The Adverse Health Outcomes, Economic Burden, and Public Health Implications of Unmanaged Attention Deficit Hyperactivity Disorder (ADHD): A Call to Action to Improve the Quality of Life and Life Expectancy of People with ADHD

Proceedings of the ADHD Public Health Summit Washington, DC October 7, 2019

Presented by CHADD – Children and Adults with Attention-Deficit / Hyperactivity Disorder¹

On October 7, 2019, a select group of invited participants from health care, public health, insurers, and other thought leaders gathered in Washington, DC for a one-day summit to discuss groundbreaking findings regarding ADHD and life expectancy, as well as the impact of ADHD on healthcare financing and public health. The purpose of the Summit was to bring together a select group of representatives to discuss the implications of this research as it pertains to current policies across these different communities. Specifically, the goal was to discuss polices that may need to be modified to recognize the impact of ADHD and to consider new interventions to address these health related risks.

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is currently recognized in official diagnostic manuals as a neurodevelopmental disorder comprising two interrelated sets of symptoms or neuropsychological deficits: inattention and hyperactivity-impulsivity.² The inattention is characterized by problems with distractibility, poor sustained attention and following through on instructions, poor listening to instructions, difficulties initiating work or other tasks, forgetfulness of what is to be done, and

¹ The Board of Directors at CHADD wishes to thank the Summit Steering Committee and the outside expert advisors: Russell A. Barkley, PhD, Louis, Matza, PhD, Peter Jensen, MD, Nina Schor, MD, PhD, Jeffrey Katz, PhD, Ingrid Alpern, JD, LLM, Eli Tomar, JD, Max Wiznitzer, MD, Heide Bajnrauh, Terri Johnson, Belynda Gauthier, April Gower-Getz, Kathleen Nadeau, PhD, Ari Tuckman, PsyD, David Keepnews, PhD, JD, RN, Ruth Hughes, PhD. and Robert Cattoi for their leadership with the ADHD Public Health Summit, October 7, 2019, Washington, DC and their contributions to this summation of that summit.

² *Diagnostic and Statistical Manual for Mental Disorders* published by the American Psychiatric Association, Washington, DC: 2013.

poor organization of materials needed for work, among other problems. The hyperactive symptoms comprise excessive movement and speech, restlessness and fidgeting in situations requiring restraint, excessive running or climbing, difficulties remaining seated as required, and other problems. Linked to these problems with regulating activity level to situational demands are problems with impulsive behavior, interrupting or intruding on others' interactions or activities, and blurting out comments at inappropriate times. Though not usually mentioned in official descriptions of diagnostic symptoms, people with ADHD have problems with waiting or being patient, taking turns, and thinking before they act; they're easily frustrated, emotionally impulsive, and gravitate toward activities offering immediate rewards as opposed to delaying gratification. These symptoms often arise early in childhood, although less often they can emerge later in adolescence (and often go undiagnosed until adulthood). They occur across several situations or contexts, are developmentally inappropriate, and lead to harm, suffering, or other forms of impairment as reflected in ineffective functioning in major life activities (home, community, school, social, occupation, etc.) and in greater adverse consequences. Affecting approximately 5-8% of children and 3-5% of adults, conservatively estimated,³ ADHD is known to arise from various genetic and neurological sources, though these can be influenced by interactions with hazards in the environment that lead to neurological damage or maldevelopment, especially during prenatal development.⁴ Over 80% of children and adults with ADHD are likely to have a second psychiatric, learning, or developmental disorder and more than 50% have two or more such disorders, such as oppositional defiant disorder, learning disabilities, conduct disorder, anxiety disorders, depression, and to a much lesser extent autism spectrum disorder and bipolar disorder.⁵ The presentation of ADHD is often different in females. Females typically experience internalizing disorders such as anxiety and depression and much more rarely exhibit externalizing disorders such as oppositional-defiant disorder. Research indicates a greater risk of suicidal behavior in girls.⁶ Hormonal issues that begin with puberty may result in more extreme reactions. As such, young girls with ADHD are often overlooked by primary care providers.

Although considered a medical disorder when initially described in the first medical textbook published in Germany by Weikard in 1775,⁷ for much of the past

³Willcutt, E. G. (2012). The prevalence of DSM-IV Attention-Deficit/Hyperactivity Disorder: A meta-Analysis Review. *Neurotherapeutics*, *9*, 490-499.

⁴ Faraone, S. C., Asherson, P., Banaschewski, T., Biederman, J., Buitelaar, J. K., Ramos-Quiroga, J. A. et al. (2015). Attention-deficit/hyperactivity disorder. *Nature Reviews (Disease Primers), 1*, 1-23.

⁵ Pliszka, S. R. (2015). Comorbid psychiatric disorders in children with ADHD. In R. A. Barkley (ed.) *Attention deficit hyperactivity disorder: A handbook for diagnosis and treatment (4th Ed)*(pp. 140-168). New York, NY: Guilford Press.

