control in the United States.

At its core, the SCLC embraces a non-hierarchical, supportive, and friendly approach aimed at facilitating dialogue and partnerships among national organizations, some of which may not initially realize that tobacco control is an important part of their missions.

Streamlined and nimble, the SCLC provides technical assistance and some financial support to help organizations create and quickly implement action plans. Connie Revell, who was the deputy



director of the SCLC from 2003-2010, describes the approach as “catalytic leadership.” It is part of an implementation model called the Performance Partnership Model—a strategy in which everyone involved agrees on a mutual goal, without necessarily having to agree on how to reach that goal.

“You have 100 percent agreement on what it is you are going to do, but you can have multiple strategies about how you’re going to get there,” said Revell. “The key is that everybody is doing something. Then you measure how you’re doing, and how all the various strategies are working. You track your progress along the way, and you regroup if you’re not making it.”

In 2006, Legacy approached the SCLC to partner on an initiative focusing on cessation efforts for priority populations. SCLC Director Steven A.

Schroeder, MD had been the head of Robert Wood Johnson Foundation for 13 years. In considering the initiative, Schroeder's thinking immediately turned to the world of behavioral health, a blanket term that encompasses both mental health care and substance abuse/addiction treatment.

The timing was right: A study had recently been released demonstrating that people with serious mental illness and co-occurring substance abuse disorders were dying 25 years earlier than the general population. One of the leading culprits behind this enormous disparity in life expectancy was tobacco.<sup>105</sup>

"Steve [Schroeder] knew the behavioral health world was important as one of the last bastions of smoking, and he had a very strong sense that if we didn't penetrate that behavioral health world, we just were never going to get to where we needed to get," said Revell. "He knew the subject backward and forward, and he knew where the remaining pockets of resistance were. And he was willing to take on the challenge even though a lot of his peers discouraged him from doing it."

Schroeder's peers discouraged him because what he was proposing was far from an easy task. Deep cultural divides both between the fields of mental health and substance abuse treatment, and between the worlds of medicine and public health, had engendered an atmosphere of mutual distrust.<sup>106,107</sup> Added to that were issues of tobacco use as a patient/consumer right, and the fact that female mental health care providers themselves used tobacco at a higher rate than their contemporaries in other fields.<sup>108,109</sup>

**"We didn't have to create the need; when people realized that there was a 25-year gap in life expectancy for their constituents, that was a tipping point. All we had to do was point out that perhaps the number one reason for that was smoking and then they were very quickly and eagerly looking for some solutions."**

*—Connie Revell, Former Deputy Director, SCLC*

In order to confront those obstacles, the SCLC staff knew they'd have to start forming partnerships among the major organizations involved.

"We decided to act the way we always had, which had been very successful," said Revell. "So we set out to meet with some of the leaders of those groups and make personal connections and start building some trust."

### **SCLC: Bringing Everyone to the Table**

The SCLC decided to start the process by reaching out to the world of mental health care providers and consumers. But no one at the SCLC had the right connections. So Revell turned to a colleague, Gail Hutchings, CEO of the consulting firm Behavioral Health Policy Collaborative.

"She literally knows everybody in the field. She is just a phenomenal networker and leader, and she's got the zeal of the converted," said Revell. "She used to be the Chief of Staff at SAMHSA [Substance Abuse and Mental Health Services Administration], where she also ran the Center for Mental Health Services, and before that she was deputy executive director of the National Association of State Mental Health Program Directors. But she told us that in all that time, the concept of smoking as an issue for this population never once crossed her mind. Not once."

Hutchings' background and experience proved invaluable to what initially seemed like an insurmountably complex situation.

"When systems don't collaborate together, it's often because they don't know of one another or know about one another," said Hutchings. "My first job was to help SCLC get to know the mental health and addictions world and especially its leaders. I started to talk to them about things like, 'Here are current issues in mental health. Here is the way we refer to people with mental health issues,' and then, most importantly, 'Here's who the main players are in the field, including within the Beltway, what their main issues are, and how we need to start new collaborations and partnerships with them using what's important to them, and understanding what challenges and barriers they might face as well as the opportunities that are before us.' "

Once the SCLC staff had a clear understanding of the issues and players involved, they teamed up with Hutchings for a series of individual meetings with key stakeholders to begin broaching the topic of tobacco control and wellness.

**“At SAMHSA, I oversaw more than a billion-dollar budget while running the Center for Mental Health Services, and I didn’t put one single dollar into tobacco cessation, the factor that I’ve come to learn was killing at a highly disproportionate rate the very people whose lives I was spending my career trying to improve. I realized that it makes no sense to spend all this money, resources, and time to try and bring recovery to people with mental health issues only to have them die 25 years early, mostly attributable to smoking related diseases. When Steve Schroeder and Connie Revell came to me, I had this sudden revelation about my professional priorities, and I have not looked back since.”**

*—Gail Hutchings, CEO, Behavioral Health Policy Collaborative; Former Chief of Staff, Substance Abuse and Mental Health Services Administration*

### **Project Goals**

The SCLC project was established to accomplish the following outcomes:

- Focus on tobacco control as a first step toward making health and wellness a priority for people with mental illness and for the providers who serve them.
- Reach out to key players and stakeholders to build a common agenda.
- Involve consumers at all stages of the process.

### **National Summit on Smoking Cessation and Wellness**

The meetings Gail Hutchings and her SCLC colleagues had with mental health care leaders led to the convening of an historic 2007 summit in Lansdowne, Virginia.

“Nothing like this had ever been done before,” said Catherine Saucedo, SCLC deputy director. “Gail

was able to help us identify not only the important organizations, but also the opinion leaders who happened to be leading some of these organizations. SCLC brought together leaders from both mental health and tobacco control fields, which had never been done.”<sup>110</sup>

The result was the formation of the National Mental Health Partnership for Wellness and Smoking Cessation, a membership organization that includes 48 leaders from a variety of governmental, consumer, advocacy, academic, and provider organizations.

In just two days, the summit participants used the Performance Partnership Model to develop an action plan in the form of a preliminary list of mutual goals. The list included:

1. Person-centered education: Embrace the 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 on consumer-specific information about smoking rates and behaviors.

Although the members of the Partnership focused more broadly on wellness for their constituents, they agreed to begin by tackling the issue of tobacco control in particular. The impact of this set of goals can be seen in several of the other case studies outlined in this publication.

The SCLC was able to continue to support the process after the summit by providing technical assistance and small stimulus grants to various member organizations, such as the National

#### **The National Mental Health Partnership for Wellness and Smoking Cessation Mission Statement**

We the undersigned resolve to bring forth and lead a national partnership campaign to make health and wellness a priority for people with mental illnesses and for the providers who serve them. As a first and immediate focus, we commit ourselves to addressing the serious consequences of smoking and to emphasizing smoking cessation in all mental health service delivery settings.

Council for Community Behavioral Healthcare and the National Alliance on Mental Illness, to help them begin to develop and implement strategies designed to reach this set of common goals.

### **SAMHSA and the 100 Pioneers**

At the federal level, the Substance Abuse and Mental Health Services Administration (SAMHSA) is the agency responsible for working with and providing services for people with mental illness and substance abuse issues. But tobacco control had never been part of SAMHSA's mission. Dr. Steven Schroeder and his team at the SCLC wanted that to change.

Using the connections that Gail Hutchings had retained from her tenure as SAMHSA chief of staff and other national-level positions, and the new momentum generated by the formation of the National Mental Health Partnership for Wellness and Smoking Cessation, the SCLC approached Terry Cline, Ph.D., who was then the administrator of SAMHSA, to propose a partnership.

"He was the perfect ally, and one that needed little education and little cajoling," said Hutchings. "He really got behind us in the blink of an eye.

Cline, a clinical psychologist, had served as a mental health and substance abuse commissioner, and as a public health commissioner in Oklahoma prior to becoming SAMHSA's administrator in 2006.

"There had never been a SAMHSA administrator with that kind of background before," said Connie Revell. "He brought a huge understanding of the commonalities involved, and the ability to work together."

Cline worked with the SCLC to spearhead an in-service training to educate SAMHSA staff and program officers about the issues specific to tobacco control for their constituents.

Tobacco cessation is now a central part of SAMHSA's work, and the partnership has continued under the current SAMSHA administrator, Pamela Hyde, J.D.

