Overview

In December 2016, the Substance Abuse and Mental Health Services Administration (SAMHSA) released the National Tribal Behavioral Health Agenda (TBHA) (SAMHSA, 2016a). The TBHA represents the culmination of a multi-year effort led by tribal leaders and intergovernmental agency leads. It was developed to encourage collaboration with and among federal agencies to address a broad range of behavioral health needs among American Indian and Alaska Natives (AI/AN). The TBHA discusses the systemic factors essential for generating sustainable change in the areas of trauma, depression, substance use, and suicide. Its Cultural Wisdom Declaration makes clear the essential role of cultural wisdom and traditional practices in programs, policies and activities that aim to improve behavioral health in tribal communities. The TBHA is intended to be a framework to guide future program and policy directions, and its dissemination to and utilization by tribal leaders, health professionals, policy advocates and policymakers will ultimately guide its impact.

One of the foundational elements of the TBHA is to create national awareness and visibility to improve understanding of behavioral health disparities among AI/ANs and their impact on physical health and well-being. The purpose of this paper is to compliment the core messages of the TBHA by examining the link between diabetes and behavioral health conditions as comorbidities that often occur together in the same individual and therefore require coordinated prevention, treatment, and policy strategies.

Diabetes in American Indians and Alaska Natives

A persistent challenge. AI/ANs have experienced diabetes at epidemic levels for several decades. Rare reports of diabetes in AI/ANs were noted by health care providers until the 1960s when the National Institutes of Health (NIH) began conducting research in the southwest with the Pima Indians. The NIH researchers noted an increased prevalence of diabetes in the tribe while they were working on another NIH study focused on arthritis (Pratley, 1998). NIH then established a longitudinal study in this community and confirmed rates of diabetes that were among the highest rates in the world. They found more than half of Pima adults were diagnosed with diabetes, and they were found to be virtually all insulin resistant, or type 2 diabetes (Knowler, 1990).
Other subsequent research studies revealed that the epidemic of diabetes was occurring in other AI/AN communities and rates varied among regions. The Strong Heart Study, a longitudinal study of cardiovascular disease in three American Indian populations, reported epidemic proportions of diabetes in individuals age 45-74 that were several times higher than the U.S. population in the 1990s, including age-adjusted rates of diabetes of 65 percent in men and 72 percent in women in Arizona tribes that participated in the study. Lower rates were found in other areas (47 percent in Oklahoma and 33 percent in the Dakotas), but those rates were still much higher than the prevalence of diabetes in the U.S. general population (Lee, 1995). A review of additional studies revealed individual tribes experiencing prevalence rates from around 10-12 percent to up to 50 percent of the adult population (Ghodes, 1995). The epidemic was widespread, but varied among regions.

In some of the first overall national data, a 1987 survey of American Indians eligible for the Indian Health Service (IHS) documented the overall age- and sex-adjusted rate of diabetes in American Indian adults to be 12.2 percent, which at the time was over twice as high as the rate for the U.S. general population (5.2 percent) (Johnson, 1991). By 2002, the age-adjusted prevalence of diabetes in AI/ANs increased to 15.3 percent, which was 2-3 times higher than the prevalence in U.S. adults overall, with alarming increases in prevalence in younger age groups (CDC, 2003).

The latest national data in 2013-2015 reveal that the prevalence of diabetes in AI/ANs continues to be the highest among other racial and ethnic groups at 15.1 percent, with slightly more women than men having been diagnosed with diabetes in this population (Figure 1). The prevalence of diabetes in AI/ANs still varies by region, from 6.0 percent in Alaska Natives to 22.2 percent in the Southwest (CDC, 2017). However, the IHS recently reported that the prevalence of diabetes in its patient population has remained relatively stable over the last decade, compared to the continued rise in prevalence in the U.S. during the same years (IHS, 2014a). While this trend is encouraging, the prevalence of diabetes in AI/ANs is still higher than other racial/ethnic groups in the U.S. These promising results point to the need for ongoing and additional efforts to prevent and treat diabetes in AI/ANs.

![Figure 1. Age-adjusted prevalence of diagnosed diabetes by race/ethnicity, adults aged ≥ 18 years, United States, 2013-2015](image_url)

Understanding the risk for diabetes in AIANs. The risk factors for diabetes in AI/ANs are similar to other populations, and include age, obesity, family history (parental diabetes), percent American Indian ancestry, some specific genetic markers, high calorie/high fat diet, decreased physical activity, a history of gestational diabetes, and pre-diabetes (impaired fasting glucose/impaired glucose tolerance). Hypertension, high triglycerides, and low HDL cholesterol are often also commonly associated with risk for diabetes. (Ghodes, 1995) (Lee, 1995) (Narayan, 1996) (Lee, 2002) (Hanson, 2002) (ADA, 2017). While some of these risk factors seem as though they are not modifiable, such as family history and genetic makeup, several risk factors of diabetes are potentially modifiable, such as weight, physical activity, and food choices. In fact, if genetic variance only explains about 5-10% of the risk for type 2 diabetes (Drong, 2012), the role of modifiable environmental and lifestyle factors is potentially significant.

In fact, the NIH’s Diabetes Prevention Program clinical trial was stopped early in 2002 when results showed that it is possible to reduce the incidence of type 2 diabetes in those at risk with medication or offering education on lifestyle changes promoted through an intervention comprised of a 16-week curriculum focused on promoting increased physical activity and healthier food choices. The achieved goal was weight loss, which was associated with a reduction in new cases of diabetes. These results were found in all racial and ethnic groups that participated in the study, including American Indians (Diabetes Prevention Program Research Group, 2002). This research began an era of hope that diabetes can be prevented through risk factor modification.

Promising trends but disparities persist. There have been some promising trends in research on diabetes prevention and treatment in AI/ANs, including evidence that the rates of some of the complications of diabetes have been declining over the past several years. Nationally, the rate of new cases of end stage renal (kidney) disease in AI/ANs has declined at a faster rate compared to other racial and ethnic groups in the U.S. over the past decade (Figure 2) (Bullock, 2017), and other complications, such as retinopathy, or eye disease, are declining as well (IHS, 2017a).