⁶ Chronis-Tuscano A; Molina BS; Pelham WE; Applegate B; Dahlke A; Overmyer M; Lahey BB Arch Gen Psychiatry. 2010; 67(10):1044-51

⁷ Weikard, M. A. (1775). Drittes Hauptstück Mangel der Aufmerksamkeit Attentio volubilis in Der *Philosophische Artzt (pp. 114-119)*. Frankfurt, Germany: Zmenter Band. See Barkley, R. A., & Peters, H. (2012). The earliest reference to ADHD in the medical literature? Melchior Adam Weikard's description

century, ADHD and its precursor labels (brain injured child syndrome, minimal brain dysfunction, hyperkinetic reaction of childhood, hyperactive child syndrome, attention deficit disorder, etc.), had been understood to be principally a psychiatric disorder. More recently within that field it is now viewed as a neurodevelopmental disorder.⁸

Largely starting in the 1970s and over the next 25 years, the impact of the disorder was broadened to consider it as a condition having not only an adverse influence on the individual, but also on a person's social functioning (family and peer relationships). Simultaneously it was also seen as a disorder negatively affecting learning and educational adjustment more generally. Kuriyan et. al.9 reported that individuals with ADHD are also less likely to hold undergraduate and graduate degrees than people without the disorder. And that between 32% and 35% of ADHD teens will drop out of school before graduation, compared to only 15% of teens who don't have a psychiatric disorder. Such findings concerning impaired functioning led not only to the creation of parent support groups, parent training interventions, and social skills programs, but also to the eventual recognition of ADHD under the Individuals with Disabilities in Education Act as well as Section 504 of the Rehabilitation Act of 1973 and commensurate entitlements, protections, and special educational services within the public schools.¹⁰ A somewhat later, parallel, and distinct path of understanding the mental health and sociological impact of ADHD occurred as a result of numerous studies on the role of ADHD in the development and maintenance of antisocial, aggressive, violent, and unlawful behavior. While ADHD can precede and be associated with aggressive behavior in childhood, its role in antisocial activities certainly increases in the adolescent and young adult years, where it is found to coexist with chronic antisocial activities. Thus, ADHD became recognized (in a minority of cases) as a possible precursor to delinguency, conduct disorder, antisocial personality disorder, substance use and abuse disorders, and therefore, as a disorder creating higher risks for arrest and imprisonment. And so it came to be viewed as an important factor within the criminal justice systems in understanding predispositions to adolescent and adult legal offending.¹¹ To summarize, over the last two or more centuries, ADHD has gone from being a viewed as a specific medical malady to a psychiatric syndrome which is understood to be a disorder with familial, social, and educational

in 1775 of "Attention Deficit" (Mangel der Aufmerksamkeit, attentio volubilis). *Journal of Attention Disorders, 16,* 623-630.

⁸ See the last four editions of the *Diagnostic and Statistical Manual for Mental Disorders* published by the American Psychiatric Association, Washington, DC: 1967, 1980, 1987, 1994, 2013.

⁹ Aparajita B. Kuriyan, William E. Pelham, Jr., Brooke S. G. Molina, Daniel A. Waschbusch, Elizabeth M. Gnagy, Margaret H. Sibley, Dara E. Babinski, Christine Walther, JeeWon Cheong, Jihnhee Yu, and Kristine M. Kent J Abnorm Child Psychol. 2013 Jan; 41(1): 27–41.

¹⁰ Barkley, R. A. (2015). History. In *Attention Deficit Hyperactivity Disorder: A Handbook for Diagnosis and Treatment (4th Ed.)*. New York: Guilford Publications.

¹¹ Mohr-Jensen, C., & Steinhausen, H. C. (2016). A meta-analysis and systematic review of the risks associated with childhood attention-deficit hyperactivity disorder on long-term outcome of arrests, convictions, and incarcerations. *Clinical Psychology Review, 48,* 32-42.

impairments and, possibly, a disorder that creates a higher risk of entering the criminal justice system.

Adverse Health Correlates and Consequences of ADHD

Although hints of such began emerging in the 1960s, it has really been during the last 10-15 years that substantial evidence has begun to accrue on the adverse health correlates and consequences of ADHD. More than 50 years ago, researchers found that parents of children with ADHD were 2-10 times more likely to describe their children as having been in poor health during infancy or early childhood.¹² More recently, children with ADHD followed to adulthood as well as self-referred adults with ADHD seen in clinics were found to report having significantly more general health complaints or somatic symptoms than do typical people, such as headaches, stomachaches, fatigue, or other vague bodily symptoms.¹³

Specifically, research studies¹⁴ have documented a greater occurrence of:

- Upper respiratory infections (39-44%), asthma (22% or 2x greater risk), otitis media, allergies such as rhinitis, and skin disorders like eczema or acne (2.5x greater risk) in children with ADHD.
- *Nonspecific lung, cardiovascular, and other chronic diseases* in adults with ADHD.
- Poorer dental hygiene and greater risk for diseased, missing, filed, or traumatically injured teeth, gum disease, and bruxism in children with ADHD. For instance, the risk for oral trauma alone is 5x greater than in typical children.
- *Greater substance use, misuse, dependence, and abuse* such that 20-30% of teens and adults with ADHD may qualify for a substance dependence or abuse disorder. ADHD has been specifically linked to excess use of alcohol by adulthood, tobacco use in adolescence and adulthood, and marijuana use by adulthood. Teens and adults with ADHD are 2-3 times more likely to use tobacco than typical peers. If comorbid with conduct or antisocial personality disorder, those with ADHD are also predisposed to abuse of cocaine, meth, heroin, or illegal use of prescription drugs.
- *Obesity*: Although not evident in studies done 30-50 years ago, within the past 10 years, numerous studies have found that teens and adults with ADHD are more likely to be overweight and 1.5-3x more likely to qualify as obese

¹² Stewart, M.A., Pitts, F. N., & Craig, A. G. (1966). The hyperactive child syndrome. *American Journal of Orthopsychiatry, 36,* 861-867. Stewart, M. A. et al. (1970). Accidental poisoning and the hyperactive child syndrome. *Diseases of the Nervous System, 31,* 403-407.

¹³ Barkley, R. A., Murphy, K. R., & Fischer, M. (2008). *ADHD in adults: What the sciences says.* New York: Guilford Press. See also Brook, S. J. et al. (2012). Adolescent ADHD and adult ophysical and mental health, work, and financial stress. *Pediatrics*.

¹⁴ Barkley, R. A. (2015). Health problems and related impairments in children and adults with ADHD. In R. A. Barkley (ed.) *Attention deficit hyperactivity disorder: A handbook for diagnosis and treatment (4th Ed)*(pp. 267-313). New York, NY: Guilford Press.

with several studies showing up to 41% as being obese. Longitudinal studies find that this risk, while small in childhood, increases over development. This more recent evidence of obesity being linked to ADHD likely reflects the greater availability of junk food to more recent generations than was available in earlier decades.

- *Eating pathology*: Females with ADHD, especially in late adolescence, are 3.6 times more likely (than females without ADHD) to suffer from eating pathology, specifically impulsive eating and binge eating, and 5.6x more likely to have bulimia, such that 15-20% qualify for a diagnosis of an eating disorder.
- *Enuresis* (2-5x) and *encopresis* (5x) in children with ADHD than typically developing children.
- Seizure disorders (2.5-4x) in children with ADHD.
- *Sleeping problems* (52-64%) in ADHD as compared to typical children (21-27%), including insomnia, frequent night waking, noisy sleep and breathing difficulties while sleeping (such as snoring, sleep apnea or airflow obstruction), restless sleeping and even restless leg syndrome, inefficient sleep, early waking, and consequently greater daytime sleepiness and inattention. Though less well studied, several studies found adults with ADHD to be more likely to experience these same sorts of sleeping difficulties.
- Excessive internet use and addiction, and gaming addiction (34%).
- Accidental injuries of all types (wounds/lacerations, broken bones, burns, poisonings, closed head trauma, etc.) in children with ADHD: Probably the most well investigated health risk arising as a consequence of ADHD is the 1.5-3x greater likelihood of accidental injury as well as repeated such injuries, with such findings dating back nearly 50 years in the scientific literature on ADHD. This risk for injury in children and youth with ADHD extends now into pedestrian-automobile accidents, cyclist-auto accidents, vehicular driving accidents, as well as accidents during motor sports participation. More recently, adults with ADHD have been shown to have significantly elevated risks for injury and repeated injury as well.
- *Exposure to traumatic events and victimization*, with figures as high as 62% for children with ADHD and 91% for those with comorbid oppositional defiant disorder, with rates of physical abuse estimated to be 3x greater (14.3% vs. 4.5% of typical children).
- Risky sexual behavior, earlier age at first sexual intercourse, greater number of sex partners, 4x risk for sexually transmitted disease, and 8-10x risk for teenage pregnancy.
- *Suicide attempts and completions* (3-5x risk): Research to date demonstrates that while comorbid depression with ADHD is the best predictor of suicidal thoughts in adolescence (36% ADHD vs. 22% typical teens), it is the impulsivity linked to ADHD that is the better predictor of attempts and completions, with ADHD teens being 5x more likely to attempt suicide than typical teens if they had considered it (16% vs. 3%). Though less well

studied, the few studies of adults with ADHD likewise show an elevated risk for suicide attempts and completions.