Together, SAMHSA and the SCLC have created the "100 Pioneers for Smoking Cessation Virtual Leadership Academy," a project that offers 100 of SAMHSA's existing mental health and substance abuse prevention and treatment grantees an additional \$1,000 grant to incorporate the following cessation strategies into existing programs and projects:

Take Control  
**1-800-QUIT-NOW**  
Call. It's free. It works.  
1-800-784-8669



- Promote smoke-free environments and effective smoking-cessation efforts in treatment facilities.
- Promote community-based efforts to reduce tobacco use.
- Establish partnerships between behavioral health and nicotine-cessation organizations to increase available tobacco-cessation resources in communities.

In addition to the grants, Pioneers also receive technical assistance from SCLC and SAMHSA, access to national smoking-cessation experts, and participation in a series of SCLC webinars designed to help organizations reach their objectives.

### **Replication/Results**

Facilitating the creation of the National Mental Health Partnership for Wellness and Smoking Cessation and partnering with SAMHSA are only a few of the activities the SCLC has undertaken to reach its overarching goal of putting tobacco control on the mental health and addictions recovery agenda.

The SCLC partnered with the American Psychiatric Nurses Association (APNA) to create a Tobacco Dependence Task Force. In conjunction with UCSF, the SCLC helped to create "Tobacco Free for Recovery: Assisting Mental Health Consumers with Tobacco Cessation," an adaptation of the widely used toolkit, *Rx for Change*.

The SCLC funded the 2007 meeting of the National

Association of State Mental Health Program Directors (NASMHPD) that led to the development of “Tobacco-Free Living in Psychiatric Settings,” a guide and toolkit used widely by state psychiatric hospitals.

The SCLC also funded two national NASMHPD Research Institute (NRI) surveys of state-operated psychiatric facilities. These surveys demonstrated both a significant increase in the adoption of tobacco-free policies at state facilities, and a connection between hospitals permitting smoking and reporting more problems with coercion and violence.<sup>111, 112</sup>

In addition, the SCLC has contributed technical assistance and guidance for Bringing Everyone Along, and CHOICES (Consumers Helping Others Improve their Condition by Ending Smoking), two of the projects featured in this publication.

The next challenge for the SCLC is to fully incorporate the substance-abuse community in the push for integrating tobacco-cessation strategies into their agendas and treatment programs. According to Hutchings, “SAMHSA’s Dr. Cline helped us to see that we could no longer focus solely on helping people with mental health disorders to quit smoking, but rather that we needed to expand our efforts to include helping clients and staff of addiction treatment programs as well. While we had planned on doing this all along, he helped us realize that it had to happen now. And, he was absolutely right.”

Under the leadership of SAMHSA’s Pamela Hyde, SCLC and SAMHSA recently partnered to create the “State Leadership Academies for Wellness and Smoking Cessation.” This is a new initiative currently being piloted in New York, Arizona, Oklahoma, and Maryland that brings people from mental health departments, tobacco control departments, and drug and alcohol departments together with consumer groups. The initiative seeks to create state-level action plans for integrating tobacco-cessation services with mental illness and substance abuse programs. The first of these Leadership Academies took place in New York in late 2010.

It’s all part of the SCLC’s fundamental approach of bringing diverse stakeholders together to create a common set of goals.

**“The SCLC is not about credit, they understand the bidirectional nature of partnership. They give all their resources away, which is the beauty of having Legacy support—they’re able to do that. They’re also lean and mean, and they move quickly. There are many people who would take a year to ponder putting together a summit, but not SCLC. They say, ‘We’re going to pull this thing together in eight weeks,’ and they’ve done it over and over again. There’s something about that agility, and I also think they’ve got right on their side. They’ve got the data, they’ve got the science, and they’ve got compelling anecdotal evidence that shows that systems and people can change with the right combination of forces.”**

*—Gail Hutchings, CEO, Behavioral Health Policy Collaborative; Former Chief of Staff, Substance Abuse and Mental Health Services Administration*



## LESSONS LEARNED

- Don't give up when people say something cannot be done.
- Take time to build strong, face-to-face personal relationships with key stakeholders and influence leaders.
- To get consensus, focus first on finding common goals, rather than common strategies.
- Involve many different consumer advocacy groups and health care agencies in the national conversation.
- Use data to measure progress but also as a motivator.
- Focus on better use of existing resources.
- Leadership, advocacy, education, training, technical assistance, and systems change are essential, overarching strategies necessary to bring tobacco cessation to mental health and substance abuse treatment settings.



# Bringing Everyone Along:

A Resource Guide for Providers




## Project Overview

**T**he Tobacco Cessation Leadership Network (TCLN) is a knowledge network comprised of over 450 members from 50 states, the District of Columbia, and a variety of national organizations. Based in Portland, Oregon, the TCLN utilizes collaboration among its members to address and refine comprehensive tobacco-cessation efforts at the state level.

In 2005, the TCLN advisory committee met to discuss new areas of focus for the organization. The consensus was clear: An important and relatively unexplored arena for states was tobacco control for people with mental illness and substance use disorders. The TCLN decided to survey its membership to build a knowledge and resource base that could help state programs better understand and bridge the gap in cessation services for this population.

Wendy Bjornson is the project director for the Bringing Everyone Along project at the TCLN. She already had many years of work in tobacco

**BEA**  
Bringing *Everyone* Along

 **California Smokers' Helpline**  
1-800-NO-BUTTS

control under her belt, but the intersection between tobacco control and mental illness was new to her. When the TCLN conducted a comprehensive assessment survey of members to catalog emerging practices in the field and gauge interest in the new project, Bjornson couldn't believe the response.

"It really did create a kind of firestorm. There was a real deficit of information, and such an interest," she said. "I got feedback from people saying, 'Thank you for finally paying attention to this, we've been trying to get attention for this and it seemed like nobody was listening.'"<sup>113</sup>

Bjornson knew that no agency or program could go it alone: Her experience told her that state

**“What comes through so clearly is how this project tapped both an unmet need in our tobacco-cessation, mental health, and substance-use communities and, at times, a hidden nerve. There were so many health professionals, taking care of these very vulnerable populations, who shared their stories and their advice with great patience and compassion and often with a sense of relief that these untold stories were being heard.”**

*—Wendy Bjornson, Project Director, Bringing Everyone Along*

tobacco-cessation programs rely on the sharing of information and resources to meet the needs of their constituents. But the initial survey of TCLN members showed that smokers with mental illness and substance abuse disorders were caught in a complex and often disjointed array of systems and providers—mental health treatment, substance abuse, tobacco treatment services like quitlines, and primary care physicians. There was very little coordination of care between these systems and, as a result, many smokers were not getting the services they needed.

“What we really learned is that to have treatment for tobacco use work well for this group of people, you need to have it delivered in the same place they usually go for their mental health care,” said Bjornson. “People who provide that care need to be able to provide the care for tobacco at the same time so that it’s integrated into the overall treatment plan, and the people taking care of them have the full picture.”

In order to find common ground among the different providers, and to address the lack of resources for coordinating cessation services for this population, the TCLN decided to put together a resource guide and continuing medical education (CME) course for multiple providers that treat persons with mental illness and substance use disorders.

### **Bringing Everyone Along: Reaching Smokers with Mental Health and Substance Use Disorders**

*Bringing Everyone Along* (BEA) is a resource guide and training course that incorporates strategies from tobacco-dependence programs, tobacco quitlines, mental health treatment programs, substance use treatment programs, and primary care providers.

The TCLN formed an expert advisory committee that did an extensive review of the existing literature, and used the results of the TCLN member survey about emerging practices to begin the work of creating the BEA guide. Dr. Chad Morris, a clinical psychologist in the Department of Psychiatry at the University of Colorado, Denver, and Director of the Behavioral Health and Wellness Program, was part of the expert advisory committee.

“It’s one thing to have a toolkit, but it just sits on the bookshelf and often doesn’t get used unless there’s buy-in,” said Dr. Morris. “A lot of the needed buy-in was around issues of coordination of care. Historically, mental health and addictions providers didn’t really see themselves as having any role with tobacco cessation. And providers that offered tobacco-cessation services in the community didn’t really want to deal with behavioral health issues. That’s why the coordination part was so important.”

The resource guide outlines six recommendations for integrating tobacco control, mental health care, and addiction treatment. Those recommendations are: 1) Change existing beliefs; 2) Provide tailored treatment services; 3) Use results from comprehensive assessment to help tailor services; 4) Provide cessation pharmacotherapy and monitor psychiatric medications concurrently; 5) Tailor behavioral treatment; and 6) Increase training and supervision for counseling staff.

The guide then breaks into chapters that apply expert advice for tobacco-dependence programs, quitlines, mental health treatment programs, substance use treatment programs, and primary care providers. There are also sections dedicated to resources that aid in program development, including sample intake questions, a nicotine replacement therapy (NRT) medication prescription guide, and online resources.

