



# California Behavioral Health Planning Council

Advocacy • Evaluation • Inclusion

Older Adults Experiencing First Episode Psychosis  
and Late Onset of Serious Mental Illness

June 2018

The California Behavioral Health Planning Council (Council) is under federal and state mandate to advocate on behalf of adults with severe mental illness and children with severe emotional disturbance and their families. The Council is also statutorily required to advise the Legislature on behavioral health issues, policies and priorities in California. The Council advocates for an accountable system of seamless, responsive services that are strength-based, consumer and family member driven, recovery oriented, culturally and linguistically responsive and cost effective. Council recommendations promote cross-system collaboration to address the issues of access and effective treatment for the recovery, resiliency and wellness of Californians living with severe mental illness.

**Introduction:**

The California Behavioral Health Planning Council (CBHPC) serves as a federal and state mandated advisory body to the California Department of Health Care Services and Legislature on policies and priorities for the behavioral health system and to provide recommendations for behavioral health services across the life span. In response to recent legislative activity around First Episode Psychosis (FEP) to amend current law for the use of Prevention and Early Intervention funding, the Council explored available literature and data regarding late onset of serious mental illnesses such as Bipolar and Depression. While early intervention for transition age youth (TAY) has become increasingly vital to help prevent the full-onset of chronic serious mental illness (SMI) and to improve long-term outcomes - there is another segment of the population that experiences FEP later in life. “The issue of late age of onset (over the age of 40) of psychosis has been less well studied than early onset psychosis, but about 25% of all new cases of schizophrenia emerge after the age of 40, 3% being older than 60 at the time of onset (very late-onset).”<sup>1</sup> Similarly, there are a significant number of persons, approximately 10 percent, that experience onset of Bipolar disorder after the age of 50, and 5 percent after the age of 60.<sup>2</sup> We are also seeing rising rates of depression and death by suicide, often overlooked not as symptoms of this condition but rather seen

as a normal part of aging. Providing extensive resources to our youth for prevention and early intervention is well intentioned and suits a critical need, but the occurrence of FEP and SMI is a much broader concern. Without equal attention to the needs of early intervention across the lifespan, adults and older adults will potentially miss the

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opportunity to be identified and treated for specialized mental health services. Too often, late and very-late onset SMI goes undiagnosed because older patients with SMI tend to be socially isolated. The dearth in literature and research, particularly concerning the evolution of psychotic symptoms in late life is a barrier; but sufficient evidence suggests a much needed investment for their wellness and to reduce the public health challenge that comes with increasing costs to care for this population.

**Background:**

Baby boomers are aging, and the number of people in the United States older than 65 is growing rapidly. By 2030, it is projected that this group will exceed more than 60 million, and by 2060, more than 100 million which will ensue that 1 in 5 of these seniors will have one or more behavioral health conditions.<sup>3</sup> Hence, we can predict with great accuracy that by 2060, more than 20 million seniors will be in need of some form of behavioral health services.<sup>4</sup> That number is equivalent to the *total* number of people receiving specialty behavioral healthcare services today, an exceptional disproportionate increase in the number of elderly Americans who suffer from a mental illness.<sup>5</sup> Not nearly enough attention or consideration is

given to the mental health needs of our senior population. Due to improved healthcare leading to greater longevity, the number of persons who will develop psychotic disorders in later life will increase. Younger adults who have a SMI currently have a significantly shorter life span than those without a mental illness, but due to improved health care, and general improved health, the average life span is expected to increase. There is also a dramatic urgency in the State of California and across the nation for geriatric expertise to address the complex needs of older persons with both medical and mental health symptoms.<sup>6</sup>

Late-onset depression is very common among older adults - over 2 million of the 34 million people in the U.S. facing depression each year are over the age of 65 which accounts for 6% of the elderly that suffer from late-life depression.<sup>7</sup> Unfortunately, many older adults do not know about depression - or are fearful of the stigma of mental illness - and consider it to be a normal part of aging instead of a legitimate concern. "Many of the stressful events faced by older adults, such as the loss of a long-term partner, complicated grief over repeated deaths, cognitive impairment, the stigma associated with mental illnesses, chronic physical illnesses, and financial worries that accompany advancing age can result in similar symptoms to depression."<sup>8</sup> Depression in late life is not to be considered normal and as with any person experiencing signs of mental illness, should be treated promptly. "Untreated late-onset depression can lead to increased mortality, decreased quality of life, increased healthcare needs, and less ability to perform activities of daily living among older adults."<sup>9</sup> Immediate intervention is key at the first signs of mental illness and that family supports become aware of the illness. It is not uncommon that caregivers and even physicians mistake the symptoms of late-onset depression for dementia as the severity of the depression may be so disabling that an older adult is not able to properly verbalize his or her distress and seek the help he or she needs. Fortunately, depression in the elderly is one of the most treatable mental disorders.