- *Poorer nutrition*, greater consumption of sugars and carbohydrates.
- Greater sedentary lifestyle, less physical exercise.
- *Type II diabetes*: As a correlate of their greater rates of obesity, poorer diets, and limited exercise, teens and adults with ADHD are 2.8-3.3x more likely to develop Type 2 Diabetes.¹⁵
- *Coronary heart disease*: As a result of the factors cited just above along with their greater penchant for substance use and abuse, some evidence now suggests that those with ADHD may also manifest a significantly greater risk for future coronary heart disease as early as age 27¹¹ and double the risk for dementia in later life¹⁶

Importantly, all of the research that has been examined has found that those people who are more likely to experience these various adverse health outcomes are significantly more likely to qualify for a diagnosis of ADHD than would be expected for the base rate prevalence of the disorder in the population. Hence, the effects here are bidirectional. People with ADHD are more likely to experience such adverse health correlates and consequences and those having these adverse health events are significantly more likely to have ADHD. This illustrates that ADHD should not just be a concern of professionals working in the field of mental health, but should also be a significant and widespread focus of professionals working in primary care and public health where these adverse health outcomes are likely to be evaluated and treated.

Greater Risk for Earlier Mortality and Reduced Life Expectancy in ADHD

Each of these findings of adverse health conditions linked to ADHD is significant and serious in its own right. But when considered in their totality, as well as the fact that such risks interact and are cumulative over the lifespan, it is logical to infer that ADHD will be associated with a high risk for early mortality in childhood or by midlife and eventually, should they survive into later life, a shortened life expectancy. But evidence of such was lacking until the past decade, when both longitudinal studies of children with ADHD followed into midlife and population-wide epidemiological studies began to report such results. For instance:

¹⁵ Chen, J. J. et al. (2013). Association of attention-deficit/hyperactivity disorder with diabetes: a population-based study. Pediatric Research, 73, 492-496. Also Chen, M. H et al. (2018). Risk of Type 2 diabetes in adolescents and young adults with attention-deficit/hyperactivity disorder: A nationwide longitudinal study. Journal of Clinical Psychiatry, 79(3), 17m11607.

¹⁶ Goodwin, R. D. et al. (2009). Do mental health problems in childhood predict chronic physical conditions among males in early adulthood? Evidence from a community based prospective study. *Psychological Medicine, 39(2), 301-311.*

- in 2012, Rachel Klein, Salvatore Mannuza, and colleagues, who have conducted the longest follow-up study of ADHD children into midlife, found that twice as many had died by age 41 as in their control group (7.2% vs. 2.8%).¹⁷ But the sample sizes in such studies of clinic-referred children are inadequate to detect such differences as being significant with any degree of statistical power.
- Even so, such findings have now been confirmed in multiple epidemiological studies of populations in the United States,¹⁸ Denmark,¹⁹ Sweden,²⁰,²¹ and Taiwan.²² These studies show that
 - o children with ADHD are nearly twice as likely to die in childhood and
 - *adults with ADHD are 3 to nearly 5 times more likely to die in adulthood by midlife* compared to typical people.
 - Indeed, during any 4-year period, adults with ADHD in the US are almost twice as likely to die than typical adults.

The greatest cause of early mortality in these studies is accidental injury. But death by suicide is also a significant factor although in a far lower percentage of cases. And the Taiwanese study found that death from homicide was twice as likely than in typical peers.

• This risk of dying younger than usual was also found in the genome-wide study of ADHD genetics and its relationship to medical and psychological factors in affected patients and families where the parents of people with ADHD also were more likely to experience earlier mortality.²³

These studies do not address, however, the cumulative risk of chronically engaging in adverse health and lifestyle activities that can reduce life expectancy after midlife. They only address the risk of early mortality by midlife, which of course would be more related to accidental injury and suicide than to chronically engaging in poor health-related behaviors and lifestyles. However, in 2019, Barkley

¹⁷ Klein, R. G., Mannuzza, S., Olazagasti, M. A. R., Roizen, E., Hutchinson, J. A., Lashua, E. C., & Castellanos, X. (2012). Clinical and functional outcome of childhood attention-deficit/hyperactivity disorder 33 years later. *Archives of General Psychiatry*, *69*, 1295-1303.

¹⁸ London, A. W. & Landes. S. D. (2016). Attention deficit hyperactivity disorder and adult mortality. *Preventive Medicine*, *90*, 8-10.

¹⁹ Dalsgaard, S., Ostergaard, S. D., Leckman, J. F., Mortensen, P. B., & Pedersen, M. G. (2015). Mortality in children, adolescents and adults with attention deficit hyperactivity disorder: a nationwide cohort study. *Lancet*, *385*, 2190-2196.

²⁰ Virtanen, M. et al. (2018). Work disability and mortality in early onset neuropsychiatric and behavioural disorders in Sweden. *European Journal of Public health, 28,* 32.

²¹ Sun, S. et al. (2019). Association of psychiatric comorbidity with the risk of premature death among children and adults with attention-deficit hyperactivity disorder. *JAMA Psychiatry*. Epub ahead of print.

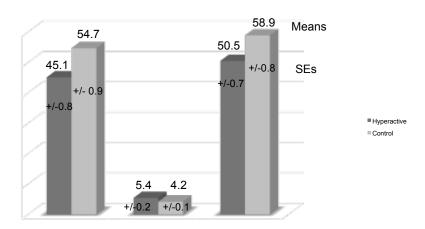
²² Chen, V.C.H., et al. (2019). Attention-deficit/hyperactivity disorder and mortality risk in Taiwan. *JAMA Network*. Epub ahead of print.