## Project Goals

*Bringing Everyone Along* was designed to accomplish the following outcomes:

- Develop a Resource Guide for integrating tobacco-dependence treatment into inpatient and outpatient services for smokers with mental health and substance use disorders.
- Disseminate the Resource Guide through conference calls, a website, and in-person training programs to reach tobacco-cessation and/or mental health programs.
- Assess potential changes in the planning, development, or implementation of cessation services reaching smokers with mental health and substance-use disorders.

**“Tobacco is what’s killing people, and disabling the individuals that we serve. This needs to be a part of everyone’s scope of work, and everyone has a part to play in this. The message of *Bringing Everyone Along* is that if everyone is playing a role, no one is doing it alone.”**

*—Dr. Chad Morris, Director, Behavioral Health and Wellness Program; Clinical Psychologist, Department of Psychiatry, University of Colorado, Denver*

### **Learning Each Other’s Language: Clients, Consumers, Patients, and Smokers**

Putting together a resource guide that would work for practitioners from many different disciplines was challenging. While the overlap among services is high, and the aims of the practitioners are often complementary, the professional identification, and thus the language used by each discipline, is different.

For example, the terminology used to refer to people receiving services varies widely. In a primary health care setting, these people are called patients; in mental health care, they’re often called consumers; in substance abuse settings and on quitlines, they’re known as clients; and in tobacco control, they’re called smokers.

“These are important differences,” said Bjornson. “They are part of the culture of the different disciplines.”

The expert advisory committee decided to use the term “client” as a blanket term to refer to smokers with mental illness and substance use disorders—a practical compromise necessary for streamlining the writing process. An explanation of that decision appears in the introductory section of the guide.

Data from the TCLN member surveys also proved difficult to summarize. Bjornson initially assumed that the survey results about emerging practices would be filtered back to her through tobacco control agencies, but she quickly realized that she was hearing directly from mental health professionals who had little understanding of tobacco control.

“I found myself helping them to understand more about the nature of tobacco control,” said Bjornson. “They had no idea why things worked the way they did, and how it was organized from the federal to the state level. This mutual information flow really helped people. We all had to learn each other’s different languages and different cultures.”

**“One of the big takeaways from this project is how differently our different disciplines approach this issue, how they talk about it and how they work with their clients or their patients.”**

*—Wendy Bjornson, Project Director, Bringing Everyone Along*

### **Coordination of Care**

Dr. Gary Tedeschi, licensed psychologist at the University of California, San Diego and clinical director of the California Smokers’ Helpline, was also part of the expert advisory committee that put the BEA guide together. In California, the quitline receives over 30,000 calls every year, and Dr. Tedeschi said about half of callers say they have at least one mental health condition such as anxiety disorder, depression, bipolar disorder, schizophrenia, or substance use disorder.<sup>114</sup>

“We don’t just make an assumption that because someone says they have depression or schizophrenia that they need a completely different protocol,” said Dr. Tedeschi. “It really focuses us more on their psychiatric stability.”

Knowing clients have a mental health condition



prompts counselors to ask clients about what kinds of medications they may be taking, he said. And knowing a client has a mental health condition might also alter the duration of treatment at the quitline. Dr. Tedeschi said that people with mental health issues sometimes need more frequent contact, and for a longer duration of time, to successfully quit smoking.

However, although many quitline counselors have some background in psychology or social work, their primary training is in tobacco-cessation strategies, not in mental health care.

“This was where coordination of care was really key,” said Dr. Morris. “Quitlines didn’t really want to say that they’re treating these folks unless they had buy-in from the [mental health] community and vice versa. It’s a much easier sell to say, ‘Hey, you quitline guys, you’re already serving these individuals, and you should serve them. Don’t worry about their mental health issues, because that’s being handled in the [mental health] community.’ So, it’s making that linkage, through referrals coming from the community, and it’s building the relationships between the leadership from these different sectors.”

Dr. Tedeschi agreed with this assessment. He said that he’d like to see quitlines develop a protocol in which they try to help callers with mental illness get connected with mental health

**“The quitline is like a bridge between a clinical model and a public health model because we are reaching very large numbers of people and providing a rich individual intervention. I think it was eye-opening for the others to realize the number of clients with mental health and substance use disorders that call. And, contrary to popular belief, these smokers want help to quit and they are calling quitlines to get it.”**

*—Dr. Gary Tedeschi, Clinical Director,  
California Smokers’ Helpline*

services in their community, even if they don’t decide to continue on with the quitline.

“We know a lot of people with behavioral health issues are coming through, and even though they are calling for smoking, it really is an opportunity to reach them,” said Tedeschi. “They show up here, and it would be great to be able to do something to make sure they are not just getting

their treatment for their smoking, but that they are also getting connected through to the behavioral health community.”

### **Replication/Results**

After its completion, the BEA resource guide was disseminated online and at conferences, and is currently available as a free download at <http://www.tcln.org/bea/>.

In addition, TCLN partnered with the Smoking Cessation Leadership Center (SCLC) to share the resource guide with NASMHPD (National Association of State Mental Health Program Directors) members and the SCLC’s long list of partners.

Once the guide was distributed and disseminated, a series of conference calls and workshops was held to discuss content, and to strategize about how to adapt policies and procedures for different treatment settings. Participation in the conference calls, which were sponsored by the Centers for Disease Control and Prevention (CDC), was so large that participants overloaded the available phone lines and a second conference call had to be scheduled in order to meet demand. In the end, over 200 people representing 43 states took part.

“It was one of the best projects I’ve ever worked on,” said project director Wendy Bjornson. “Everybody was just so terrific and helpful and innovative.”

In addition to the resource guide, the BEA project developed an online continuing medical education course for health professionals, based on the best practices of the guide. *Meeting the Challenge of Tobacco Cessation for Persons with Mental Illness and Substance Use Disorders* has two modules, and takes about one hour to complete. The course addresses “Problems, Barriers, Challenges, and Evidence of Success,” and “Clinical Solutions, Clinical Systems, and Policies Needed to Support Treatment.” Two supplemental modules, “Treating Persons with Mental Illness/Substance Use Disorder on Quitlines,” and “Addressing Smoking Policy Changes for Mental Illness/Substance Use Disorders” are also available.

According to TCLN, in 2008, a follow-up survey of the original TCLN survey participants showed an increase to 89 percent from 56 percent in routine tobacco-data collection among mental health and substance use treatment providers.

Eight programs had enhanced their tobacco treatment services, and eight had developed new partnerships.<sup>115</sup>

In addition, the BEA website received over 260,000 hits between January 2008 and February 2009, with nearly 5,000 visits to the Resource Guide section of the site. Visitors downloaded more than 3,500 copies of the Resource Guide and more than 1,600 copies of the Resource Guide Summary.

**“From a mission perspective, whether in addictions or mental health, the buzzword is recovery. At base, what recovery means is that you’re trying to help individuals lead meaningful lives in the community. What I hit providers with pretty hard is that in order to lead a meaningful life in the community, you have to be alive. And to be alive, you need to quit smoking and using tobacco products.”**

*—Dr. Chad Morris, Director, Behavioral Health and Wellness Program; Clinical Psychologist, Department of Psychiatry, University of Colorado, Denver*

## LESSONS LEARNED

- Coordination of care is vital in treating tobacco dependence in people with mental illness and substance abuse disorders.
- Quitting is usually more complicated for this population, and may require more complex and lengthier treatment management than for other tobacco users.
- Tobacco-dependence treatment for these populations needs to be tailored based on case-by-case circumstances, and an initial assessment is critical to the decisions about tailoring.
- Tobacco treatment management for clients with mental illness should include the health professional responsible for treating the mental illness.
- Attention to both cessation medications and psychotropic medications is critical.
- For many clients with mental illness, behavioral treatment for tobacco needs to be adjusted (more focused, shorter sessions, prolonged contact) and written materials should be limited.
- Building relationships among the leadership of different behavioral health providers is an essential component of provider engagement in cessation strategies.



# Building Blocks:

A Multipronged Approach to Tobacco Control for Mental Health Care Consumers in New Jersey



*(Seated left to right) Yasmin Halim, CTA and Wayne Holland, CTA. (Standing left to right) Jill Williams, MD, Founder; Deidre Stenard, CTA; Patricia Dooley, Current Program Director; and Nancy Szkodny, Newsletter Editor/Program Assistant.*

## Project Overview

**T**he need for tobacco-cessation programs for people with mental illness is well-documented: People with mental illness and substance abuse disorders smoke more and suffer substantially higher rates of smoking-related disease and death than do people in the general population.<sup>116,117</sup> Yet, treatment options tailored for smokers with mental illness remain extremely limited.

