# WHITE PAPER: Effective Treatment for Prevention and Remediation of Early Psychosis

## A. Description of Problem

### 1. Morbidity:

Schizophrenia, bipolar disorder, and other chronic psychotic disorders are illnesses that devastate not only the lives of their sufferers, but also those of family, friends, and the larger community. With first onset usually occurring in the mid-teens to early twenties, these diseases are characterized by hallucinations, delusions, disorganized thinking, bizarre behavior, paranoia, and/or depression. Schizophrenia and bipolar disorder each afflict about 1% of the adult population, and the less common psychotic disorders afflict another 1% in total. This means that, in San Francisco, about 18,000 adults are suffering from psychosis at any one time. About 1,200 teens and young adults at any one time are within two years on either side of their first break.

Only one in five people with schizophrenia are able to hold a job. About 30% of the chronically homeless and 50% of chronic criminal offenders suffer from schizophrenia. Because schizophrenia is a disease that begins early and lasts a lifetime, about 7% of our nation's hospital costs are incurred for care for people with schizophrenia.

### 2. Mortality:

Due to the ravages of the disease itself; of attendant homelessness, substance abuse, and misadventure; and of the side effects of medication, the average lifespan of people with schizophrenia is shortened by 25 years. Ten percent of sufferers kill themselves within ten years of their first psychotic break. It is one of our nation's most lethal diseases measured in terms of years of life lost.

## B. Current Standards of Care:

In developing medical treatments for many chronic medical illnesses (such as heart disease or diabetes), early detection and preventive intervention efforts have revolutionized standard protocols, resulting in substantial improvements in patient longevity and quality of life and in reductions in the costs of care. In contrast to this preventative approach to medical illness, the standard treatment for serious mental illnesses such as schizophrenia responds *only after the condition is already in full expression with a first full psychotic break*. The onset of schizophrenia or bipolar disorder typically occurs in late adolescence or early adulthood. Manifestations of the disorder develop gradually, and it is only after the symptoms reach a threshold of severity and sustainability that a person is said to experience "onset of psychosis."

Research has shown that it takes an average of two years *after* the full onset of psychosis for an individual to receive a correct diagnosis and begin an appropriate course of treatment. As one editorial asserts, "studies have revealed that throughout the world, individuals suffering a first episode of psychosis experience an alarming delay between the onset of psychotic symptoms and the initiation of treatment."

Once a person with psychosis enters treatment, treatment received is characteristically far below even minimum standards of care. The Patient Outcomes Research Project, in a study of actual schizophrenia treatment led by Drs. Anthony Lehman of the University of Maryland and Donald Steinwachs from Johns Hopkins, found the following:

- "Only 29.1 percent of people with schizophrenia receive the appropriate dose of antipsychotic medication over the long-term. Nearly one-third of these consumers get overdoses that put them at risk of serious side-effects.
- Fewer than half of people with schizophrenia who suffer symptoms of depression receive antidepressant medication, even though 15 percent of people with schizophrenia go on to commit suicide.

- Only half of those suffering from serious side effects of medication receive appropriate and effective treatment to counteract these problems.
- African Americans are almost twice as likely as Caucasians to be overmedicated with antipsychotic medications and accordingly suffer higher rates of side effects. In addition, African Americans are twice as likely to be denied medication for serious depression.
- Fewer than one in 10 families receive even minimal education and support, even though the vast majority of families are in regular contact with their relative with schizophrenia and family education and support has been shown to improve clinical outcomes."

## C. What would a best practice early intervention system look like?

Recent research has confirmed that the onset of psychosis is in fact usually preceded by an extended period when recognizable but sub-acute symptoms are beginning to appear. As one report puts it, there is a "growing realization that psychosis is 'brewing' long before its manifestation in the official diagnostic symptoms." Historically, such early symptoms have been overlooked or, even worse, have contributed to a misdiagnosis.

Multiple studies show that shorter delays between onset of symptoms and treatment are correlated with better outcomes across a range of measures and with increased likelihood of remission. In the past few years, several early detection and intervention programs for psychotic disorders have been established around the world, including programs in Australia, the United Kingdom, and Scandinavia. Initial evidence from these programs indicates that individuals at high risk for psychosis can be reliably identified *prior to disease onset* and that an array of intervention strategies are effective in preventing the progression of the illness and in improving social, school, and work outcomes in this population.

