

THE STATE OF  
**DEPRESSION**  
IN AMERICA



Depression and Bipolar  
Support Alliance

EXECUTIVE  
SUMMARY  
FEBRUARY 2006

*For more than twenty years the Depression and Bipolar Support Alliance (DBSA) has provided help, hope and support to patients and families coping with depression and bipolar disorder. "We've been there. We can help." We say this because more than half of us – Board members, volunteers and staff alike – live with a mood disorder. Because of our personal struggles, we viscerally know what needs to be done.*

*The State of Depression in America initiative reflects the huge unmet need to examine all aspects of this illness and to fully educate the public about depression. Perhaps the greatest challenges are the wide disparities in the quality of care and access to treatment – disparities that cross socio-economic populations, state boundaries and throughout the public and private payor systems.*

*We have many opportunities to transform mental health care. But to meet the needs of the millions suffering with depression and the millions more touched in other ways by this illness, we need far-reaching partnerships. To that end, DBSA compiled The State Of Depression in America and presents its findings so that together we can make change happen.*

*Thank you to the patients and their families, policymakers, regulators, insurance companies and other payors, pharmaceutical manufacturers, government agencies and employers for the generous amount of time spent speaking with us. The State of Depression in America would not have been possible without their dedication.*

Ellen Frank, Ph.D.

Miriam Johnson-Hoyte, J.D.

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## Acknowledgements

The **Depression and Bipolar Support Alliance (DBSA)** is the leading patient-directed national organization focusing on the most prevalent mental illnesses. The organization fosters an environment of understanding about the impact and management of these life-threatening illnesses by providing up-to-date, scientifically-based tools and information written in language the general public can understand. DBSA supports research to promote more timely diagnosis, develop more effective and tolerable treatments and discover a cure. The organization works to ensure that people living with mood disorders are treated equitably.

Assisted by a Scientific Advisory Board comprised of the leading researchers and clinicians in the field of mood disorders, DBSA has more than 1,000 peer-run support groups across the country. Over four million people request and receive information and assistance each year. DBSA's mission is to improve the lives of people living with mood disorders.

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\* \* \*

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# Executive Summary

In recent years, a number of studies and government reports have underscored mental health care as a critical component of health policy and public health. Often misunderstood, feared and stigmatized, nearly 19 million Americans suffer from depression, which can have high costs for individuals, their families and society.<sup>1</sup> The social and economic consequences of untreated depression are substantial, including disrupted family and social relationships and increased risk of suicide. Depression has a significant impact on well-being and national prosperity, accounting for direct and indirect costs totaling over \$80 billion per year.<sup>2</sup> Symptoms for depression can range from mild to severe. In many cases, individuals diagnosed with depression do not have adequate access to quality care, which impedes their ability to lead full and productive lives.

The United States health care delivery system and its stakeholders face a critical challenge: developing and implementing effective strategies that can bridge the various gaps to improve health care for people with depression. Within the past several years, mental health issues have gained increased public awareness leading to President Bush's creation of the New Freedom Commission on Mental Health, which issued a report in July 2003, *Achieving the Promise: Transforming Mental Health Care in America*. Mental health research has made promising breakthroughs in developing successful treatments. Despite the sustained activism in recent years, there is still a sense of unease that improvements (e.g., depression prevention, improving recovery methods and improving the quality of life of those living with depression) are not happening quickly enough and are not having an impact on the lives of consumers. A lack of funding, public stigma and an extremely complex, uncoordinated system of care, have all combined to create significant challenges for accessing adequate treatment for depression.

This report aims to create a thorough, comprehensive and actionable body of information to inform legislators, policymakers and other critical stakeholders about the state of depression in the United States and the urgent need for action. In order to present a thorough understanding of depression, primary and secondary research was conducted in preparation of this report, including extensive interviews and literature reviews. Approximately 100 interviews were conducted across a wide range of stakeholders, including policymakers, regulators, payors, providers, employers, consumer advocates, pharmaceutical manufacturers\* and researchers. The interviews focused on developing a comprehensive understanding of the key issues facing the mental health system, specifically related to depression, as well as identifying the opportunities for stakeholders to address the needs of those suffering from depression. Specifically, the report provides a landscape of the current state of depression, followed by more in-depth discussions related to the economic and social impact of the illness, access issues, quality issues and emerging recovery options.