The reasons behind this disparity are complex and systemic: They run the gamut from culturally biased attitudes that stigmatize mental illness<sup>118</sup> to a belief that people with mental illness can't or don't want to quit smoking,<sup>119</sup> to a perception—particularly among family members and mental health care staff—that smoking is a pleasure that shouldn't be taken away from people with mental illness.<sup>120</sup> In addition, a lack of provider training in evidence-based tobacco control adds to the disparity.<sup>121</sup>

Dr. Jill Williams is an associate professor of



psychiatry and director of the Division of Addiction Psychiatry at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey (UMDNJ). She's been developing initiatives designed to address the lack of tobacco control and treatment options in mental health care settings for most of her career.

“When I work with individual patients who are trying to quit, they will identify that a trigger or a high-risk place for smoking is the mental health center. That creates a conflict for them. On one hand they have to go to this place for treatment and support, on the other hand it's undermining their tobacco-free goals,” she said. “And some professionals still think we shouldn't even be bothering to talk to people about tobacco, and so they may also give a mixed message to clients. We are trying to counter some of the negative messages that are still out there.”<sup>122</sup>



Dr. Williams and her colleagues at UMDNJ have developed a model called Mental Health Tobacco Recovery in New Jersey (MHTR-NJ)<sup>123</sup> an overarching systems change strategy designed to increase the demand for (and therefore the availability of) tobacco-cessation services for people with mental illness, and to support those people in their efforts to quit.

This case study explores two of the initiatives integral to this model—a statewide peer-to-peer counseling project, and an intensive tobacco control training workshop for practitioners—both of which received funding from Legacy.

**“This is being portrayed as a teeny-tiny segment of smokers, when in fact that’s probably not true. I think, increasingly, the data is going to show that this is a sizeable portion of the people who smoke in this country. I think people need to accept that this is not just a fringe element that we can disregard.”**

*—Dr. Jill Williams, Director, Division of Addiction Psychiatry, Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey*

### **CHOICES and Treating Tobacco Dependence in Mental Health Settings**

CHOICES (Consumers Helping Others Improve their Condition by Ending Smoking) is a project that hires nonsmoking mental health consumers called Consumer Tobacco Advocates, or CTAs, to educate and reach out to their peers about tobacco use and cessation.

CTAs are paid employees who travel statewide to mental health clinics, day programs, psychiatric hospitals, and residential facilities. They give lecture-style presentations about tobacco, and provide individual feedback sessions to interested consumers about the health effects and financial implications of tobacco use.

The project not only utilizes a peer-to-peer approach to educate mentally ill smokers, but was also designed to create a demand for tobacco-cessation services.

“Administrators in mental health were telling us that that they wanted to hear from their constituencies who wanted these treatments before they took steps to develop them,” said Dr. Williams. “So we wanted to build some consumer demand. We wanted these smokers to be able to say that they wanted treatment, and that they understood the risks of tobacco.”

However, even if mental health consumers want to quit, their doctors and nurses often don’t have the training or resources to help them. Despite the high rates of tobacco addiction among people with mental illness, tobacco-treatment education is still not required in psychiatry residency programs.

To address the gap between demand and available services, Dr. Williams and her team at UMDNJ developed a two-day continuing-education workshop for psychiatrists and advance-practice nurses to provide training in how to implement and integrate tobacco cessation into mental health care settings.

### **Project Goals**

The CHOICES project was designed to accomplish the following outcomes:

- Hire and train peer counselors to become Consumer Tobacco Advocates (CTAs).
- Educate mental health care consumers about tobacco, especially using one-on-one motivational interviewing techniques.
- Create, distribute, and solicit consumer contributions to a newsletter targeting mentally ill smokers.

**“Peer-to-peer-level counseling is a cost-effective way to deliver services to a peer network, and also removes some of the barriers involved in working from a health care perspective. You can reach people who may not be motivated, and who are more likely to engage in a casual peer discussion.”**

*—Dr. Jill Williams, Director, Division of Addiction Psychiatry, Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey*



*(Left to right) Jill Williams, MD, Founder; Deidre Stenard, CTA; and Martha Dwyer, Former Program Director.*

- Increase demand for tobacco treatment services in mental health settings.
- Educate and train psychiatrists and advance practice nurses in tobacco control and treatment options for people with mental illness.

### **CHOICES: Empowerment and Personal Choice**

Wayne Holland, a 50-year old musician with bipolar and schizoaffective disorders, smoked two packs of cigarettes a day for 25 years. Smoking ran in the family, and it scared him.

“I was afraid that I was going to get sick from tobacco smoke,” he said. “My mother died from emphysema, my stepmother and my aunt died from lung cancer, and my uncle died from emphysema, too. I was really worried.”<sup>124</sup>

But when Holland decided to quit eight years ago, there weren’t any treatment options available to him. He had to do it on his own. He used nicotine patches and took up karate and Tae Kwon Do to help him cope with his cravings. That was eight years ago, and he hasn’t smoked since.

Several years later, while looking for work at a job center for people with mental illness, Holland saw an ad for a position as a Consumer Tobacco Advocate. He knew right away he would be a

good fit, and after being hired has been doing the job ever since.

Holland works 20-30 hours a week as part of a team of three CTAs who make site visits to mental health facilities all over New Jersey. The team gives a 45-minute presentation about the basic health consequences of tobacco use, offers information about how medications can be affected by tobacco, and uses a timeline to illustrate the benefits of quitting.

After the lecture, CTAs meet one-on-one with consumers, using carbon monoxide meters to gauge a smoker’s progress in quitting or reducing the use of tobacco, and a chart that helps consumers calculate the amount of money they’re spending on tobacco. It’s a motivational interviewing technique developed by Dr. Marc Steinberg at UMDNJ that helps smokers focus on the tangible effects of tobacco use, and set their own goals.

“Motivational interviewing essentially accepts whatever goals that smoker wants to have. It’s a very gentle style; it’s very encouraging, not confrontational in any way. It’s not really goal setting. It allows the patient to do that, but one of the ways that the technique is useful is to help the person learn more about their smoking and how

tobacco may be harming them,” said Dr. Williams. Holland also uses his personal “tobacco stories,” and his history with mental illness to connect with fellow consumers.

“We’re less threatening than somebody with a white coat on,” said Holland. “People tend to shy away from that. We’re more of a peer. We understand what they are going through, and we’ve been there ourselves. That puts them more at ease and it’s more comfortable for them to talk to us than it would be with the clinician or health care professional.”

In addition to being able to connect more directly with their peers, the CTAs also serve as role models.

“It’s really changed my own perspective about the value and recovery aspect of work, and the value these providers bring to their peers,” said Dr. Williams. “When Wayne goes into a facility, it provides hope. They may not know anyone else who is a mental health consumer who has quit smoking, who comes in with a sport jacket on, is well-spoken and poised and has a job. It’s tremendous modeling that’s going to occur from that, and that’s a very positive influence.”

CTAs also give presentations at professional conferences, and contribute to the CHOICES newsletter. The newsletter is a dissemination tool designed for consumers, and showcases their personal stories. In a recent issue, for example, Holland wrote an article about how quitting smoking allowed him to start playing the trumpet again.

The CHOICES newsletter also serves as a vehicle

**“One thing we say in the very beginning is that even though we have [used] ‘Ending Smoking’ in our acronym, we don’t tell people that we’re going to try to force anybody to quit. That is something they have to do with their own free will. We’re basically providers of information. We try to educate people about smoking and smoking cessation, especially in relationship to being a consumer.”**

—Wayne Holland, *Consumer Tobacco Advocate*

for advocacy alerts—a way to get the word out about things like a recent increase in the Medicaid benefit that allowed people greater access to nicotine replacement therapy (NRT). It is available online at <http://njchoices.org/Pages/Newsletters.htm>

The CHOICES program doesn’t charge for its services. In addition to funding from Legacy, substantial support comes from the New Jersey Division of Mental Health Services, as part of a statewide initiative for wellness and recovery. Another major partner is the Mental Health Association of New Jersey, a consumer advocacy group with many years of experience in helping consumers find employment.

### **Owning the Problem: Treating Tobacco Dependence in Mental Health Settings**

Part of the problem in drumming up a demand for cessation services is that these services are often hard to find.

“Ideally, we hope that we’re increasing consumer demand among the population so that the population is getting more interested in quitting,” said Dr. Williams. “The reality is that there are not that many resources to send people to in terms of referral. All along, there has been a hope that the actual mental health treatment agency would develop the services locally for that person.”