Figure 2. Incidence of Diabetes-related end stage renal disease among adults age > 18 years, by race and ethnicity – United States, 1996-2013
However, the overall rates of complications from diabetes are often still greater than other racial and ethnic groups. Diabetes related mortality has decreased in AI/ANs since the late 1990s, but is still almost three time higher than U.S. all races mortality and continues to be the fourth leading cause of death in AI/ANs (IHS, 2014b) (Figure 3). The trends are positive, but the disparities are still present.

**Figure 3. Indian Health Service Age-Adjusted Diabetes Mellitus Death Rates**

![Chart 6.44 Age-Adjusted Diabetes Mellitus Death Rates](chart.png)


Even with these promising improvements, the practical impact of diabetes on AI/AN individuals, families and communities continues to be significant. As a chronic disease that requires treatment over many years or even decades throughout an individual’s lifetime, diabetes impacts all aspects of life and well-being. Given the high prevalence of diabetes in AI/AN communities and an awareness of the risk factors, many AI/ANs learn about diabetes at a young age. Many young AI/ANs are involved in the care of parents and grandparents with diabetes, and may carry the concern that the occurrence of this condition in themselves is inevitable. If diagnosed with diabetes, their lives likely change to incorporate regular doctor visits, potential changes in lifestyle factors, and they must deal with both the mental and physical health challenges of being diagnosed with diabetes. If the individual with diabetes also lives in an area with high unemployment, poverty, low educational attainment rates, and lack of access to primary and specialty health care, preventing and treating diabetes and its complications can be a great challenge.

The costs of treating individuals with diabetes are significant. A study using IHS electronic medical record data for a large IHS Service Unit in 2004 and 2005 found that even though the percent of adults with the diagnosis of diabetes was 10.9 percent, the treatment costs were 37 percent of all treatment costs for adults, nearly half of all hospital days, and 32.3 percent of all hospital inpatient costs (O’Connell, 2012) (Figure 4).
Overcoming a troubling history. Perhaps the most challenging part of the diabetes epidemic in AI/ANs is the knowledge that this condition likely occurred in part because of the significant and externally driven changes in lifestyle and environmental factors impacting tribal communities over the past two centuries. While there is evidence of some increased genetic risk of diabetes in AI/ANs, the evidence that environmental or acquired factors have contributed to this epidemic is clear.

For example, studies of the Pima Indians noted that the tribe thrived in the desert environment in Arizona for more than 2000 years by farming with a system of irrigation canals from their main sources of water, the Salt River and the Gila River. However, in the late 19th century, these irrigation systems were disrupted by new settlers in the area and the Pima's way of life changed dramatically. Without the ability to farm, they relied on government surplus commodities that often were high in carbohydrates and fat while at the same time experiencing a reduction in physical activity. As they transitioned to this new lifestyle, the prevalence of obesity increased, leading to insulin resistance, and eventually an epidemic of diabetes (Pratley, 1998).

While this transition is well described in the Pima Indians, the pattern was repeated in numerous AI/AN communities over the years. The details of this transition may differ by tribe, yet the outcome – the epidemic of diabetes – is unfortunately the same. As the number of people with type 2 diabetes grows in the U.S. and around the world, the same types of contributing factors are recognized: increased urbanization, economic development, aging populations, reduced physical activity, and other lifestyle changes (IDF, 2013).
Behavioral Health Conditions in American Indians and Alaska Natives

Another significant challenge for AI/ANs. Behavioral health, defined as mental and substance use disorders, is a topic that tribal leaders discuss frequently in terms of the significant impact of these conditions on their community. In fact, the compelling stories told by tribal leaders during discussions with federal agencies led to the development of the TBHA by SAMHSA. AI/ANs experience high rates of interpersonal violence, depression, unresolved grief and loss, substance use disorders and suicide, which adversely impacts the well-being of individuals, families and communities (SAMHSA, 2016a).

The burden of behavioral health conditions in AI/ANs. Data on behavioral health conditions suggest that the burden on AI/AN individuals and communities is on average greater than the U.S. general population. Research has documented this trend for many years. In a large epidemiological survey conducted among a southwest tribe and a northern plains tribe in the 1990s, American Indians age 15-54 years demonstrated high rates of some behavioral health disorders. The most common diagnoses found were alcohol dependence, posttraumatic stress disorder, and major depressive episode. Lifetime rates of any Diagnostic and Statistical Manual (DSM)-III-R disorder studied (depressive disorders, anxiety disorders or substance use disorders) were 54 percent in the southwest tribe and 50.3 percent in the northern plains tribe (Beals, 2005), compared with 48 percent in the general population (Kessler, 1994). In the 2016 National Survey on Drug Use and Health, AI/AN adults age 18 and older experienced higher rates of mental illness in the past year (22.8 percent) than the U.S. general population (18.3 percent) (SAMHSA, 2017a) (Figure 5).

![Figure 5. Mental Illness in Past Year, Age 18 or Older by Race/Ethnicity, 2016](chart)

Source: 2016 National Survey on Drug Use and Health, SAMHSA, Table 10.1B
Depression. The data on depression in AI/ANs show that it is at least as common and sometimes found to be more common than the U.S. general population. In a study in a southwestern IHS primary care clinic, the prevalence of major depression was 8.9 percent, and any depressive symptom was 20.7 percent (Wilson, 1995). Two decades later in the 2016 National Survey on Drug Use and Health, 8.7 percent of AI/AN adults experienced Major Depressive Episode in the past year, which was higher than the U.S. general population and other racial/ethnic groups except for the category of Two or More Races (SAMHSA, 2017a). A recent report from the 2012-2015 Behavioral Risk Factor Surveillance System found depression to be reported more commonly among AI/ANs (23.2 percent) compared to non-Hispanic whites (20.3 percent) and other racial/ethnic groups (James, 2017).

In a report on urban Indian health, results of some small studies were noted to indicate that up to 30 percent of all AI/ANs suffer from depression (Urban Indian Health Commission, 2007). Also, a review of medical records in an Alaska Native primary care system found that a diagnosis of depression was found in 35 percent of charts and that 38 percent had depression symptoms noted (Hiratsuka, 2015).