²³ Demontis, D. et al. (2018). Discovery of the first genome-wide significant risk loci for attention deficit/hyperactivity disorder. *Nature Genetics*. Epub ahead of print.

and Fischer²⁴ used the findings from their Milwaukee longitudinal study to examine the possibility of reduced life expectancy in their ADHD and control children at their young adult follow-up (mean age 27 years). They did so by entering 14 variables related to disability, health, and lifestyle into a recently available estimated life expectancy (ELE) calculator provided by the University of Connecticut Goldenson Center for Actuarial Research. Their study found that:

- cases having hyperactive child syndrome, or ADHD-Combined presentation (ADHD-C), in childhood manifested *a 9.6-year reduction in estimated healthy life expectancy* in remaining years, a 1.2-year period of greater unhealthy life expectancy in remaining years, and an overall 8.4-year reduction in total life expectancy than did control children by young adulthood (see Figure 1).
- Moreover, the persistence of ADHD to adult follow-up was associated with an even worse impact on these ELE measures, with *a 12.7-year reduction in healthy life expectancy* and an 11.1-year reduction in total ELE than was seen in control cases (See Figure 2). Persistent cases had a 5.3-year reduction in healthy life expectancy and a 4.6-year reduction in total ELE than nonpersistent ADHD-C cases. And both persistent and nonpersistent ADHD cases had significantly lower ELE by adulthood than did control cases.

This is the first study to compute estimated remaining years of life expectancy by adulthood in children with ADHD-C and to compare persistent and nonpersistent ADHD cases on these ELE parameters.



Estimated Life Expectancy (yrs. Left) Hyperactive (ADHD-C) Children vs. Controls

Figure 1. From Barkley, R. A. & Fischer, M. (2019). *Hyperactive child syndrome and estimated life* expectancy at young adult follow-up: The role of adult ADHD and other potential predictors. *Journal of Attention Disorders*, 23, 907-923.

²⁴ Barkley, R. A. & Fischer, M. (2019). Hyperactive child syndrome and estimated life expectancy at young adult follow-up: The role of ADHD persistence and other potential predictors. *Journal of Attention Disorders, 23,* 907-923.

Why is ADHD so dramatically associated with reduced life expectancy? Because ADHD has been found to predispose individuals to engage in a number of adverse health and lifestyle activities. Indeed, the Barkley and Fischer study found that those with ADHD engaged significantly more often in 8 of the 14 risk factors they used to estimate years of remaining life. For instance, they noted that the disorder reduced ELE through its association with not only the demographic factors of reduced education, lack of high school graduation, and lower annual income in the ADHD-C groups but also in the health and lifestyle factors of greater alcohol consumption, poorer overall health, reduced sleep, increased likelihood of smoking and of smoking more than 20+ cigarettes per day, and possibly greater adverse driving consequences resulting in license suspensions and revocations.

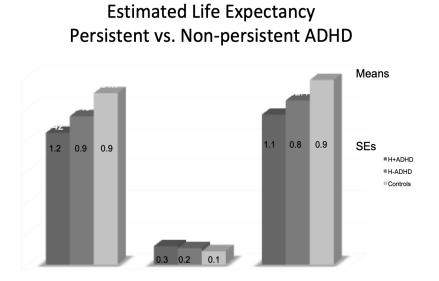


Figure 2. . From Barkley, R. A. & Fischer, M. (2019). *Hyperactive child syndrome and estimated life expectancy at young adult follow-up: The role of adult ADHD and other potential predictors. Journal of Attention Disorders, 23, 907-923.*

The magnitude of such reductions in life expectancy can be best appreciated by placing them in context with other adverse health conditions. Such reductions are far greater than those associated with smoking, obesity, alcohol use, high cholesterol, and high blood pressure either individually or combined! For instance, obesity is associated with a -4.2 year reduce in life expectancy,²⁵ or -7 months per unit of BMI overweight,²⁶ smoking 20+ cigarettes per day with approximately -6.8 years,²⁴ excessive alcohol use with -2 years in men and -0.4 years in women,²⁷ substance use

²⁶ Joshi, P. K., Pirastu, N., Kentistou, K. A., Fischer, K., Hofer, E., Schraut, K. E. et al. (2017). Genomewide meta-analysis associates HLA-DQA1/DRB1 and LPA and lifestyle factors with human longevity. *Nature Communications*. Epub ahead of print: DOI: 10.1038/s41467-017-00934-5.

²⁵ Fekri, N. et al. (2019). Association of body mass index with life expectancy with and without cardiovascular disease. *International Journal of Obesity.* Epub ahead of print.

²⁷ Makela, P. (1998). Alcohol related mortality by age and sex and its impact on life expectancy: Estimates based on the Finnish death register. *European Journal of Public health*, *8*(1), 43-51.

disorder with 10 years,²⁸ elevated blood pressure with -5.2 years, for every year of education after high school was +11 months.²⁴ Thus, ADHD has a more adverse effect on life expectancy than any single adverse health event noted above, and on which insurers, governments, and individuals spend billions of dollars to reduce those risks.