## I. Landscape

Depression is one of the most pressing public health issues in the United States. Depression can have devastating effects on quality of life, relationships and employment or academic achievement. Depression is one of the leading causes of disability worldwide and is associated with increased morbidity and mortality. Despite the high prevalence and tremendous impact of depression, it often remains undiagnosed and/or untreated. Although more consumers are seeking help for depression and rates of antidepressant use are

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\* For the purposes of this report, the Pharmaceutical Manufacturers stakeholder group includes pharmaceutical manufacturers, as well as manufacturers of other forms of treatment.

rising, less than 22 percent of individuals diagnosed with depression receive adequate treatment for their illness.<sup>3</sup> The Landscape section of the report discusses the following:

- **Depression is a real illness** Depression is a type of mood disorder characterized by severe, persistent depressed mood or diminished interest or pleasure in almost all activities, accompanied by symptoms such as insomnia or hypersomnia, weight loss or gain, fatigue, feelings of worthlessness, diminished ability to think and recurrent thoughts of suicide.
- **Depression can be deadly** Suicide is the 11th leading cause of death among persons of all ages in the United States. While 30,000 Americans die by suicide each year, a staggering 730,000 people attempt suicide, with suicides outnumbering homicides three to two in the United States.<sup>4</sup> Research has shown that more than 90 percent of people who die by suicide have depression or another diagnosable mental or substance abuse disorder.
- **Mental health problems can affect anyone** Some subpopulations have an elevated risk of developing problems, being diagnosed with a mental illness or experiencing difficulty accessing appropriate services. Higher rates of depression are found among women, older adults, low-income individuals, individuals with comorbidities and individuals who have experienced trauma. Access to quality mental health treatment may decrease for individuals within some racial and minority ethnic communities, people with chronic illness, children and adolescents and individuals in the criminal justice system.
- **Mental health care delivery is evolving and complex** Striking changes have occurred in the delivery of mental health care over the past few decades. Treatment has transitioned from primarily inpatient, hospitalized settings, to care in outpatient and community settings. The development of Medicaid and Medicare and other public programs have increased access to mental health services for some populations. Managed behavioral health care has also fostered the emergence of markets providing greater choice to individuals with depression as consumers of health care. However, the development of the health care delivery system has resulted in fragmented care across a patchwork of public and private insurance programs and delivery settings, making it difficult for consumers to navigate the system and receive needed care.
- **Tremendous variation exists presently in state mental health services and funding** Mental health services have traditionally been provided at the state level. Government programs (e.g., juvenile justice, Medicaid and SCHIP) can differ drastically from state to state due to variations in state agency mental health expenditures, mental health mandates and parity laws.

## II. Economic and Social Impact of Depression

Depression is a devastating mental illness that has profound economic and social implications. Depression affects not only the individual suffering from the illness, but also the extended family and community in which that person lives. Depression does not occur in isolation and its affects on cost and personal well-being are often magnified through a direct correlation with other factors. The findings on the economic and social impact of depression include:

- **Depression is an expensive illness** It is estimated that the cost of depression is over \$80 billion annually.<sup>5</sup> Direct and indirect cost factors include prevalence of illness, prescribed treatments, treatment effectiveness, comorbidity, adherence and population characteristics.