Substance Abuse. Statistics on alcohol abuse in AI/ANs show a mixed picture that does not exactly match the stereotypes that some may have for this population. In the 2016 National Survey on Drug Use and Health, AI/AN adults age 12 and older experienced lower rates of alcohol use compared to the U.S. general population for lifetime (76.7 vs. 80.2 percent), past year (57.0 vs. 64.8 percent), and past month (34.4 vs. 50.7 percent) categories (SAMHSA, 2017a). However, the pattern of use matters. In a behavioral risk survey of four tribes in North Dakota, participants were less likely to drink alcohol yet more likely to be heavy drinkers compared to North Dakota and U.S. participants, and more likely to be binge drinkers than the U.S. participants, with men more likely to drink heavily and binge drink than women (Holm, 2010). In FY2013, the total alcohol-related discharge rate for IHS and Tribal hospitals was 82 percent lower than the rate for U.S. short stay hospitals (IHS, 2014b). Still, in data combined for years 2003-2011, AI/ANs were more likely to need treatment for alcohol or illicit drugs in the past year compared to other racial/ethnic groups (17.5 vs. 9.3 percent) (SAMHSA, 2012).

The impact on this population is significant. In a study linking National Death Index records with IHS registration records, age-adjusted alcohol attributable death rates from 1999-2009 were higher in AI/ANs compared to Whites, with some variation by region (Landen, 2014). The latest published data from the IHS revealed that the age-adjusted alcohol-related death rate for AI/ANs in 2007-2009 was 46.9 per 100,000 population which was over six times the U.S. all races rate for 2008, with death rates greater in AIAN men than women (IHS, 2014b).

In the 2016 National Survey on Drug Use and Health, the rates of substance use disorder, defined as meeting criteria for illicit drug or alcohol dependence or abuse, in persons aged 12 or older in the past year, were greater in AI/ANs compared to the U.S. general population for illicit drugs (4.1 vs. 2.7 percent) and alcohol (9.2 vs. 5.6 percent) (SAMHSA, 2017a). In the same survey data, AI/AN adults age 12 and older experienced higher rates of lifetime illicit drug use compared to the U.S. general population in lifetime (58.7 vs. 48.5 percent), past year (23.6 vs. 18 percent) and past month use (15.7 vs. 10.6 percent) (Figure 6) (SAMHSA, 2017a). In the same data for AI/ANs, any use of prescription psychotherapeutics in the past year was greater and misuse of prescription psychotherapeutics was lower than the U.S. general population (SAMHSA, 2017a).
Data also show that this problem is increasing in AI/ANs. The age-adjusted drug related death rate for AI/ANs in 2007-2009 was reported by IHS to be 1.8 times greater than the U.S. all races rate in 2008 and the AI/AN rates appear to be increasing at a faster rate than the U.S. all races rates. The age-adjusted drug related death rate for AI/ANs in IHS service areas increased from 4.1 deaths per 100,000 population in 1979-1981 to 22.7 in 2007-2009, which represents a 454 percent increase (IHS, 2014b). In more recent data, age adjusted drug overdose deaths from 1999-2015 reveal that AI/ANs had the highest rates in 2015 compared to other racial/ethnic groups and the highest percent change in number of deaths over the time period was in non-metropolitan AI/ANs (519%) (Mack, 2017).

Measuring mortality related to behavioral health conditions can be a challenge, since death certificates often record the final cause of death, which may or may not have been related to any behavioral health conditions present in the individual at the time of death. An individual with depression or posttraumatic stress disorder may have actually died in a car accident, or from a heart attack, and the comorbid diagnoses may not be known when the death certificate is completed. Yet the data suggest that AI/ANs continue to be negatively impacted by substance use.

**Suicide.** According to IHS data, the age-adjusted suicide death rate for AI/ANs in 2007-2009 was 1.6 times greater than the U.S. all races rate. The impact is most significant in AI/AN youth. Suicide was found to be the second leading cause of death in AI/ANs ages 5-24 years. Age specific suicide death rates were higher for AI/AN men than women for all age groups, and the greatest differences between men and women were in the age group 15-24 years (2.9 times greater) and in the age group 65-74 years (11.4 times greater) (IHS, 2014b). In the 2015 National Survey on Drug Use and Health, AI/AN adults age 18 and older experienced higher rates of attempted suicide in the past year compared to the U.S. general population (1.2 vs. 0.6 percent) (SAMHSA, 2016b). The 2016 data show the rates for AI/ANs to be slightly lower than the U.S. general population data (0.3 vs. 0.5 percent), but the percent who made any suicide plans in the last year continues to be higher (1.4 vs. 1.1 percent) (SAMHSA, 2017a).
Similar to the general population, individual suicide risk increases with comorbid substance use, which is illustrated in tribal samples where as much as 44 percent of documented suicide attempts used substances at the time of the event (Mullany, 2009). With respect to current trends and emphases in the utility of behavioral health and primary care integration, suicide, in particular, may be amenable to early prevention with such collaborative programs. The importance of these types of initiatives are highlighted by findings that 82 percent of AI youth who attempted suicide presented to an emergency room within one year of the index suicide attempt (Ballard, 2014). Other data in the general population have shown that 39 percent of people who later died by suicide had visited an emergency room in the year before death (Gairin, 2003). While there are likely a number of opportunities to intervene, there remains a paucity of literature on the validity of suicide screening and risk assessment for AI/ANs.

**Etiology - Genetics vs. environment.** In the past, mental health disorders were thought to be the result of transmission of a single gene that ran in families or of abnormal levels of specific neurotransmitters. A more current concept is that of “genetic complexity,” which defines the risk for a mental disorder to be the result of the interaction between multiple genes and non-genetic factors including environmental stressors. This explanation gives some hope that both targeted therapies from genetic studies as well as identification of modifiable environmental risk factors can impact risk for certain mental disorders (Hyman, 2000).

A recent analysis of the 2001-2002 National Epidemiologic Survey on Alcohol and Related Conditions found that while AI/ANs had higher rates of meeting criteria for at least one Diagnostic and Statistical Manual-IV lifetime disorder compared to non-Hispanic whites, many of the differences were reduced after adjusting for sociodemographic factors. Comparisons for specific disorders varied. For example, AI/ANs had higher rates of substance use disorders even with adjustment for sociodemographic factors. However, alcohol use disorder rates were not consistently greater than non-Hispanic whites especially when adjusted for sociodemographic factors (Brave Heart, 2016). The latter finding contradicts stereotypes of alcoholism in AI/ANs and points to a role for environmental risk factors.

The concept of “epigenetics” is gaining interest as a way of explaining the impact of environmental stressors and trauma on risk for health disparities and even behavioral health conditions in AI/ANs. In a recent review, a framework was proposed for how exposure to trauma, stress and adverse childhood experiences (ACEs) may impact how an individual’s genes regulate the body’s stress response, which may increase risk for psychiatric disorders later in life (Brockie, 2013). However, this review also indicated the need for more research to better understand these mechanisms and how they might help inform future interventions to promote health for AI/ANs.