This finding concerning the impact of ADHD on shortening life expectancy is quite consistent with research on life expectancy associated with a failure to engage in at least 5 well-known health improvement practices. Li and colleagues (2019)²⁹ used the ongoing longitudinal study of 120,000 people in the nurses health study and divided them into those who engaged in five well-known health maintenance practices or not. These practices were: (1) nonsmoking, (2) moderate exercise (30+ min. per day), (3) maintaining a body mass index below 25, (4) engaging in moderate alcohol intake, and (5) adopting a high quality diet (low in fats, red meat, carbs, and sugar). Those who engaged in all five practices had a life expectancy 12-14 years greater than those who did not. As shown above, people with ADHD are far less likely to engage in these health maintenance practices and thus would be expected to have this much reduction in their life expectancy - precisely what the Barkley and Fischer study found.

Just as important was the finding by Barkley and Fischer that, beyond these first order or more proximal factors that were adversely affecting life expectancy, the background trait of behavioral disinhibition (linked to greater ADHD symptoms or low conscientiousness) explained more than 30% of the variance in life expectancy in their samples, consistent with the findings noted previously by many others concerning the role of low conscientiousness in reducing lifespan.³⁰ Behavioral inhibition is one of the major executive functions that is routinely deficient in ADHD. In other words, it is ADHD and its underlying executive function deficits [especially its dimension of high impulsivity or disinhibition] that is accounting for the predisposition to routinely engage in these various adverse health related activities and so to predispose toward a shorter life expectancy. Failing to appreciate this substantial second order background factor of ADHD and particularly related disinhibition could easily lead to both (a) overlooking its role not only in contributing to poor health-related behavior but also (b) understanding why certain individuals may have such limited success with adhering to recommendations for health improvement activities intended to lessen those first order risk factors. Thus, professionals must identify and address the second order background risk being posed by ADHD and especially behavioral disinhibition when dealing with patients who experience the first order health risks.

²⁸ Chesney, E. et al. (2014). Risks for all-cause and suicide mortality in mental disorders: a metareview. *World Psychiatry*, *13*, 153-160.

²⁹ Li et al. (2018). *Circulation*, 138, 345-355.

³⁰ Hampson, S. E. (2008). Mechanisms by which childhood personality traits influence adult well-being. *Current Directions in Psychological Science*, *17*, 264-268. Friedman, H. S., Tucker, J. S., Schwartz, J. E., Tomlinson-Keasey, C., Martin, L. R., Wingard, D. L., & Criqui, M. H. (1995). Psychosocial and behavioral predictors of longevity: The aging and death of the "Termites." *American Psychologist*, *50*, 69–78.

The evidence to date is more than sufficient to justify alarm at the substantial adverse impact ADHD poses for long-term quality of life and reduced life expectancy, as well as the call to action posed in this white paper report. But that call to action is made all the more compelling when one considers the economic costs and burden that ADHD poses to affected individuals, their families, employers, insurers, government public health agencies, and society at large.

The Economic Costs Associated with ADHD

There are about 29 relevant studies on the economic costs associated directly or indirectly with ADHD, each one focusing on a very narrow aspect of the issue.³¹ In sum, research shows that ADHD poses a considerable cost to families, insurers, government health care providers, and society more generally. These specific findings can be summarized as follows:

Direct Costs of ADHD - Medical Care

- Incremental costs of \$949³² to \$1,220³³ per ADHD child per year over that for typical children, extrapolated to a minimum of \$3.92 billion in US child population; found to be \$885 incremental costs in euros per child with ADHD per year in the Netherlands (vs. children with behavioral problems) and \$996 euros (vs. control children).³⁴
- Incremental costs over 9-year period were \$3,378, for children with ADHD in the US being more than double those for children without ADHD (\$6,158 vs. 2,780)³⁵
- Incremental costs per year for adolescents with ADHD were \$1,447 per adolescent in the US.²⁶
- Total medical costs in Australia over a 6-year follow-up period for children with ADHD were estimated to be \$25-30 million (AUS dollars).³⁶

³¹ Matza, L. S. & Howell, T. (2019) *A review of the economic burden of ADHD*. Invited presentation at the CHADD Summit on Health Outcomes, Life Expectancy, and Economic Costs of ADHD. Washington, DC, October 7, 2019.

³² Gupte-Singh K, Singh RR, Lawson KA. Economic Burden of Attention-Deficit/Hyperactivity Disorder among Pediatric Patients in the United States. *Value Health.* Apr 2017;20(4):602-609.

³³ Swensen AR, Birnbaum HG, Secnik K, Marynchenko M, Greenberg P, Claxton A. Attentiondeficit/hyperactivity disorder: increased costs for patients and their families. *J Am Acad Child Adolesc Psychiatry.* Dec 2003;42(12):1415-1423.