- Depression places an economic burden on all stakeholders** Major depressive disorder is the leading cause of disability in the United States and results in more days of disability, lost work days and presenteeism (the result of one showing up for work even if one is too sick, stressed or distracted to be productive) than many other medical conditions, placing a large financial burden on employers.<sup>6</sup> Payers incur direct cost charges as more consumers receive treatment, including antidepressant medication, psychotherapy and care in a variety of settings, including inpatient hospitalization and outpatient and community-based services. Federal and state governmental programs, including Medicare, Medicaid, criminal justice and state mental health agencies are becoming increasingly burdened by the costs of mental illness. Depending upon the severity of the illness, the quality of care received and one’s insurance status, depression can cause varying levels of financial strain on families.
- Key economic drivers impact cost** Key cost drivers of depression include undetected depression and inadequate treatment, comorbidity of depression with other medical conditions and substance abuse disorders and an aging population.
- Impact of depression on society is tremendous** Depression affects families, marriages and other relationships, as well as the development of children and adolescents. Depression in a loved one, whether it is a family member or a friend, is a major source of pain, suffering and disruption. Depression has pronounced effects on childhood development, academic achievement and social well-being. Without adequate treatment, depression can lead to suicide, which represents a significant drain on the economic, social and health resources in the United States.

Unless properly diagnosed, depression will increasingly impose unnecessary and severe economic and social costs on American society. All stakeholders must play a role in affecting change. The following opportunities represent actions for stakeholders to contribute toward the improvement of the United States mental health system.

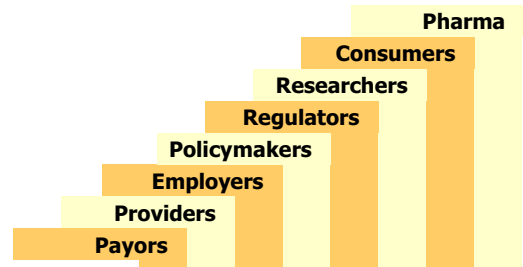
	Payors	Providers	Employers	Policymakers	Regulators	Researchers	Consumers	Pharma
<b>OPPORTUNITIES FOR STAKEHOLDERS</b>								
<b>ECONOMIC/SOCIAL</b>								
Introduce disease management programs and preventive care in the workplace.	●		●					
Promote Employee Assistance Programs (EAP) within the workplace.			●					
Improve treatment within criminal justice system to address disease management.				●	●			
Increase awareness of the prevalence of co-occurring chronic illnesses and depression.	●	●					●	●
Implement treatment adherence programs for consumers.	●	●						
Promote open communication and therapy for depression within families and communities.	●	●	●	●	●	●	●	●
Educate at-risk populations such as adolescents, elderly and their family members about suicide and its indicators.	●	●	●	●	●	●	●	●

### III. Access

Inadequate access to care is a primary constraint to the development of a robust national mental health system. The current system is constrained at multiple levels, which include societal, health system and individual factors. These barriers result in a mental health system that is not adequately accessible and often non-responsive to consumers who need treatment for depression. Access related findings in the report include:

- **Stigma** surrounding mental illness is one of the major barriers to access of mental health services. While recent public awareness and education campaigns have helped to decrease stigma, it is still one of the most prominent access barriers for the American consumer.
- **Inadequate public awareness and education** impedes access to mental health services. The public often does not understand mental illness, where to seek care or the efficacy of available treatments.
- **Inadequate funding and reimbursement** is a key barrier to care. Funding streams for mental health are separate and limited in scope without coordination between private and public payors. The lack of parity in mental health insurance is one of the most troubling barriers to accessing mental health services. Health insurance companies often put limits on per episode reimbursements and charge higher copayments for mental health services.
- **Lack of screening and early intervention** for depression prevents access to mental health services. Additionally, current reimbursement procedures do not give providers incentives for identifying or managing complex cases of chronic depression.
- **Fragmentation of the mental health system** has been cited as a barrier to access for several years. Identified areas of focus include treatment in primary care settings, coordination between different service sectors and care of individuals with comorbidities, such as substance abuse disorders or general medical conditions. Primary Care Physicians (PCPs) offer an important point of access to treatment and have helped more consumers receive care, but fragmentation problems can often occur at this point. PCPs time constraints and lack of expertise with diagnosing and treating depression can impede access to appropriate treatment.
- **Lack of available providers**, particularly psychiatrists and other mental health providers who specialize in children, adolescents and the elderly, is one of the most critical gaps in the mental health care system. The growing number of mental health consumers has far outpaced the number of physicians specializing in psychiatry and other qualified providers. As a result of this shortage, some consumers may wait weeks or even months before receiving mental health treatment.
- **Lack of resources** to seek treatment, such as health insurance, income and transportation are substantial barriers to care. Homelessness, addiction, unemployment and lack of education are also obstacles to getting necessary treatment for depression. Inadequate resources may disproportionately affect racial and ethnic minorities and individuals in rural communities, who often have lower incomes and lower likelihood of having health insurance.