The rising rates of suicide of our older adult population is another grave concern. Suicide for those over 65 years of age in 2010 was 16.8 per 10,000, more than double the rate for adolescents.<sup>10</sup> "In 2013, the highest suicide rate (19.1%) was among people 45 to 64 years old."<sup>11</sup> Certainly, the recent deaths of

Kate Spade and Anthony Bourdain bring this startling statistic front and center. "The second highest rate (18.6%) occurred in those 85 years and older. According to the Center for

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Disease Control and Prevention, an estimated 10,189 older Americans (ages 60 and up) died from suicide in 2013. Notably, the suicides are particularly high among older, white males (32.74 suicides per 100,000 people). In fact, the rate of suicide in the oldest group of white males (ages 85+) is over four times higher than the nation's overall rate of suicide."<sup>11</sup>

The onset of nonorganic psychoses first manifesting in the elderly, which requires careful evaluation to exclude organic pathology, especially in the later years, is not a rare occurrence and is evident in various studies. A study that followed patients for 10 years for retrospective analysis involved 2,072 persons that upon admission, 604 had their first known psychotic disorder - of the 604, 83 were attributed to mental illness after excluding organic psychoses.<sup>12</sup> The age ranges for the initial emergence of psychosis as a precursor to a SMI is divided by three categories: early onset (EOS) typically between 16-24 years of age, late onset (LOS) after the age of 40, and very-late onset (VLOS) after the age of 60 or 65. There is a substantial difference from VLOS schizophrenia to psychosis associated with dementia, both in terms of neuropsychological and brain imaging findings. Additionally, EOS schizophrenia compared to LOS schizophrenia exhibit different clinical presentations. While it is still debatable whether to consider LOS as a separate diagnostic entity than EOS, what's certain is its rising prevalence.

### **Cost of Care:**

Schizophrenia affects about 1% of the population and is arguably the most expensive mental illness in adults - and the cost of healthcare is typically the highest for the oldest of these patients.<sup>13</sup> A study conducted in the State of New Hampshire compared health care costs for adults with schizophrenia, depression, dementia, or physical illnesses. Excluding dementia, cost of care increased with age and those over the age of 85, incur the greatest per-capita expense.<sup>14</sup> Among those that are 65 and older, annual per-person care for those with schizophrenia, \$40,000 or more, was the most costly: about 50% higher than for those with depression and about 3 times higher than for those receiving care for only physical illnesses.<sup>15</sup> This report also calculated the costs associated with the various treatment settings, such as outpatient clinics, inpatient hospitals, and nursing homes, where people with schizophrenia in each age cohort received their treatment. Among the younger patients (aged 19 to 44), outpatient mental health treatment consumed approximately 50% of the annual expenditures (\$10,244 in outpatient costs, \$20,066 in total costs).<sup>16</sup> In contrast, in those patients aged 75 and older, only 5% of the annual expenditures were for outpatient care (\$1755 of \$34,320), and the vast majority of expenditures were for nursing home care (\$28,395 or 83%).<sup>17</sup> Even in old age, schizophrenia is expensive. The costs of treating schizophrenia increase with age, across the entire adult life span and the need for this level of care reflects the degree of profound disability. In California, older adults utilize 6% of the \$22.2 billion of the State's Medi-Cal Specialty Mental Health Services (SMHS).<sup>18</sup>

### **Barriers to Treatment:**

Older adults and aging adults transitioning in to the older years are often isolated and lacking family and social support, which can create a barrier to getting treatment. "Many older adults with schizophrenia live alone, in assisted care facilities, in homeless shelters, or on the street."<sup>19</sup> Another barrier to these persons receiving care is "because of their cognitive deficits, as well as insight deficits, which are sometimes present among those with schizophrenia, some schizophrenia patients may lack the capacity to provide independent consent for treatment."<sup>20</sup>

Patients who are experiencing symptoms such as paranoia that make a person reluctant to seek help creates a significant barrier in getting the help they need. As provided and available for young persons, outreach in the community, is also needed for this population. Being able to provide in-home care fosters a bridge to care and reduces crises and hospitalizations, thus reducing cost of medical care.

### **Course of Schizophrenia Diagnosis in Late Life:**

The Diagnostic and Statistical Manual (DSM) developed by the American Psychological Association (APA) to establish universal standardized criteria for classification of mental disorders has produced five versions beginning in 1952 to the most recent published in 2013. Criteria for the diagnosis of schizophrenia after the age of 45 was once restricted until the DSM-III, published in 1980. Furthermore, subsequent revisions of DSM contain no diagnostic restrictions for age of onset although it is still a debatable issue whether to consider LOS as a separate diagnostic entity or same as EOS. However, over the years, it has been realized that psychotic symptoms can occur in old age and can be a part of various disorders. Due to the time it took for professionals to recognize that schizophrenia, as well as other SMI, can emerge in late life, many seniors have gone undiagnosed, misdiagnosed and untreated. The implication of evidence-based practices for treating this population is still growing and becoming more recognized but a sizeable segment of the older population is still going undiagnosed and untreated due to lack of outreach, resources and awareness.

### **Conclusion:**

A substantial portion of our elderly population needs our help, arguably the most vulnerable and disenfranchised. The fiscal bearing of untreated mental illness is undeniable and will only increase with our aging population, a public health challenge that affects us all. While the issue of diagnostic universality for psychoses among the elderly remains unparalleled in psychiatry, the fact that this population is increasing at an alarming rate is indisputable - this matter calls for the attention of our legislators. It is pertinent that planning begin now, including building and training our workforce, to prepare for the inevitable growth in service needs for the older adult population or we could face an even larger societal cost. While onset of FEP and SMI is

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most associated with the youth population, emerging research has shown us that it occurs in late-life more often than commonly perceived. There has been immense progress through expansion of services for our youth

population, and we need the same investment for our older adults. After all, we will all be an older adult one day. "In view of the 2006 Age Discrimination Act, the elderly functionally ill group of patients should be entitled to the same level of care and equal access to services as younger people."<sup>21</sup> The onset of serious mental illness in late life remains underdiagnosed but responsive to treatment; and will require adequate resources and funding to provide care. This

subject matter certainly is in need of further development and research but nonetheless is an overlooked group, often isolated and lacking social supports, that needs our careful consideration. Serious mental illness in late life is becoming a public health concern not only in the State of California, but across the nation and worldwide. Through advocacy, appropriate funding, and continued research we can begin to adequately and compassionately care for our senior population.

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