³⁴ Hakkaart-van Roijen L, Zwirs BW, Bouwmans C, et al. Societal costs and quality of life of children suffering from attention deficient hyperactivity disorder (ADHD). *Eur Child Adolesc Psychiatry.* Aug 2007;16(5):316-326.

³⁵ Leibson CL, Katusic SK, Barbaresi WJ, Ransom J, O'Brien PC. Use and costs of medical care for children and adolescents with and without attention-deficit/hyperactivity disorder. *JAMA*. 2001;285(1):60-66.

³⁶ Sciberras, E. et al. (2013). Health care costs associated with parent reported ADHD: A longitudinal Australian Population-Based Study. *Journal of Attention Disorders*. Epub ahead of print.

 Incremental costs for adults with ADHD per adult per year were estimated to be \$2,880³⁷ to \$3,456 in US.³¹

Indirect Costs

Burden to Families

- A recent study by Zhao and colleagues³⁸ estimated the burden to families of raising a child with ADHD over a 12-year period to be 5 times the total financial burden evident in control families (\$15,036 vs. \$2,848), which is \$1,000 per year more for raising the child with ADHD than was borne by the families of control children. While these costs for families having ADHD children included those connected to behavioral and educational problems, they did not include the costs of direct treatment with medication or other forms of therapy. Also included were costs associated with accidents, injuries, legal involvement, and discipline. Indirect costs were incorporated that reflected loss of parental income related to missing work, loss of a job, additional childcare expenses, and parental mental health concerns. Though not computed in dollar terms, parents of children with ADHD reported being more tired, stressed, less able to concentrate at work, and needing to reduce their work hours to deal with their child's problems (20% vs. 3% for controls).
- Altszuler et al. (2016)³⁹ also reported an increased burden on parents of a young adult with ADHD as a consequence of being more likely to provide funds for living expenses, 20% more likely to provide emergency funds, and more likely to have a child move back home after attempting to live independently. Another study found incremental indirect costs to be \$337 per child with ADHD related to disability and absenteeism.³¹ Criminality
- Incremental costs per child with ADHD over a 13-15 year interval of follow-up were estimated to be \$12,370 inclusive of victim and criminal justice system costs.⁴⁰
- Other research shows the total victim costs associated with child and adolescent ADHD to be \$50-70 million dollars per year in the US population and total criminal system related costs to be \$2-4 billion annually.⁴¹ Work Loss

⁴⁰ Swensen AR, Secnik K, Buesching DP, Barkley RA, Fischer M, Fletcher K. Young adult outcome of childhood ADHD: Cost of criminal behavior. Paper presented at: Poster presented at the American Academy of Child and Adolescent Psychiatry (AACAP); October 23-28, 2001; Honolulu, HI.
⁴¹ Fletcher, J. & Wolfe, B. (2009). Long-term consequences of childhood ADHD o n criminal activities. *Journal of Mental Health Policy and Economics*, *12(3)*, 119-138.

³⁷ Secnik K, Swensen AR, Lage MJ. Comorbidities and costs of adult patients diagnosed with Attention-Deficit Hyperactivity Disorder. *Pharmacoeconomics*. 2005;23(1):93-102.

³⁸ Zhao et al. (2019). *Journal of Abnormal Child Psychology*, 47, 1327-1338.

³⁹ Altszuler AR, Page TF, Gnagy EM, et al. Financial Dependence of Young Adults with Childhood ADHD. *J Abnorm Child Psychol.* Aug 2016;44(6):1217-1229.

- Adults with ADHD earn \$543,000 to \$616,000 less income over their lifetime than do typical adults, or about 25% less per month.³²
- In the Netherlands, reduced work productivity for mothers associated with ADHD in their child is estimated to be \$2,243 compared to just \$408-647 Euros for mothers of typical children or those with behavioral problems.²⁷
- Studies show that significantly fewer children with ADHD followed to adulthood complete high school and fewer still are employed on reaching young adulthood (24% vs. 59%), with average household incomes being approximately \$10,000 less per year than in control cases followed at the same time.⁴²
- Employees with ADHD cost employer health plans \$2,643 more than typical employees per employee per year and an economic loss of \$4,336 per worker with ADHD.⁴³

Educational Costs

- Annual costs to school systems for each ADHD student are \$4,689 per year more than costs for typical students including costs for special education, grade retention, disciplinary actions, and total additional staff time.⁴⁴
- Preschoolers with ADHD cost 2-6 times more per student than those without ADHD, with an average cost of \$16,548 per student totaling to \$16-48 million overall for preschool care.⁴⁵ Driving
- Research demonstrates that teens and adults with ADHD receive significantly more traffic citations, are more likely to speed with a motor vehicle, and have 2-3 times the frequency of car crashes than do typical peers. Incremental costs per crash were estimated to be \$2,600 per incident multiplied by an average of 3 incidents and applied to 5% of the US population estimated to have ADHD results in total costs for crashes alone as being 93.6 billion.⁴⁶

Total Direct and Indirect Costs

At least four studies have attempted to compute the total economic costs of ADHD in the US. The earliest of these followed a large sample of children with ADHD and those with comorbid conduct disorder (CD) to late adolescence. It estimated the costs for mental health, school services, and the juvenile justice system to be

⁴² Biederman J, Faraone SV. The effects of attention-deficit/hyperactivity disorder on employment and household income. *MedGenMed.* Jul 18 2006;8(3):12. See also Barkley, R. A. et al. (2008). *ADHD in Adults: What thet Science Says.* New York: Guilford Publications.