Assuring that all Americans have access to treatment for depression is critical. The following are opportunities for stakeholders to improve access to treatment for depression. Improving access will provide necessary and critical treatment to more consumers and significantly lessen the impact of depression.



**OPPORTUNITIES FOR STAKEHOLDERS**

ACCESS	Payors	Providers	Employers	Policymakers	Regulators	Researchers	Consumers	Pharma
Provide education about depression to employees and create a stigma-free work environment.				•				
Improve reimbursement for PCPs to take the time to screen, diagnose and treat depression.	•		•	•				
Provide easy-to-use mechanisms, such as a website or a dedicated toll-free telephone number, for PCPs to easily alert the payor that the consumer needs to be referred to a mental health specialist.	•	•						
Offer higher rates of reimbursement or bonuses to providers who agree to practice in designated shortage areas.	•	•		•				
Provide the same coverage for mental health services and treatments as for other medical conditions.	•		•	•	•			
Provide peer support linkage to payors and providers to offer consumers access to peer support in their communities.	•	•					•	
Develop programs that specifically reach out to minority groups to address their culturally specific issues with accessing treatment.	•	•	•	•	•	•	•	•
Develop programs to ensure prisoners have access to follow-up mental health treatment in the community once released.				•	•			
Expand programs to provide loan repayments for students in social work, nursing or medical school who agree to specialize in mental health.				•	•			

## IV. Treatment and Emerging Recovery Methods

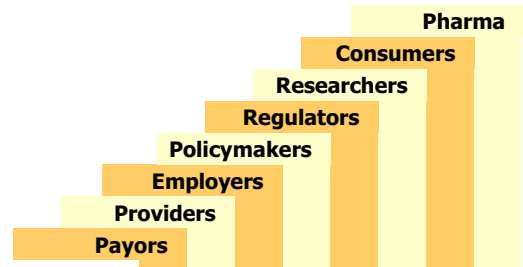
Depression is a complex and serious medical condition, therefore its treatment is a multifaceted undertaking, with the road to recovery incorporating many elements. Treatment of depression has evolved significantly over the last half of the 20<sup>th</sup> and the beginning of the 21<sup>st</sup> Century. A wide spectrum of treatments with documented efficacy have made an impact on individuals suffering from depression. More than 80 percent of people with depressive disorders improve with appropriate treatment.<sup>7</sup> Medical treatment models that focus on the reduction, elimination and control of symptoms based on psychopharmacological care are increasingly used in conjunction with psychosocial treatment models. These psychosocial treatment models incorporate methods such as counseling, psychotherapy, social skills training and peer support – focusing on overall improvement in quality of life and recovery. Findings related to treatment and emerging recovery methods include:

- **Treatment modalities include antidepressants and psychosocial treatments** and recent studies provide evidence that psychotherapy combined with antidepressant therapy is associated with a significantly higher improvement rate than drug treatment alone.<sup>8</sup> In longer term treatment, the addition of psychotherapy has been shown to have a lasting effect on patient wellness. There are several other available treatment options often utilized to treat depression and other mental illnesses.
- **Case management and coordination of care** is needed to combat the fragmentation and disorganization of the current mental health care system. The variety of disciplines involved in mental health treatment

highlights the need for improved coordination of care for individuals with depression. Case management and coordination of care helps to ensure that depression is managed across all providers, including those treating depression and any other co-occurring illnesses.