In fact, argued Dr. Williams, it makes sense for mental health providers to provide tobacco-cessation treatment and resources. Because of the high prevalence of co-occurring substance abuse and mental health disorders, providers already have much of the expertise required. They are trained in assessment, motivational techniques, counseling, and can help mental health consumers navigate medication issues. Mental health providers also tend to see patients more frequently, and for longer periods of time, than do primary care providers.<sup>125</sup>

“People have not seen it as their scope of practice in the mental health setting to treat this addiction,” she said. “So this is really rethinking mental health service delivery for them to own this problem and say we need to develop services locally.”

With that concept in mind, UMDNJ developed a two-day continuing medical education (CME) workshop. *Treating Tobacco Dependence in Mental Health Settings* uses 11 modules to train providers in how to assess and treat tobacco dependence, the neurobiology of tobacco use and mental illness, pharmacotherapy and interactions with psychiatric

**“We’re still not even educating the next generation of these providers in how to do this. When you become a psychiatry resident, there is not a stipulation that you become educated in tobacco dependence. The reason for CME [Continuing Medical Education] is to at least try to get them caught up with this information so that they can be better treatment providers.”**

*—Dr. Jill Williams, Director, Division of Addiction Psychiatry, Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey*

medications, and how to integrate tobacco control into existing evaluation and treatment plans.<sup>126</sup>

The workshops are scheduled on Fridays and Saturdays to make participation easier. Participants receive CME credits, and a training manual to take home with them. Live trainings mean that participants have the chance to collaborate and to learn from each other’s experiences.

### **Replication/Results**

The *Treating Tobacco Dependence in Mental Health Settings* workshop that was started as a pilot project in 2006-2007 became so popular that it is now offered twice a year, and attracts providers from all over the United States and as far away as Spain and Australia.

CHOICES has won multiple awards, including the 2009 American Psychiatric Association Silver Achievement Award, and the 2007 Innovative Programming Award from Mental Health America.

CHOICES is now listed as a best-practice resource by the Smoking Cessation Leadership Center (SCLC) and the Behavioral Health and Wellness Program at the University of Colorado; the project is a mainstay at conferences and advocacy events, as well as a regular part of programming in mental health facilities of all types in the state of New Jersey. The CHOICES project is also being adapted by other programs, such as the Genesis Clubhouse model featured in this publication.

Training mental health care providers in tobacco

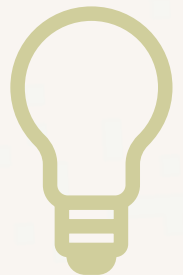
treatment and using peer counselors to reach smokers with mental illness are only two pieces of a complex puzzle, however. Dr. Williams and her colleagues at UMDNJ believe that there isn’t just one approach to address the disparity in available treatment options for mentally ill smokers. They advocate a series of concurrent, complementary approaches.

But the resources to continue doing the work are limited. “[Tobacco control] is still not a priority ... for funding,” said Dr. Williams. “I’ve been doing this for a long time, and there still aren’t any resources.”

It’s frustrating, she said, because initiatives like CHOICES and the provider training workshops are not only effective, but also relatively inexpensive. In the past ten years, the team at UMDNJ has piloted and implemented eight tobacco control initiatives. Total annual cost for all eight initiatives? \$250,000

### **LESSONS LEARNED**

- Multiple, concurrent approaches are needed to address disparities in tobacco treatment options.
- Using peer counselors is a cost-effective way to reach unmotivated mentally ill smokers.
- Educating mentally-ill smokers builds demand for local development of treatment services.
- Work is a strong component of recovery for people with mental illness.
- Live trainings energize collaborative learning among professionals.
- Mental health care providers already have the skills needed to integrate tobacco control into treatment plans—continuing education can help them do so effectively.



# The Power of Teamwork:

## Changing the Culture of the Clubhouse



*A member refusing a cigarette from another member outside of the Clubhouse.*

### Project Overview

**G**enesis Club a psychosocial rehabilitation center, or “Clubhouse,” based in Worcester, Massachusetts, is part of an international network of 400 Clubhouses that are affiliated with the International Center for Clubhouse Development (ICCD) and serve approximately 50,000 members worldwide.

Participants in the Clubhouse model are called “members,” rather than clients or consumers. This terminology reflects the model’s overarching philosophy. Membership connotes a sense of belonging, as well as a sense of shared responsibility and ownership for the Clubhouse and its activities, rather than defining someone with a disability.

Clubhouses function as therapeutic communities that provide supports including employment, education, and housing and social opportunities. Staff and members work side-by-side as peers, and share extensive responsibility for the organization, from orientation of new members to

decision making and governance, and even janitorial duties.

Like the subjects of other case studies highlighted in this publication, Genesis Club made a strategic decision to add health and wellness to Clubhouse activities based on a series of studies showing extremely high rates of morbidity and mortality for people with Serious Mental Illness (SMI) as compared to the general population.<sup>127, 128, 129, 130, 131</sup>

“We saw many members who were in poor physical health, many members who were obese, many members struggling with their ability to work two or three hours—not because of their psychiatric symptoms, but because of their physical symptoms,” said Kevin Bradley, executive director of Genesis Club. “It hit us really hard. In a six-month period we had three or four members, all under the age of 50, who passed away. We said,





*A Clubhouse employee and a member from the leadership team using the CO meter during one of the tobacco free days at the Clubhouse.*

**“Mental illness for a long period has had a community stigma, and at times we find the stigma more disabling than the symptoms of mental illness. We have heard from some physicians that their colleagues also hold this stigma about smoking and those with mental illness: ‘They are mentally ill, so what can we do?’ Well, UMass Medical School and Genesis Club have set out to change these attitudes in the community.”**

*—Kevin Bradley, Executive Director, Genesis Club*

‘Maybe we ought to be doing something more about this.’”<sup>132</sup>

In 2002, members and staff at Genesis partnered with John Pelletier from Assumption College and Colleen McKay, assistant professor and director of Clubhouse research in the Department of Psychiatry at the University of Massachusetts Medical School

(UMass), to start a structured exercise program at Genesis.

“We were curious about what other health-promotion needs Clubhouse might have,” said McKay.<sup>133</sup> “What we found are the big three: exercise, nutrition, and tobacco cessation. Genesis was already providing supports for exercise and nutrition, but they weren’t really addressing tobacco yet.”

According to the Program for Clubhouse Research at the Center for Mental Health Services Research in the Department of Psychiatry at UMass, about 80 percent of Genesis members said they either smoke or endorse smoking. However, about half said they wanted help quitting or cutting down on tobacco use. Others asked for help dealing with relapses.

Based on the earlier experience of forming an academic/community partnership to create a structured exercise program at the Clubhouse, Genesis and UMass teamed up again, this time to address tobacco cessation in the Clubhouse model.

### **Integrating Tobacco Cessation**

In 2008, Genesis and UMass secured funding from Legacy’s Innovative Grants Program to develop and tailor tobacco-cessation strategies to the Clubhouse model.

The UMass team provided Genesis staff and members with technical assistance and training, which allowed the Clubhouse to tailor several tobacco control interventions appropriate for the Clubhouse Model of Psychosocial Rehabilitation: Addressing Tobacco Through Organizational Change (ATTOC); Learning About Healthy Living (LAHL); and Consumers Helping Others Improve their Condition by Ending Smoking (CHOICES).

### **Project Goals**

The Clubhouse project was created to accomplish the following outcomes:

- Create organizational change around tobacco use.
- Train Genesis members and staff in tobacco-cessation strategies and interventions.
- Tailor evidence-based tobacco-cessation interventions for Clubhouse settings.
- Develop Clubhouse peer tobacco leaders.
- Create resources and training materials, including a wellness/tobacco-oriented toolkit.
- Increase health and wellness by reducing or eliminating tobacco use among members and staff.
- Disseminate and replicate findings throughout the Clubhouse network through ICCD training sessions held consistently at Genesis Club.

### **Organizational Change in the Clubhouse**

CHOICES is a member-driven intervention developed by Dr. Jill Williams at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey. It utilizes peer training to develop peer leaders who encourage individuals with SMI to make healthy lifestyle changes.

Because the Genesis Club works on a model in which members and staff participate together in all aspects of Clubhouse life, the CHOICES activities at Genesis involved members and staff in developing educational materials and disseminating information. The strategy also addressed the needs of Genesis staff who were also smokers.

“Typically with the organizational change process, what happens is that there are program-level goals with the agency itself, there are goals around tobacco cessation for the staff or providers, and then there are goals for the members,” said

**“We think change [in tobacco policy] needs to come from within. The community has to come together to make it successful. At Genesis this would be a decision made through a house-wide consensus. We have heard that some Clubhouses and programs are mandated to be smoke-free, and they are struggling with the process.”**

*—Kevin Bradley, Executive Director, Genesis Club*

McKay. “In this case, because of the nature of the Clubhouse program, the goals for staff were essentially the same as those for the members. Everyone was getting the education.”