A comprehensive early psychosis program would target teenagers and young adults ages 15 through 24 who are San Francisco residents and who exhibit high risk for psychosis or who have recently started experiencing psychotic symptoms. A comprehensive program would have the following components:

**A.** **Outreach and Education:** Three key issues prevent youth with early symptoms of psychosis and their families from seeking help: (1) They fear the stigma of mental illness, (2) They don't understand which behaviors may be indicators of mental illness and which are symptoms of the normal problems of adolescence, and (3) They don't know where to seek help. An Early Psychosis Project should develop informational and outreach campaigns specifically targeted to primary care physicians, human service providers, teachers and school administrators, therapists, and individuals and families. Secondly, it should have a single telephone number and website where concerned individuals can have questions answered and where they can make appointments for diagnostic assessment.

**B.** **Assessment:** There are several research validated tools for early diagnosis, including one developed by and in use at UCSF. Each youth should receive a comprehensive diagnostic assessment administered at a location that is most comfortable and convenient for the youth and family. It is important to recognize that, at this point, engagement is critical and difficult to obtain. Sensitive, culturally competent approaches are critical to sustained engagement.

**C.** **Clinical case management and evidence-based treatment:** In the early stages of psychosis, it is important to establish a therapeutic alliance with both the youth and the family, so that, if symptoms worsen, medication can be introduced at the appropriate time with a lessened risk of non-compliance. During the early phase of care, rigorous evidence-based psychosocial treatment has been shown to positively impact the course of the disease. Cognitive Therapy specifically designed for psychosis has been shown to be a key element in improved outcomes. Unstructured psychotherapy has not been shown to be effective, although it may be a useful engagement strategy. Once again, it is important that services be culturally competent and available in home or community settings when that is most conducive to engagement. Engagement should be persistent, since individuals and families often experience high levels of denial during this period. Treatment adherence is improved by well-

coordinated care among providers including therapists, psychiatrists and work or school settings, as appropriate. The primary goals are to assist the young person in staying connected to family and community, and to continue to meet developmental goals.

**D.** **Medication management:** Rigorous and careful medication management, with close collaboration between the therapist and the psychiatrist, are essential to positive outcomes. Currently, there is no conclusive evidence that medication in the prodromal phase has a positive benefit. Therefore, treatment with antipsychotic medications should begin when symptom severity progresses to the psychosis onset stage while other psychotropic medications, such as antidepressants and mood stabilizers, should be prescribed once mood symptoms reach a significant threshold, as well. Evidence has shown that medication algorithms (such as the Texas Medication Algorithm) overall improve the effectiveness of treatment. However, these algorithms have not been tested or adapted for an early psychosis project and should consequently be applied flexibly. Medication should be carefully managed to use the lowest possible therapeutically effective dose and side effects should be carefully monitored. Medication regimens should also take into account other mental health conditions—particularly depression—from which the client is suffering. Untreated depression is very common in normal care for psychosis and is a major cause of the high suicide rate in this population.

**E.** **Multi-Family groups:** Multi-family groups have been shown to be highly correlated with positive outcomes for people with psychosis. Groups should be available for all families who are dealing with psychotic illness in a loved one, even when the psychosis sufferer is not willing to participate in treatment. Education and support provided to families in crisis improves the chances that the family will be able, in turn, to support the young person through what can otherwise be devastating episodes of illness.

**F.** **Cognitive and social remediation:** Normal care for psychosis focuses on the "positive" symptoms, such as mania, delusions, hallucinations, paranoid symptoms. Research is now showing that the acuity of the "negative" symptoms and "cognitive" symptoms are equal or more important predictors of the course of the disease. Negative symptoms are the social deficits experienced by psychosis sufferers that inhibit their abilities to constructive engage with the world. "Cognitive" symptoms include the difficulty with attention, planning, problem solving, organizing thoughts and memory that characterize psychosis. There are a number of cognitive and social remediation approaches that have been shown to be effective. Rigorous, evidence-based cognitive and social remediation is a key element of any comprehensive early psychosis program.

## D. Outcome Objectives

A comprehensive early psychosis project would have the following outcome objectives:

1. Provide outreach and services to identify and treat early signs of psychosis.
2. Prevent psychosis from becoming severe and disabling.
3. Assist clients to mitigate and cope with the disease in a way that allows them to achieve their personal life goals.
4. Reduce rates of suicide, school failure or dropout, unemployment and incarceration.
5. Reduce the stigma associated with psychosis.
6. Ensure timely access to culturally competent, evidence-based practices for underserved populations.