- **Early screening and detection of depression, when** combined with adequate treatment, can prevent depression from worsening and in some cases, can prevent long-term disability. It can also save significant expense, both for the individual facing depression, who will be able to undergo shorter and less intensive treatment if their depression is detected at an earlier and less debilitating stage, and for the health care system. Early screening has the potential to reduce costs for employers, who will benefit from the decrease absenteeism and staff turnover and from an increase in motivation and productivity that early detection can facilitate.
- **Peer support programs in depression treatment** are one form of self-help treatment that has proven effective and has been described as a key component of the process of recovery.<sup>9</sup> Peer support programs consist of individuals, in either a group or individual setting, sharing personal knowledge and strategies of living with depression and can be mutually beneficial for all those involved. Participants in peer support programs report improvements in self-esteem, decision-making skills and social functioning, as well as decreased psychiatric symptoms (lower hospitalization rates), lower rates of isolation, larger social networks and increased support seeking.<sup>10</sup>
- **Cultural competency in depression treatment** is necessary to meet the mental health needs of racial and ethnic minority groups. Stigma, language barriers and inability to handle the costs of health care services are also major issues that prevent minority groups from seeking and receiving appropriate treatment.<sup>11</sup> Improving provider awareness of their patients' cultural orientation and backgrounds and improving provider skills in interacting with specific different cultural groups is critical for improving mental health services for racial and ethnic minorities. Developing ethnic or culturally-specific and responsive services is critical to appropriately engaging minorities in treatment programs for depression.
- **A consumer-driven approach to mental health** should take into account the consumer's personal preferences, goals and particular circumstances, thus tailoring treatment at the individual level. Consumer groups indicate that being a part of the decision-making process is empowering for individuals with depression and helps to provide a sense of self-worth that can be a powerful force in the road to recovery.
- **Recovery-oriented treatment** defines recovery as the desired outcome or goal of depression treatment. Recovery is a complex multi-dimensional process involving personal growth, healing and development that transforms an individual from an illness-dominated identity to one marked by meaning and well-being.<sup>12</sup> Key facilitators of the recovery process include supportive relationships, engagement in meaningful activities that provide an opportunity for consumers to continue growing and learning about themselves, access to additional treatments and an active role in the decision making about the treatments they are undergoing.

Providing adequate treatment for depression involves many challenges that should be addressed in order to increase the effectiveness of the care provided and improve the chances for individuals with depression to achieve recovery. The following are opportunities for stakeholders to improve treatment for depression.



**OPPORTUNITIES FOR STAKEHOLDERS**

TREATMENT	Payors	Providers	Employers	Policymakers	Regulators	Researchers	Consumers	Pharma
Shift focus from treating symptoms to achieving and maintaining recovery.	●	●	●	●	●	●	●	●
Promote consumer self-empowerment and decision making in treatment and services.	●	●	●				●	
Increase consumer access to peer support programs.	●	●			●	●		
Improve coordination of care and increase case management.	●	●						
Provide grants or other funding to States for the development of depression screening and treatment services.					●			●
Improve cultural competency in the delivery of mental health services.	●	●			●	●		
Educate consumers and providers about different treatment options.	●	●	●	●	●	●	●	●

## V. Quality

Providing high quality health care is one of the major challenges currently facing the medical field, especially in the field of mental health. Although a variety of evidence-based treatments for depression exists, the gap between knowledge and practice is still vast. The disparity between the quality of existing clinical treatments for depression and the quality of care that is actually delivered is distressing. Closing this gap in the application and implementation of proven treatment methodology must be a priority in order to improve outcomes for those suffering from depression. Findings related to quality of mental health care include:

- **Lack of prevention and long term care management** due to the crisis-oriented and reactionary structure of the mental health system. The system is often set up for episodic care focusing on crises, such as suicide attempts, rather than on prevention, proactive treatment and long-term wellness.
- **Fragmentation of mental health services** resulting from a lack of coordination across service sectors is a major obstacle to quality mental health treatment. As a result, consumers often face inadequate assessment, treatment, referrals and follow-up.
- **Insufficient funding and reimbursement** for mental health services is also a primary impediment to achieving quality mental health care. Both public funding and private reimbursement are inadequate, which negatively impacts the number of quality providers and available services for individuals with depression. As a result, mental health programs often do not retain the best providers due to low salaries and poor working conditions.
- **Inadequate training of providers**, including PCPs and mental health specialists, influences the quality of care. There is also significant variation in licensing requirements across different types of providers that commonly treat consumers with depression. The treatment approach selected by providers from these different disciplines can vary widely, as can the quality of care they provide. Additional training should focus on optimal treatment approaches, as well a patient’s mental, social and economic situation to ensure positive outcomes.