Colleen McKay and her team from UMass conducted tobacco-dependence training for a leadership group composed of three staff and three members from the Genesis Clubhouse. The training focused on developing peer tobacco leaders, screening for interest in tobacco cessation during member intake and at orientation, and incorporating tobacco cessation and wellness into the “goal plans” set by members and their staff advisors.

The group learned how to discuss tobacco issues with peers, as well as how to organize cessation activities (e.g., tobacco-free days), facilitate outreach, and develop communication efforts and educational materials (e.g., newsletters and website posts). Clubhouse members and staff also learned how to offer brief, personalized feedback about readings from carbon-monoxide (CO) meters, as well as how to talk with smokers about the money they were spending on tobacco.

### **Culture Shift: The Great American Smokeout**

Genesis Club makes policy and programmatic decisions by consensus. While all benefit from an inclusive process, consensus building naturally takes more time than would an executive mandate.

“We used to allow smoking in our snack shop. The smoke was so thick that you could barely see the other person in front of you,” said Genesis Executive Director Kevin Bradley. “In 1991 we decided, through the consensus model of decision making, to move smoking outside. It took us six

months to make that decision.”

In 2009, Genesis was faced with another decision about tobacco use at the Clubhouse. Encouraged by the tobacco-cessation training from the team at UMass, the Clubhouse considered the possibility of being completely tobacco-free on the day of the Great American Smokeout on November 20, 2009.

Bradley was skeptical that the members and staff would be able to reach an agreement, but he brought the idea to the Clubhouse for consensus. “As the executive director in leadership I could have made that decision myself,” he said. “But at Genesis we just won’t do that.”

As Bradley expected, the decision-making process quickly reached a deadlock. Then, one of the members stood up and addressed the group. He said that even though he was a smoker, and wasn’t ready to quit, he was willing not to smoke for the day. It proved to be the tipping point for the Clubhouse. To Bradley’s great surprise, the Clubhouse reached a consensus in just two meetings: The entire campus and grounds of Genesis would go smoke-free for the day.

“There are some myths that say if you go smoke-free your attendance will plummet for that day,” said Bradley. “In fact, our attendance was above average. We found that the key was providing support to the smokers.”

It was a festive event. The Genesis tobacco leadership team handed out pamphlets about tobacco cessation. Members offered healthy snacks like carrot sticks and smoothies to help people deal with their cravings.

Genesis used Legacy funds to purchase two CO meters. During the event, the leadership team gave 40 CO meter readings, taking the time to explain to each member the results of the readings, showing how the number went down as the day progressed. Genesis also made nicotine replacement therapy (NRT) patches available. Fourteen members and one staff person used the patch to observe the Smokeout. Another member quit cold turkey. For those smokers not ready to quit, members and staff agreed to accompany them on walks off campus so that they could smoke and then return to the Clubhouse.

The event was such a success that the Clubhouse decided to make it a monthly event, and now hold Tobacco-Free Days on the first Thursday of each month.

“It’s actually at a time when a lot of people are getting their monthly disability checks,” said McKay. “So hopefully that’s getting them to think about buying things other than tobacco, as well as just supporting people who might want to try quitting. Some members have even used the tobacco-free day as their quit date.”

Genesis also established an outdoor tobacco-free area for members and staff who want to be outside, but don’t want to sit in the smoking area.

“We have some real momentum going, and there has been a cultural change around smoking at Genesis Club,” said Bradley. “The first Thursday of the month comes, and everyone knows we are smoke-free for that day. Will we ever be a completely smoke-free campus? I am not as skeptical as I used to be.”



**“People know who is trying to quit within the program. It’s not a hidden thing. So, there is encouragement and excitement for somebody who stops smoking for the day. Or with the CO [carbon-monoxide] meters, when somebody who quit blows a zero, there is a lot of excitement about that. People recognize that means they did indeed quit smoking.”**

*—Colleen McKay, Assistant Professor and Director of Clubhouse Research, Department of Psychiatry, University of Massachusetts Medical School*

In fact, the Genesis Club is planning to become a tobacco-free campus. Genesis decided through a house-wide consensus among members and staff at a Clubhouse policy meeting on May 4, 2011 to become a tobacco-free campus.

### **Andrea’s Story**

Andrea Gilligan is a Genesis Club member. A heavy smoker with a pacemaker and asthma, she



came to the Clubhouse on a tobacco-free day in March 2010 with no intention of quitting.

Gilligan had already been successful with other aspects of the wellness programs at Genesis: By making changes to her diet, and taking advantage of membership at the local gym, she had lost 60 pounds. Although, like most smokers, she had tried various times to quit smoking throughout her life, she always relapsed.

Dealing with symptoms of bipolar disorder, Gilligan had been in and out of psychiatric hospitals since adolescence. Several of her quit attempts happened while she was hospitalized in smoke-free institutions.

“Sometimes they will provide patches, depending on the doctor you have, and sometimes they don’t,” she said. “So sometimes you’re fighting through the withdrawal and everything. When I was there a couple of times, I didn’t have a patch. They wouldn’t give it to me. I really wanted to go outside and have a cigarette, but I couldn’t, so I just did what I could to keep my mind off it. But once I was released, I lit up”

This time was going to be different. Surrounded by the supportive environment of the Clubhouse on the first tobacco-free day, she took advantage of the free NRT patches, and, on the spur of the moment, decided to give quitting another try.

“I put the patch on, and I said, ‘I’m going to quit for the day,’ ” she said. “Then I called my doctor and said that I needed help on quitting, because if I don’t, because of the health issues that I have, eventually I’m going to die from this,” she said.

It proved to be a good decision: Gilligan hasn’t smoked a cigarette since that day.

“I have some friends’ numbers that I always call when I want a cigarette,” she said. “I know where

**“I feel like my relationships are better, because a lot of friends and family members are nonsmokers. Or if they do smoke, they understand why I quit, and they’re kind of in the same boat. They want to quit. So they’re actually asking me how I quit.”**

—Andrea Gilligan, Genesis Member

they live, so sometimes I go over to their house and go for a walk. And here at Genesis, I just go for a walk with them here, or I do unit work here, just to keep my mind off of things,” she said.

It’s not just the members at Genesis who need support with quitting. Various Genesis staff members still smoke. Gilligan said she understands where they’re coming from, and stands prepared to help.

“I never give them a hard time, because I understand where they’re coming from,” she said. “A couple of them, I know that they want to quit. When they’re ready to quit, they’re actually going to come to me and ask me for some advice.”

### **Learning About Healthy Living**

Another Genesis activity that helps Gilligan remain healthy and tobacco-free is the Clubhouse’s weekly Learning About Healthy Living (LAHL) meetings.

Designed as a treatment manual focused specifically on tobacco control interventions for people with Serious Mental Illness, Learning About Healthy Living is a manual-driven approach to addressing tobacco addiction in mental health settings. LAHL was developed by a team that includes Dr. Douglas Ziedonis, chair of the Department of Psychiatry at the University of Massachusetts, and Dr. Jill Williams, director of the Division of Addiction Psychiatry at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey.

LAHL outlines a two-tiered system of educational groups: one for lower-motivated smokers who are seeking information about and motivation toward quitting, and the second for higher-motivated smokers who are ready to quit.

LAHL Group One is designed as a series of 20 weekly meetings that address topics such as “How Much Does Smoking Cost?” “Why Do So Many Consumers [Other mental health systems generally call their clients “consumers” or “patients,” not “members.”] with Mental Illness Smoke?” “How Are My Medications Affected by Smoking?” “How Much Physical Activity Do I Need?” and “Is It Really Possible For Me to Quit Smoking?”

LAHL Group Two is focused around tobacco cessation, and meets for six weeks. Group participants make quit plans and set quit dates,

establish a medication plan for quitting, strategize about how to deal with setbacks and relapses, learn how to refuse cigarettes and avoid triggers, seek out support while they're trying to quit, and celebrate being tobacco-free.

Because the LAHL manual was designed to be used in more traditional mental health settings, the team created a new toolkit for clubhouse settings. The "Promoting Healthy Lifestyles Clubhouse Toolkit" has chapters on the effects of tobacco use on employment, education, and housing. The new toolkit incorporates organizational change activities and personal narratives from members and staff to share successful strategies and inspire others. Nutrition, exercise, and stress-management techniques are discussed, and images of healthy and cancerous lungs have been included. Language was also an issue. The Clubhouse toolkit refers to participants as "members" rather than "consumers" and incorporates clubhouse supports.