**Exposure to Trauma.** Trauma is unfortunately a common thread in the lives of many AI/ANs and is related to the burden of behavioral health conditions in AI/ANs (SAMHSA, 2016a). The historical trauma, intergenerational trauma, unresolved grief, and current trauma that AI/ANs may experience has been described as contributing to high rates of alcoholism, suicide, homicide, domestic violence, child abuse and other challenges in AI/AN communities (Brave Heart, 1998). The loss of lands, forced relocation, and loss of language and culture, as well as the experience of parents and grandparents being forced to go to boarding schools, along with long-standing problems with racism and discrimination, certainly has resulted in pain and grief over the generations in AI/AN communities.

SAMHSA developed a Concept of Trauma to help inform efforts by public health agencies to support survivors of trauma. The definition states “individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life
threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being.” (SAMHSA, 2014c).

AI/ANs experience many forms of trauma. For example, age-adjusted death rates from homicide are two times greater than the U.S. all-races rate (IHS, 2014b), and rates of violent crimes for American Indians are more than twice the national average (Perry, 2004).

Other data reveal that AI/ANs experience high lifetime rates of sexual and intimate partner violence. According to results from the National Intimate Partner and Sexual Violence Survey in 2010, American Indian women experience higher lifetime rates than Non-Hispanic Whites of all categories of sexual violence studied, including rape, other sexual violence, stalking, and intimate partner violence (both physical violence and psychological aggression). For example, the prevalence of lifetime experience of rape in American Indian women was found to be 27.5 percent, compared to 20.5 percent in Non-Hispanic White women. The prevalence of intimate partner violence that was physical violence was 51.7 percent in American Indian women compared to 30.5 percent in Non-Hispanic White women. In the same survey, American Indian men were also found to experience higher lifetime rates of other sexual violence and intimate partner violence (physical violence and psychological aggression) (Breiding, 2014).

One result of experiencing trauma can be the development of posttraumatic stress disorder (PTSD). In a survey of two American Indian communities, 15.9 percent of individuals exposed to DSM IV trauma exposure qualified for a diagnosis of lifetime PTSD, with the majority of women experiencing this condition as a result of interpersonal trauma exposure (sexual and physical abuse) and men experiencing this condition due to a number of trauma categories (Beals, 2013). A recent review of published studies on posttraumatic stress disorder in AI/ANs revealed that several studies document higher rates of PTSD compared to other racial and ethnic groups, with combat experience and interpersonal violence being leading causes (Bassett, 2014).

The Role of Adverse Childhood Experiences. The Adverse Childhood Experiences (ACE) Study was conducted in the 1990s to study the long-term relationship of childhood experiences of abuse and household dysfunction to long term medical and public health outcomes in patients evaluated at large a health maintenance organization. The study reviewed the occurrence of seven categories of adverse childhood experiences: psychological, physical or sexual abuse; violence against mother; living with household members who were substance abusers, mentally ill or suicidal, or ever imprisoned. The initial results revealed that more than half of the respondents reported at least one ACE, and one fourth of respondents reported two or more ACEs. The study found a strong relationship between ACEs and multiple risk factors for several leading causes of death in adults (Felitti, 1998). ACEs are strongly related to ever using and initiating alcohol use (Dube, 2006), and an increase risk of both lifetime and recent depressive disorders (Chapman, 2004).

The impact of trauma on American Indian youth is significant. In a survey of American Indians age 15-24 years from a remote Plains Indian reservation, 78 percent of respondents reported at least one adverse childhood experience (ACE), and 40 percent reported at least two. In the same survey, each additional ACE reported increased the odds of suicide attempt by 37 percent, posttraumatic stress disorder by 55 percent, poly-drug use by 51 percent, and depression symptoms by 57 percent (Brockie, 2015). Another study of American Indian youth ages 15-24 in two closely-related reservations found a dose-response relationship between the experience of severe trauma and alcohol use disorders (Boyd-Ball, 2006). In a survey of AI women, age 18-45 in an outpatient setting, 76.5 percent reported some type of childhood
abuse or neglect, and over 40 percent reported severe maltreatment exposure, and the severity of child maltreatment was associated with increased risk for lifetime PTSD, substance abuse disorders, and mood disorders (Duran, 2004).

In another recent study using the 2011-2012 National Survey of Children’s Health, AI/AN children were 2-3 times more likely to have multiple ACEs compared to non-Hispanic White children but these differences were eliminated when adjustments were made for differences in socioeconomic factors. However, for those children with multiple ACEs, poorer outcomes were found, including school problems, behavioral disorders, more medication and services such as counseling (Kenney MK, 2016).

The burden of behavioral health conditions in AI/ANs is significant, and research shows the extent of these challenging problems. Tribal leaders often bring up these issues as top priorities for action when talking with government officials and congressional representatives. They see the impact in their communities each day, and they are constantly seeking solutions. But these conditions do not occur in a vacuum, and new strategies are needed to address these issues in the context of other conditions and circumstances that individuals face each day.

Comorbidities

Definitions. For centuries, many tribal cultures have thrived under worldviews that recognize physical health as just one aspect of overall wellness and acknowledge that the health of humans is connected to that of other living things within the ecosystem. Appreciation of these concepts within western medicine is relatively recent. In 1954, the first director of the World Health Organization noted that “without mental health there can be no true physical health,” drawing attention to a routine error of health sciences at the time to disregard the importance of mental health conditions on the health outcomes of an individual (Kolappa, 2013).

The term “comorbidity,” a medical term for any coexisting ailment in a patient with a particular index disease, was not introduced into western medicine until 1970 when Dr. A. R. Feinstein, a researcher and epidemiologist, coined the term (Feinstein, 1970). Another term, “multimorbidities“ has been used to describe “the co-occurrence of multiple chronic or acute diseases and medical conditions within one person” without indicating the index condition, particularly in the context of dual psychiatric and physical disorders that co-exist without implicit ordering (e.g. mental illness and substance abuse) (Valderas, 2009). Similar terms, such as “co-occurring disorders” or “dual diagnoses” have also emerged especially in reference to co-occurring mental health and substance abuse (Watkins, 2001). All these terms are used in research and in the provision of care to describe when one or more conditions or diseases occur in an individual.