- **Lack of standardized outcome measures** negatively impacts consumers and providers. While many evidence-based standards and guidelines have been developed for depression, they are not adequately disseminated, implemented or enforced. The greatest barrier is the establishment of a recognized quality standard. The existence of a broad diversity of disciplines that provide treatment for depression makes it difficult to establish quality measures. Establishment of quality measures would help both providers and consumers make informed decisions on treatment.
- **Inadequate follow-up and treatment adherence** for consumers is a critical issue. Often, consumers cycle in and out of treatment settings, are prescribed antidepressant medications and do not return for follow-up treatment. This lack of follow-up and treatment adherence is especially troublesome in depression, which has a high rate of suicide.
- **Lack of consumer input** in determining treatment options and evaluating care has a negative impact on quality and effectiveness of treatment. Including consumers as part of the decision-making process has shown to improve treatment adherence, satisfaction and success.

While progress has been made in the area of improving the quality of mental health care, barriers still exist to providing optimal treatment for individuals with depression. More investment and attention to quality of care must occur in order to successfully bridge the gap between research and practice. The following are key opportunities for stakeholders related to improving quality and outcomes for depression treatment.

	Payors	Providers	Employers	Policymakers	Regulators	Researchers	Consumers	Pharma
<b>OPPORTUNITIES FOR STAKEHOLDERS</b>								
<b>QUALITY</b>								
Develop a more comprehensive, coordinated system of care with access and coordination points, so consumers know where to go when they first experience depression.	•	•	•	•	•			
Fund mental health services and facilities adequately.	•				•	•		
Improve identification of depression, initial treatment and follow-up.	•	•	•					•
Improve education and training of providers.	•	•					•	•
Establish quality measures and reward providers for performance.	•	•	•	•	•			
Collaborate with mental health advocacy groups to increase their reach and influence.								•
Expand biological and genetic research to develop better treatments, identify the subtypes of depression and determine the factors that predict treatment outcomes.						•	•	•
Expand research needs to include longitudinal studies that are generalizable to different consumer populations.						•	•	•
Conduct more health services research focusing on treatment outcomes to evaluate and develop evidence based practices.							•	•

## VI. Conclusion

Depression is a devastating illness, but one that can be prevented and treated. Access to quality mental health care is fundamental to the health and well-being of Americans. Unfortunately, the current mental health system is not adequately addressing the needs of the millions of Americans with depression. When left untreated, depression can take an enormous toll on an individual's functioning, productivity and quality of life and is associated with elevated risk of certain medical conditions and suicide. If the current barriers and challenges to treatment and recovery are adequately addressed, however, the majority of people with depression can live productive and satisfying lives.

The goal of this report is to show the need for urgent action and suggest opportunities for change. Overcoming the multiple challenges in meeting the needs of those suffering from depression will require a multifaceted approach involving all stakeholders in the field of mental health. Many possible strategies emerged in the research and development of this report for improving health care delivery related to access, treatment, quality and economic and social impact related to depression. These solutions include promoting education, improving reimbursement structures, appropriate allocation of funds, coordination of care and consumer-driven treatment.

To meet the needs of the millions of Americans suffering with depression and the millions more who are affected in other ways by the illness, stakeholders must work in partnership. Stakeholders across the health care spectrum have opportunities to create a more accessible and comprehensive mental health system that will save lives and potentially reduce costs. If implemented, the opportunities outlined in this report could help transform the state of depression in America and the entire mental health care system.

## Resources

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