"Learning About Healthy Living was designed to be led by a clinician who's leading a group," said McKay, who attended all the LAHL meetings at Genesis along with her colleague Greg Seward, a tobacco-control specialist from UMass. "In the Clubhouse there aren't any clinicians. All of the meetings within the program are co-led by staff and members together. One of the first tasks the joint leadership took on was to redesign the meeting structure so that they could be led by both members and staff jointly, because it was important to really foster members to take a leadership role with those meetings."

Based on input from focus groups, feedback from the ATTOC leadership team and LAHL participants, Genesis and UMass leadership teams have written a first edition of the "Promoting Healthy Lifestyles Clubhouse Toolkit."

New chapters are discussed in weekly Healthy Living meetings, so members and staff can give feedback and generate new ideas. These chapters are also brought to Genesis as a whole.

"They bring copies of the chapters to all of the units the next day after the Healthy Living meetings," said McKay. "Genesis also has a TV monitor inside the program, and they put the information on that, too."

McKay said that one of the biggest surprises for members was the effect that tobacco use could have on their employment, housing, and education goals.

"One of the members was looking for a new apartment. He smokes a pipe, but started thinking

**"People began to see the value in doing the interventions. The focus really was on being supportive. Instead of telling somebody smoking is bad and you have to quit, members would say, 'Please come to the Healthy Living meetings. You don't have to want to quit, just come and learn and listen to what we have to share with you today.' I think that really helped increase the buy-in."**

*—Colleen McKay, Assistant Professor and Director of Clubhouse Research, Department of Psychiatry, University of Massachusetts Medical School*

maybe it wasn't worth it if it limited the options for where he could live," McKay said. Other members began to consider how difficult returning to school could be if they had to walk several miles off campus just to smoke a cigarette.

The group meets every Tuesday, and Andrea Gilligan is always there. "I like to attend them to find out a lot of different things that smoking can do—how it can affect you and how it can affect pets, how it can affect the environment," she said. "It's not all about smoking; we talk about what foods are good to eat and what drinks are not good, and what are some other alternatives. It really helps."

Gilligan said they're always inviting new members to come to the group, and emphasize that you don't have to want to quit to come to a meeting. "When we say we're not forcing anybody, it kind of makes them feel good, and makes them come to the club, because there's a lot of people that come in that smoke. We want them to come back, we want them to be a member of the club," she said.

In the first year, 12 members and 3 staff attended the LAHL I meetings weekly, and 20 attended the LAHL II. All in all, 94 people attended at least one of these meetings. As a result, 28 members tried to quit, and 11 are tobacco-free.

## Replication/Results

Genesis is a national and international training site for the Clubhouse model. The project has the long-term potential for replication in 200 Clubhouses, affecting approximately 20,000 individuals with SMI annually.

The Legacy Innovative Grants Program funds allowed the Genesis and UMass teams to offer a specialized two- to three-day Learning About Healthy Living and tobacco-cessation training to interested Clubhouses. The training, which is for and by both staff and members, covers topics like addressing tobacco through organizational change, using medications to treat tobacco dependence, using community resources, and integrating tobacco-cessation meetings into the Clubhouse setting.

The UMass team has also received requests for technical assistance and training by some residential programs funded by the Massachusetts Department of Mental Health.

Questions about tobacco dependence have been added to the Clubhouse Profile Questionnaire (CPQ), a comprehensive survey designed to gather information about characteristics of ICCD Clubhouses and the people who use them. The changes to the CPQ will allow the Program for Clubhouse Research at UMass to gather information about tobacco use and tobacco-cessation activities in ICCD Clubhouses internationally.

Information about all wellness programs at Genesis, including the Tobacco-Free Days and LAHL meetings, is now part of the orientation process for new members. Genesis Club has also added tobacco-cessation information to its website ([http://www.genesisclub.org/wellness-smoking\\_cessation.html](http://www.genesisclub.org/wellness-smoking_cessation.html)).

In addition to presenting at regional conferences and meetings, both the UMass and Genesis teams have finalized the new “Promoting Healthy Lifestyles Clubhouse Toolkit.”

**“Just several years ago, if you came into Genesis or any Clubhouse, wellness and healthy lifestyles weren’t being talked about. We were mostly concerned about employment, education, housing, and social activities. Now we are also asking about exercise, nutrition, and smoking. At Genesis, we have experienced a cultural shift in which members are now asking [about] and participating in Healthy Living activities.”**

*—Kevin Bradley, Executive Director, Genesis Club*

### LESSONS LEARNED

- Don't just focus on tobacco cessation, but also on support for relapse.
- Don't force people to quit.
- Address all types of tobacco use.
- Staff and members need training to provide support to people who wish to reduce their tobacco use or quit using tobacco altogether.
- Integrate tobacco-cessation activities with other health-promotion activities like exercise, nutrition, and stress management.
- Involve members/consumers in all aspects of the process.
- Consensus building/decision making can be a lengthy process in Clubhouse settings, but the outcomes are worth it.



# Nurturing Connection:

## A Tobacco-Cessation Model for Low-Income Smokers with Mental Illness



### Project Overview

**C**ounseling Services, Inc. (CSI) is a non-profit community mental health agency that serves low-income clients with mental illness and substance abuse disorders at a variety of outpatient clinics, social clubs, and day programs in southern Maine.

Two-thirds of applicants to CSI are heavy smokers, and have a variety of chronic health problems such as obesity, diabetes, asthma, congestive heart failure, chronic obstructive pulmonary disease, and cancer.<sup>133</sup>

Most CSI clients are also poor. Caught in a cycle of unemployment, homelessness, or housing insecurity, mental illness, substance abuse, and hunger, many live marginal, often chaotic lives, well below the poverty line. “They were continuously broke. They were often stigmatized or outcast. Most people were unemployable in today’s job market,” said Dr. Stephen Rose, a professor in the School of Social Work at the University of New England in Portland, Maine.

“We knew that a number of people who were

mental health clients were extremely heavy smokers,” said Dr. Rose. “The other thing we knew was that they very likely came from backgrounds of severe poverty, material deprivation, and family violence. What we weren’t clear about was if these backgrounds of exposure to family violence and poverty were linked to smoking and severe chronic physical disease.”

The health care implications were great—most CSI clients had no relationship with a primary care doctor, and medical issues and smoking cessation were only included in 1 percent of mental health treatment plans.<sup>134</sup>

By reviewing data from nearly 1,500 CSI intake assessment forms, Dr. Rose and his staff were able to link early exposure to poverty and abuse with smoking and other medical complications later in life. Their review of this data also showed that “the higher the level of exposure to poverty and/or family violence, the greater the probability that you started smoking and became a heavy smoker earlier. We also knew from other data that

**“If you have people who come from the background of living lives completely immersed in poverty and deprivation or family violence, with no sense of self-efficacy, no sense of internal locus of control, and a heightened sense of self-contempt, how on earth could they ever focus on smoking cessation, when that is all focused on goals? It’s as if you were speaking in a foreign language, or were from a different planet. What they experience is that they are just being judged as failures again.”**

*—Dr. Stephen Rose, University of New England School of Social Work*

the earlier you become a heavy smoker, the more difficult it is to quit.”

Understanding the role that early exposure to trauma and poverty played in the lives of CSI clients was important because of the effect that kind of exposure has on a person’s sense of self-worth, self-esteem, and their sense of control over his/her own life. All of these attributes are essential ingredients in being able to formulate and respond to any chronic illness treatment plan.

In other words, if a person believes that he/she is worthless and has no ability to control his/her life, then setting smoking-cessation goals or starting on a medical treatment plan is a futile task that is bound to fail.

### **Creating an Integrated Health Care System for Low-Income People with Severe Mental Illness and Multiple Smoking-Related Morbidity**

“Given this reality, we were faced with the question of how we would approach the issue of smoking cessation” said Dr. Rose. “We had already learned along the way that the lower down you go in the socioeconomic scale, the greater the probability that every known intervention for cessation didn’t work.”

With Legacy’s funding support, Dr. Rose and his team sought the active collaboration of heavy-smoking CSI clients to help design and implement wellness and tobacco-cessation strategies that would better fit the needs of low-income people with mental illness.

The project also sought to promote organizational change within the CSI clinics by providing staff with tobacco-cessation training.

### **Project Goals**

This CSI project was designed to accomplish the following outcomes:

- Reach out to low-income mental health clients to better understand how to tailor conventional cessation strategies.
- Develop population-specific practices and smoking-cessation model for low-income people with Severe Mental Illness.
- Integrate primary health care with mental health treatment and smoking cessation through delivery of an interdisciplinary, empowerment-centered design.
- Start “mutual aid” wellness groups at three CSI sites.
- Develop an organizational change strategy at CSI that includes tobacco cessation.