While there are various uses of these terms, a comprehensive review of the literature in 2009 proposed that additional classification is needed to illustrate whether the co-occurring diseases are somehow associated or have a causal relationship (van den Akker, 1996). In another review in 2009, the complexity of these distinctions was further discussed, including a call for more precise terminology about the associated conditions, the timing or sequence in which they occur, their burden on the individual (morbidity burden), and the impact of other factors about the patient referred to as “patient complexity.” All these factors impact what terms may be used in which settings, and also may impact how these conditions are addressed or treated (Valderas, 2009).
Diabetes is an example of a condition that often has comorbidities, whether they are complications of the disease, such as hypertension or heart disease, or conditions that may or may not have a clear temporal or causal relationship with the onset of the occurrence of diabetes in the individual. Some prefer to use the term multimorbidities, especially when the definition of the index condition does not matter, such as in a primary care setting where all conditions need to be treated regardless of their sequence (Valderas, 2009).

But in some cases, the temporal relationship may be critical for the provision of effective treatment. For example, depression that has occurred prior to the diagnosis of diabetes may manifest in an individual differently than depression that comes after the diagnosis of diabetes or even after complications of diabetes occur. As a result, behavioral health conditions that are comorbid with diabetes are of interest since their treatment often depends on the impact of both the physical and behavioral health conditions on the individual. Also, since individuals with diabetes must make several changes in their lives to comply with recommended treatment and lifestyle changes to prevent complications, the impact of other comorbid illnesses, especially behavioral health conditions, may interfere with the patient’s ability to make those changes and access the care they need.

The comorbidities, or other chronic diseases or health conditions, associated with diabetes are potentially significant and a lifelong challenge. The diagnosis of diabetes in an individual means an increased risk of complications, including cardiovascular disease (hypertension, heart attacks, and stroke), retinopathy (blindness), nephropathy (kidney disease often leading to dialysis), neuropathy (numbness and tingling in the extremities that can cause problems including amputations) and increased mortality (IDF, 2013). According to a study with comparisons to the U.S. commercially insured population, AI/ANs with diabetes receiving services in the IHS had higher rates of comorbidities such as hypertension, cerebrovascular disease, lower-extremity amputations, renal failure, neuropathy, liver disease, mental health disorders and substance abuse, and these comorbidities put them at a 50 percent greater risk for use of health resources (O’Connell, 2010).

**Comorbidity Impact.** Comorbidities, or multimorbidities have a significant impact on the individual. For example, comorbidities are associated with an increased risk of hospitalization (Wolff, 2002), in-hospital mortality (Incalzi, 1997), increased visits to physicians, especially specialists (Starfield, 2005), decreased medication adherence (Balkrishnan, 2003), and increased per capita Medicare expenditures (Wolff, 2002). Indexes such as the Charlson Comorbidity Index are used in research studies to predict the risk of death from comorbid disease and have found that increasing comorbidity is associated with increased cumulative mortality attributable to comorbid disease (Charlson, 1987). In a review of the consequences of comorbidity, several studies were cited that found associations between comorbidity and impaired functional status or quality of life, greater health care utilization, complications of treatment, readmissions, and mortality (Gijsen, 2001).

Studies in AI/AN elders have shown that comorbidities increase with age, with over half to two-thirds of elders in these studies having at least three co-morbid conditions, greater comorbidity than the general U.S. population (especially diabetes and hypertension), increased functional limitations/functional disabilities, depressive symptomatology, and lower personal mastery (Goins, 2010) (Chapleski, 1997) (John, 2003).
Diabetes and Behavioral Health Comorbidity

Research shows how diabetes and behavioral health conditions occur together and the impact of these comorbidities. Diabetes has been found in several studies to be associated with mental disorders, such as anxiety disorders (Kruse J, 2003), posttraumatic stress disorder (Vaccarino, 2014), and depression (Knol, 2006).

Numerous studies have found that diabetes and depression occur together, and in the general population, diabetes has been shown to double the odds of depression (Anderson, 2001). While depression can occur after the diagnosis of diabetes, studies have also shown that depression can be a risk factor for developing diabetes. In fact, in one study that reviewed these relationships, depression was associated with a 60 percent increase risk of type 2 diabetes, while diabetes was associated with only about a 15 percent increased risk of depression. The authors noted that depression is associated with behaviors that may increase the risk for type 2 diabetes, such as physical inactivity, increased caloric intake and smoking (Mezuk, 2008).

In American Indians, the prevalence of depression has been found to be higher among individuals with diabetes than those without diabetes, and average blood glucose levels are higher among those individuals with diabetes that are depressed (Sahota, 2008). The Strong Heart Study also found that the rate of depression is higher in individuals with diabetes compared to those without diabetes, and that a 1-unit increase in A1C results was associated with a 22 percent increase in the odds of severe depression (Calhoun, 2010). As mentioned previously, another study with IHS data found diabetes to be associated with higher rates of mental health disorders, including depression and substance abuse (O’Connell, 2010). A study with two American Indian tribes found that depressive disorder and alcohol dependence were associated with an increased likelihood of developing diabetes, even after controlling for sociodemographic factors and other conditions (Jiang, 2007).

Chronic emotional stress, not just depression, is also a risk factor for diabetes. A recent review of longitudinal epidemiological studies found that general emotional stress and anxiety, sleeping problems, anger and hostility are associated with an increased risk of type 2 diabetes (Pouwer, 2010). In a study with two American Indian communities, the burden of stress, defined as an index of conditions related to early-life stress, such as separation from parents and interpersonal trauma, and chronic stress, such as discrimination, location hassles, family dysfunction, addiction problems, and economic distress, was high overall, and was significantly higher in individuals with diabetes. Of interest, after adjustment for sociodemographic characteristics, the types of stress burden associated with diabetes differed among the two communities. In the Northern Plains community, early life interpersonal trauma and community family dysfunction was significantly associated with diabetes, whereas in the Southwest community, higher level of perceived discrimination and community addiction problems were significantly associated with diabetes (Jiang, 2008). In another study in the Pacific Northwest, two thirds of the participants with diabetes perceived racial discrimination in health care and this was associated with lower completion of recommended diabetes care services (Gonzales, 2014). Another study with AI/ANs linked racial microaggressions to diabetes distress, which can negatively impact diabetes self-care (Sittner, 2018).

Behavioral health conditions may impact an individual’s ability to prevent diabetes. In the Special Diabetes Program for Indians Diabetes Prevention Program, psychological distress and negative family support were linked to greater weight and predicted less weight loss after a 16-week curriculum that
focused on weight loss and lifestyle changes (Dill, 2016). In the Special Diabetes Program for Indians Healthy Heart Project, serious psychological distress was associated with increased weight (BMI) and glucose control (HbA1C) in individuals with diabetes (Huysen, 2015). An increasing number of research studies also show the impact of maternal and fetal stress during pregnancy and describe the potential negative impact on fetal development and future disease risk, including obesity and diabetes (Entringer, 2013).

Research on the relationship of diabetes and alcohol abuse has uncovered results that are somewhat counter to commonly held beliefs about AI/ANs and these conditions. In a literature review of studies on diabetes and its relationship with alcohol consumption in the general population, a J or U shaped curve was found, in which moderate consumption of alcohol (1-3 drinks/day) was associated with a 33-56 percent lower incidence of diabetes, and heavy alcohol consumption (greater than 3 drinks a day) was associated with up to a 43 percent increase in diabetes incidence (Howard, 2004). For American Indians in the Strong Heart Study, glucose levels also showed a similar relationship, but in longitudinal analyses, alcohol use was not found to be significantly associated with glucose tolerance (Lu, 2003).

The impact of PTSD on diabetes related outcomes is significant. In a study of AI adults with type 2 diabetes, 21.8 percent screened positive for PTSD, and those with PTSD and depression reported the highest proportion of any past month hyperglycemia, past year hospitalization, and low self-rated health status (Aronson, 2016).

These studies reveal the common occurrence, or comorbidity, of diabetes and behavioral health conditions and the significant impact they can have on the health and well-being of an individual. The evidence is clear that AI/ANs with these comorbidities need increased support and coordinated care that can help reduce the risk of further harm and complications.

**Current Efforts to Address Diabetes and Behavioral Health Comorbidity**

**Federal Response – IHS.** The IHS is the principal federal agency responsible for providing healthcare services to approximate 2.2 million AI/ANs from federally recognized tribes. Located in 35 states on or near Indian reservations, the IHS is a network of over 600 hospitals, clinics and health stations managed by IHS, tribes and urban Indian health programs that provide mainly primary care, and some secondary and tertiary care either directly or through contracting with providers outside its system (IHS, 2016).

The IHS recognized the growing problem of diabetes in its patient population in the 1970s by establishing a national diabetes program to help coordinate diabetes care system wide. In the 1990s, this program was renamed the Division of Diabetes Treatment and Prevention. The Division provides a variety of services to IHS, tribal and urban Indian health programs, including setting standards of care, monitoring trends in diabetes care delivery, providing education, developing diabetes education materials, encouraging team based care, supporting a network of diabetes consultants to provide technical support to local providers and combining both clinical and public health approaches to care (Dixon, 2001).

In 1997, Congress recognized the growing epidemic of diabetes in AI/ANs and passed the Balanced Budget Act which included new funding for the Special Diabetes Program for Indians (SDPI). This
funding was established as a grant program that is currently funded at $150 million per year and provides funding for IHS, tribal and urban Indian health programs to prevent and treat diabetes and its complications (IHS, 2014a). The IHS Tribal Leaders Diabetes Committee serves as an advisory group to the IHS DDTP and developed and regularly reviews the distribution formula for these grants and their evaluation.

![Tribal Leaders Diabetes Committee, Indian Health Service, 2014](image)

The initial phase of the SDPI, called the Community Directed SDPI programs, helped dramatically increase access to diabetes care services. In addition, grant programs were allowed to make local adaptations to their evidence-based services, and many included adaptations based on local needs and local cultural traditions and strengths. Many programs found ways to incorporate local traditions in their education and activities which helped motivate patients to receive care and make behavioral changes (IHS, 2007). An example of this type of cultural adaptation is the Diabetes Wellness: American Indian Talking Circles model, which incorporated diabetes education and local cultural beliefs and practices in a talking circle forum for patients to discuss the physical and psychosocial challenges of diabetes in a holistic manner (Struthers, 2003).

In 2002, Congress directed IHS to establish a demonstration project that was competitively awarded as grants to IHS, tribal and urban Indian health programs that would implement the latest research findings to prevent diabetes and its complications. The IHS created the SDPI Diabetes Prevention and Healthy Heart Demonstration Projects and launched a 5 year demonstration project in which 66 grantees implemented structured interventions to prevent diabetes and cardiovascular disease. Programs were also allowed to make local adaptations and implement community based activities in both demonstration projects, and many incorporated local cultural themes and practices into their activities (IHS, 2011).

The overall results of the SDPI Diabetes and Healthy Heart Demonstration Projects revealed that the group of grantees in the SDPI Diabetes Prevention Program were able to achieve weight loss in their participants and a reduction in new cases of diabetes similar to American Indians in the lifestyle intervention of the NIH-funded Diabetes Prevention Program clinical trial (Jiang, 2013). The group of grantees in the SDPI Healthy Heart Program were able to reduce risk factors for cardiovascular disease in their patients with diabetes through an intensive case management intervention (Moore, 2014). These amazing results were achieved while allowing programs to adapt their activities to their local communities, traditions and cultures.
The IHS also has implemented for the past decade its Improving Patient Care Program, which is focused on improving the quality of care for chronic and preventable diseases through team based care in a patient centered medical home model. The focus of this program on using a team of providers to improve access to quality care to address patient needs in a more timely and effective manner also highlights the importance of integration of behavioral health and primary care in IHS, tribal and urban Indian health programs. The model includes having all relevant providers focus on patient needs in team meetings in real time, including a designated behavioral health professional as a part of the team. Patient-centered medical home initiatives are a trend in the U.S. healthcare system to help improve the quality of and access to care, and can be an effective way to conduct screening and management of behavioral health conditions (IHS, 2017b) (Dwinnells, 2017). In 2017, the IHS released a call for proposals for a new Behavioral Health Integration Initiative to fund IHS, tribal and urban Indian health programs to develop, implement and evaluate behavioral health integration with primary care and community based settings (IHS, 2017c).