### **Client Consultant Teams: Finding out What Works**

Based on their understanding of the population served at CSI, Dr. Rose and his team decided that the best way to develop a tailored smoking-cessation and wellness model was to ask the clients for their input. His team hired a group of ten “client consultants” who were referred by CSI staff. All of the consultants were heavy-smoking CSI clients.

Consultants were paid \$10 an hour, and met in a group setting to help Dr. Rose’s team understand why conventional tobacco-cessation strategies weren’t working, and what could be done to improve them.

“In the beginning they thought it was some kind of therapy game, because nobody had ever asked them seriously to contribute anything substantive about their lives,” said Dr. Rose. Once they were convinced that it wasn’t a game, however, the client consultants started to develop a new kind of strategy, one uniquely adapted to their own lives.

The client consultants told Dr. Rose that smoking was one of the few things that they felt they had control over in their lives even though they knew it was harmful to their health. That sense of control, coupled with a deeply held sense of worthlessness, made taking care of their physical health and quitting smoking seem like an almost pointless endeavor.

“If you think that you are worthless or useless, and nobody in the whole world cares whether you are sick or die, this often creates hopelessness, and then it’s easy to live with the contradiction and keep smoking, even if you know it’s bad for you,” said Dr. Rose.

The first recommendation the client consultants made was to focus on the larger issue of health and wellness, rather than specifically targeting smoking cessation. Too strong an emphasis on quitting smoking could be seen as simply another form of judgment, they said, just one more in a lifetime of negative assessments. They also wanted Dr. Rose and his team to know that an effective program had to draw from life as they had lived it, not tied to clinical diagnoses.

Socializing was also a factor for many CSI clients: Smoking was one of the few social activities they enjoyed. Accountability to and support from peers was an essential ingredient, they said, that would help them overcome the feelings of worthlessness and isolation that led so many to disregard their own health. So, meeting regularly as a group to talk about health and wellness made sense.

Finally, they recommended that the groups be co- led by a client and a staff member, a strategy that turned out to be extremely effective.

“People often think that the struggle that folks who lived through this kind of trauma go through is very frequently seen as a form of pathology. We don’t,” said Dr. Rose, of his team. “We see it as a form of human resilience, strength, and capacity. We think it is definitely possible to make connections and to build relationships with them that are mutually trusting. But that can’t happen until the clients know that we are absolutely entrusting the decision-making capacity about their own lives to them.”

### **Co-facilitating Wellness: Validation and Empowerment**

The result of the information-gathering process with clients was the creation of three “mutual aid”

**“We knew from the consultant team that smoking-cessation strategies had been tried with many of them. They basically said that none of the people doing smoking cessation had ever respected them as human beings living a very complicated, difficult, marginal life.”**

*—Dr. Stephen Rose, University of New England School of Social Work*

wellness groups—two at CSI social clubs, and one at a CSI day program.

Robyn Merrill was the social worker brought on to co-facilitate the wellness groups. As a graduate student, she had worked on the initial analysis of CSI intake forms that established the link between chronic disease(s), smoking, and a history of poverty and family violence. She was familiar with the overall strategy of the project, as well as with the populations served at the clinics.

The groups were co-facilitated by Merrill and a client representative. Client representatives were elected by each of the three groups. The groups met once a week for 15 months, and served about 35-45 clients each week. They focused on health and wellness, rather than specifically on tobacco cessation.

The idea of co-facilitation meant that client representatives worked closely with Merrill to help facilitate group discussions, but the meetings were designed to let the groups themselves determine the content and flow, and to identify problems and come up with solutions on their own.

The results were innovative, and sometimes surprising.

One client, a smoker who was also overweight, started taking bike rides with another group member. Reporting back to the group every week, the client realized that he was having a hard time breathing on his rides, and made the connection to his smoking habit.

He picked a quit date, and used the buddy system he had with his bike-riding partner, as well as the accountability of the weekly group wellness

meetings to help him with his quit attempts. When the group sessions came to an end, according to Merrill, he still hadn't slipped and had a cigarette.<sup>135</sup>

Clients relied on each other's support to quit or cut down on their smoking, making agreements to call each other when they had the urge to smoke, or to meet and go for a walk instead of picking up a cigarette.

Merrill helped by referring clients to quitlines, and encouraged them to go to their CSI counselors for support with issues like nicotine replacement therapy (NRT) interaction with psychiatric medications. She also worked to facilitate exercise ideas engendered by the group. One of those ideas was to start a swimming club at the local YMCA.

"The swimming idea came out of a natural discussion with people who wanted to move towards an exercise plan," said Merrill. "We started brainstorming around how to really incorporate that, and what the obstacles were."

Affordability was an issue: YMCA memberships cost money, as did transportation to get there. Merrill negotiated with the YMCA to waive the membership fee, and arranged weekly transportation for the two social club groups.

After seven months of swimming and water aerobics, one of the clients had lost 60 pounds. Another client with debilitating arthritis started learning how to swim again, something she never thought possible.

The wellness group at the day hospital was a little different. Clients there tended to be older, and have more serious physical and mental disabilities. Traveling to the YMCA for swimming classes just wasn't realistic, so the client representative for that group started leading the group in Tai Chi classes.

At the end of the 15-month period for the wellness groups, 12 group members had decided to quit smoking. Four of them had set quit dates, and five had cut back on their smoking. Of the 45 group members in the three sites, eight had successfully quit smoking.

"What happened is exactly what the client consultant team predicted," said Dr. Rose. "When clients knew they had a place to come to talk about reality as they lived it, I think what happened was they developed some sense of validity, some kind of empowering, person-building experience. It's in that context that they began to talk about health."

Merrill agreed. "It's hard to decide to quit smoking when you are dealing with everyday mental health concerns. When you are dealing with finding food to eat or worrying about having shelter over your head, or just feeling like you are not really worthwhile," she said. "But so much growth and change can come from nurturing the connection we have with others. It's a real source of strength. Finding ways of drawing on that natural support can be really effective."

### Replication/Results

CSI staff were surprised at the success of the wellness groups, particularly at the level of continued participation from week to week. CSI clients had historically shown a strong tendency to miss appointments, and weren't systematically engaged in clinic activities from week to week.

"Clinicians rarely have experience running groups that are co-led by one of the clients," said Dr. Rose. Part of this lack of experience comes from a very practical problem—the difficulty of paying for client consultants through Medicaid. In fact, once the Legacy funding ended, the wellness groups also stopped.

The end of the wellness groups didn't end the

**"The model of co-facilitation wasn't about judgment or blame; it was more about creating a supportive environment where people could gain information, support one another, and work to empower themselves. Instead of just being told what they needed to do, they came to it on their own and owned it."**

*—Robyn Merrill, Social Worker*

positive experience for many of the clients. Robyn Merrill said that the relationships they established with each other seemed poised to continue after the groups no longer met.

"When the group ended, it felt like people were in a pretty good place. They had support in different places. New kinds of relationships were formed," she said. "Even though some of them

may have known each other just from being at the social club together, a different kind of supportive friendship came out of the groups.” CSI actively supported the groups through the social clubs’ programming.

The change wasn’t all directed at clients, however. Dr. Rose contracted with The Center for Tobacco Independence (CTI) at Maine Medical Center to provide smoking-cessation training for the senior CSI staff and four CSI clinicians. As a result of the training, several smoking-cessation groups were started at different CSI clinics.

CSI intake protocols were also redesigned to include more questions about smoking, socioeconomic status, and chronic health problems. The changes to the intake forms reflected the idea that such information can illuminate how poverty and abuse may be connected to smoking and co-occurring health problems. Such an understanding can help clinicians understand that, based on the life experiences of clients, conventional cessation protocols might not be the most effective strategy.

**“Mental health providers tend to think in terms of diagnostic categories, like schizophrenia or bipolar disorder, as these decisions often shape reimbursement. If you’re thinking in diagnostic categories, you are very rarely paying attention to the actual lived experience of the person.”**

*—Dr. Stephen Rose, University of New England School of Social Work*

### LESSONS LEARNED

- The early and current life experiences of low-income people with SMI must be taken into consideration when starting tobacco-cessation efforts.
- Asking clients to name and then solve their own problems can be a fundamental strategy.
- Co-leading wellness groups may give clients a sense of control over their lives.
- Don’t put the focus exclusively on quitting smoking; integrate smoking concerns with general medical issues and health care needs.





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