Probably the most well-known example of implementing a patient centered care model in the Indian health system is the Nuka System of Care at Southcentral Foundation in Anchorage, AK, which implements an integrated primary care team based on the input from patients who are referred to as “customer-owners.” In this system of care, access to care has increased, and the number of individuals on the waiting list for behavioral health appointments was reduced from 1300 to almost zero in a year (Gottlieb, 2013).

IHS also is addressing mental health and substance use disorders, as well as trauma, in two congressionally funded initiatives: the Substance Abuse and Suicide Prevention Programs, formerly known as the Methamphetamine and Suicide Prevention Initiative and the Domestic Violence
Prevention Initiative. Both of these initiatives encourage programs to adapt to the local culture and traditions in order to find ways to successfully prevent and treat the issues on which they focus (IHS, 2017d). The IHS has also established a successful Telebehavioral Center for Excellence that helps provide continuing education to IHS, tribal and urban Indian health providers on behavioral health issues and their treatment, and also uses telemedicine for behavioral health clinical encounters, which helps increase access to care especially in rural and remote areas (IHS, 2017e).

IHS established a National Tribal Behavioral Health Advisory Committee to provide guidance and recommendations on strategies to address behavioral health issues in AI/AN communities (IHS, 2017f). National conferences focused on behavioral health issues are held annually to help programs share best practices and cultural adaptations of evidenced based care. However, tribal leaders continue to request that the IHS commit more funding to behavioral health issues in their communities as disparities continue to exist. While IHS does encourage its programs to integrate behavioral health services into primary care, the shortage of providers, including behavioral health professionals and primary care physicians, still serves as a barrier to full integration and support for diabetes and its behavioral health comorbidities.

Federal Response - SAMHSA. The Substance Abuse and Mental Health Services Administration (SAMHSA) leads public health efforts within the U.S. Department of Health and Human Services to advance the behavioral health of the nation, and its mission is to reduce the impact of substance abuse and mental illness on America’s communities (SAMHSA, 2017b). SAMHSA has funded a number of tribally focused initiatives over the years and in general has recognized the need to focus on prevention, early intervention, treatment and recovery services with local adaptation and incorporation of local cultures and traditions. SAMHSA established an Office of Tribal Affairs to serve as a primary point of contact that supports programs and activities for tribal communities, and coordinates a Tribal Technical Advisory Committee comprised of tribal leaders that provide input on how to design its programs to better meet the needs of AI/ANs (SAMHSA, 2017c).

SAMHSA grant programs such as the Circles of Care Program and the Systems of Care Program have helped increase access to behavioral health services for mental health, substance abuse and co-occurring disorders in the context of individuals, families and systems of support in tribal communities. Other programs at SAMHSA focus on prevention and early intervention strategies for AI/AN youth. The Garrett Lee Smith State/Tribal Youth Suicide Prevention Program helps promote public/private collaboration among youth serving institutions, and the new Tribal Behavioral Health Grant program helps prevent and reduce suicidal behavior and substance abuse as well as promote mental health among AI/AN youth (SAMHSA, 2017d).

SAMHSA established a Tribal Training and Technical Assistance Center to provide tribes and tribal organizations access to culturally relevant and evidence-based support to address mental health, substance abuse disorders, and suicide prevention. Many of the resources, including publications and videos, address the etiology of behavioral health conditions and strategies that have been adopted by other tribal communities, often with local cultural adaptation. The Center also includes information on evidence based practices that have been used successfully in tribal communities (SAMHSA, 2014a).
SAMHSA’s overall efforts to promote a trauma informed approach and integration of behavioral health into primary care are helping provide opportunities for programs to address diabetes and behavioral health comorbidities. In fact, one of SAMHSA’s Six Strategic Initiatives is focused on health care and health systems integration (SAMHSA, 2014b).

**Tribal Behavioral Health Agenda (TBHA).** As mentioned previously, SAMHSA released the TBHA in 2016 as a result of conversations with tribal leaders on the significant impact of behavioral health issues in their communities. The TBHA starts with a Cultural Wisdom Declaration that recognizes the important role of cultural wisdom and traditional practices in improving well-being. The TBHA highlights the extent to which behavioral health challenges impact tribal communities and offers a framework for strategies and priorities to improve the behavioral health of AI/ANs. The TBHA was meant to serve as a blueprint to encourage further collaboration on these issues (SAMHSA, 2016a).

**Best and Promising Practices.** In addition to federal efforts to address behavioral health comorbidities, other efforts to address these co-occurring conditions are resulting in better outcomes. For example, a recent review of the literature on integration of behavioral health into medical care in indigenous health care sites found many examples of programs that helped improve mental and physical health symptoms, reduce substance use, improve education and employment status, and decrease criminal justice system involvement. The most interesting finding was that interventions which added integration of culturally relevant health beliefs and practices has the greatest impact on outcomes (Lewis, 2017). These findings further support the TBHA Cultural Wisdom Declaration.

Despite the burden of diabetes and behavioral health comorbidity, there is evidence that American Indians have ways of adapting to these challenges. In one study, American Indians with type 2 diabetes were found to have high levels of “positive mental health,” which is defined to be a “syndrome of symptoms of positive feelings and positive functioning in life.” Overall 17.1 percent of individuals in this study met criteria for depression but 51.5 percent met criteria for “flourishing” positive mental health. In addition participation in traditional cultural activities was positively associated with positive mental health (Kading, 2015).

The Together on Diabetes program is an example of a family-based home-visiting program designed for AI youth at risk for type 2 diabetes that was developed with community-based participatory research and includes home-based lifestyle education, psychosocial support, community-based healthy living activities and referral care. The need for this intervention is significant; almost 40 percent of participants reported food insecurity in the past month, 17.1 percent screened positive for depression, and 68 percent reported no physical activity in the last 3 days (Chambers, 2015). At 12 months after enrollment in the Together on Diabetes Program, improvements were measured in depressive symptoms, knowledge, BMI scores, hypertension, and A1C levels in youth participants with diabetes (Kenney A, 2016).
Another study is focusing on diabetes prevention and the impact of addressing mental health concerns and psychosocial stressors by first developing culturally tailored strategies with community members. The study will enroll participants in a randomized controlled trial that compares a standard DPP intervention with an enhanced DPP program that uses culturally tailored strategies to address psychosocial barriers to implementing lifestyles changes to prevent diabetes. The target outcomes are reduced BMI and improved quality of life, and the trial is ongoing (Rosas, 2016).

In terms of designing interventions to address both behavioral health conditions and diabetes, a study of AI patient preferences found that some patients may prefer Native providers, biomedical and/or traditional services, and family member involvement in their care depending on certain personal characteristics such as living on a reservation or their participation in spiritual activities (Aronson, 2016). Further research is needed on how to deliver interventions to address behavioral health issues and diabetes for AI/AN patients who may have diverse characteristics and preferences. This is particularly important since few studies are available that focus on the emotional and behavioral issues for AI/AN individuals with diabetes (Scarton, 2017).

Addressing both diabetes and behavioral health issues in youth may be a way to prevent these conditions in the future. The National Congress of American Indians (NCAI), in partnership with the IHS, FirstPic, Inc., Nike, Inc. and the Boys & Girls Club of America (BGCA), developed the Together Raising Awareness for Indian Life (T.R.A.I.L.) curriculum entitled “On the T.R.A.I.L. to Diabetes Prevention” in 2003 which was designed to prevent the onset of diabetes in AI/AN youth. The curriculum includes 12 chapters to help promote healthy lifestyles changes in youth to help reduce the risk of diabetes in the future. Since 2003, the T.R.A.I.L. program have served approximately 13,000 AI/AN youth, ages 8-10, from 86 tribal communities (BGCA, 2018) (NCAI, 2015) (FirstPic, 2018). The curriculum chapters include content on promoting physical activity, demonstrating good nutrition, and encouraging self-respect and self-worth and connection to community. Recently, NCAI led development of a supplemental behavioral health curriculum at the request of Boys & Girls Club local staff to provide more curriculum content to help promote healthy behaviors, such as self-awareness, self-care, stress management, resiliency and goal setting.
Policy Recommendations

The burden of diabetes and behavioral health conditions in AI/ANs is significant, and their comorbidity adds to that burden for individuals, families and communities. While some efforts are increasingly directed towards addressing these comorbidities, more research, education, prevention, treatment, and resources are clearly needed. This review led to the generation of policy recommendations and a call to action for further efforts to relieve the burden of diabetes and behavioral health comorbidity in AI/ANs.

Continue to promote awareness of diabetes and behavioral health comorbidities. Support for additional efforts to raise awareness of diabetes and behavioral health comorbidities is needed to ensure that clinical practitioners, patients, families, community leaders, tribal leaders, government staff and Congress understand the impact of these conditions when they occur together in an individual and the need for further efforts. The TBHA was designed as a resource to help promote further action and collaboration on these issues and can be used to generate discussion and ideas for action.

Continue to support integration of behavioral health in primary care. Increased support for health system changes that encourage the close collaboration of primary care and behavioral health practitioners in the care of patients with diabetes is clearly needed given the evidence for the comorbidity of diabetes and behavioral health conditions. One condition cannot be treated without awareness and treatment for the other, especially for AI/AN patients, who may view their health and well-being in a holistic manner. Team based care efforts deserve further promotion and evaluation to ensure they are effective in reducing the burden of these conditions.

Support more research on diabetes and behavioral health comorbidities. More research is needed on the impact of diabetes and behavioral health comorbidities, including more information on the etiology of the co-occurrence of these conditions, including more work on possible protective factors, and more research on outcomes of prevention, treatment, recovery, and systems of support for patients, families and communities. Further research is needed on the impact of trauma and on best practices and solutions to reduce these impacts. More research is also needed on the outcomes and effectiveness of behavioral health integration into primary care.

Support more funding for programs to address diabetes and behavioral health comorbidities. Well intended providers cannot serve patients if they do not have the resources and support they need to address the needs of their patients with both diabetes and behavioral health conditions. While the IHS call for proposals for new funding towards behavioral health integration is a great first step, more funding is needed to support and encourage all IHS, tribal and urban Indian health programs to implement behavioral health integration into primary care. More resources for telemedicine efforts that help address the access to care needs of patients in rural and remote areas can help as well since telemedicine is particularly effective in mental health and substance use disorder treatment. Finally, long term funding for the SDPI is needed to help communities implement sustainable programs that have been proven to show successful outcomes as community and culturally driven programs.

Document, evaluate and promote more examples of promising and best practices. Indian health providers often request more examples of promising and best practices to improve their services. More support for education on how programs can document and evaluate their promising programs to help add to the evidence base for addressing these comorbidities is critical. There is also a need for more
efforts to disseminate and share information about best and promising practices. The success of the Diabetes in Indian Country Conference held by IHS in 2017 indicates there is significant need for venues where programs can network, share program strategies, and learn from each other.

**Encourage support for local and cultural adaptation and creation of promising and best practices.** Tribal leaders signed on to the TBHA Cultural Wisdom Declaration because they see how culture and traditions can be a part of the strategies to prevent and treat behavioral health conditions. Also, the SDPI demonstrated that local adaptation is essential to the success of prevention and treatment efforts in AI/AN communities. More funders must allow for local and cultural adaptation in grant programs, and accept that sometimes no evaluation or research will be allowed on cultural issues. More evaluation at the program level, rather than on specific activities, can help demonstrate impact without violating the right of tribes to protect their culture and traditions.

**Encourage more federal interagency work on diabetes and behavioral health comorbidities.** Tribes supported the development of the TBHA to help encourage more federal interagency collaboration on tribal issues, and this collaboration is especially needed with comorbid conditions. In many tribal communities according to traditional ways, physical, mental and spiritual health are not considered in isolation. More collaboration, less duplication of programs, and better coordination and streamlining of data requirements for program funding will help encourage more impact from programs. Funders should do more to ensure that tribes have more access to funding streams for these issues. And federal agencies must continue tribal consultation efforts, including the regular convening of established tribal advisory committees, so that tribes can help encourage cross agency collaboration on these issues.

**Encourage more federal, state, local collaborations on these issues.** More efforts to convene stakeholders at the local, regional and national levels are needed to review the impact of diabetes and behavioral health comorbidities and to create joint priorities for action. Collaboration can lead to a better understanding of the need, the scope of the problem and more effective solutions.

**Continue to advance and implement the TBHA.** The TBHA was developed to serve as a guide for action. It is now time for further efforts to advance the TBHA and implement its recommendations with all stakeholders that can help address the challenges of diabetes and behavioral health comorbidities. The TBHA lays out a number of areas where action can be taken to improve the lives of individuals, families and communities. It is now time to take action to address and reduce diabetes and behavioral health comorbidity.
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