⁴³ Kessler RC, Lane M, Stang PE, Van Brunt DL. The prevalence and workplace costs of adult attention deficit hyperactivity disorder in a large manufacturing firm. *Psychol Med.* Jan 2009;39(1):137-147.

⁴⁴ Robb JA, Sibley MH, Pelham WE, Jr., et al. The Estimated Annual Cost of ADHD to the U.S. Education System. *School Ment Health.* Sep 1 2011;3(3):169-177.

⁴⁵ Marks DJ, Mlodnicka A, Bernstein M, Chacko A, Rose S, Halperin JM. Profiles of service utilization and the resultant economic impact in preschoolers with attention deficit/hyperactivity disorder. *J Pediatr Psychol.* Jul 2009;34(6):681-689.

⁴⁶ Barkley, R. A. & Cox, D. (2007). A review of driving risks and impairments associated with attentiondeficit/hyperactivity disorder and the effects of stimulant medication on driving performance. *J. Safety Research, 38*, 1113-128.

\$40,000 per child with ADHD and \$80,000 per child if they also had comorbid CD.⁴⁷ A more recent review of all economic research on ADHD as of 2012⁴⁸ placed the overall national annual incremental costs of ADHD in the range of \$143 to \$266 billion. Breaking down the costs for children only showed a range of \$38-72 billion while that for adults was \$105-194 billion. The largest cost for adults was lost productivity and income from work (\$87-\$138), while that for children was primarily health care (\$21-\$44 billion) followed by educational services (\$15-\$25 billion). The indirect costs to families was estimated nationally to be \$33-\$44 billion). And Daley and colleagues (2019)⁴⁹ estimated that an adult with ADHD costs \$20,000 more per year than an unaffected sibling in terms of health care costs, disability claims, and state services. Research in Israel⁵⁰ likewise has placed the cost of each ADHD case to be nearly \$290,000 USD resulting from less education, more car crashes, and a greater incidence of drug abuse. Given that the cost of treatment is \$41,667 per case this results in a benefit:cost ratio of 7:1, suggesting that society can reap up to a sevenfold reduction in the costs associated with ADHD through appropriate treatment. Earlier research in the US placed the cost of treatment costs for ADHD as being \$1.8 billion per year with total health care costs of \$12.1 billion per year, and \$14.1 billion for health care costs of family members, with work loss estimated to be \$3.7 billion per year.⁵¹

Although not included in the above, research further demonstrates that young adults with ADHD are 8 times more likely to be receiving some form of government assistance than control children followed to adulthood contemporaneously.³²

Thus, research to date clearly demonstrates that ADHD poses a substantial economic impact in the United States besides the adverse health outcomes, increased early mortality risk, and reduced life expectancy discussed above. Furthermore, at least two studies have found that treating ADHD with medication can reduce its economic costs by \$15,509 to \$27,766 per person per quality adjusted life year (QALY).⁵²

The Neglect of ADHD in Primary Health Care

⁴⁷ Jones, D. E. et al. (2008). Service use patterns for adolescents with ADHD and comorbid conduct disorder. *Journal of Behavioral Health Services and Research*, *36(4)*, 436-449.

⁴⁸ Doshi, J. A. et al. (2012). Economic impact of childhood and adult attention-deficit/hyperactivity disorder in the United States. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51 (10), 990-1002.

⁴⁹ Daley, D. et al. (2019) *European Psychiatry, 61, 41-48.*

⁵⁰ Ornoy, A., & Spivak, A. (2019). Health Economics Review, 9(1), 24.

⁵¹ Birbaum, H. G. et al. (2006). *Current Medical Research and Opinions, 21 (2)*, P.1-P11.

⁵² Gilmore A, Milne R. Methylphenidate in children with hyperactivity: review and cost-utility analysis. *Pharmacoepidemiol Drug Saf.* Mar-Apr 2001;10(2):85-94. See also Lord J, Paisley S. *The Clinical Effectiveness and Cost-Effectiveness of Methylphenidate for Hyperactivity in Childhood,* Version 2. London: National Institute for Clinical Excellence; 2000.

In view of the above findings, one would think that ADHD would be more likely to be identified and treated by primary care professionals than other mental health disorders they commonly assess and treat, such as anxiety and depression. Yet the opposite is the case. One national survey has shown that only 1 in 10 adults with ADHD ever receives an evaluation or treatment specifically for their disorder and only 1 in 4 ever receives treatment for any mental health problems.⁵³ The reasons for this profound gap in services likely have many causes, but we focus here on four major contributors to the gap in awareness among health care providers of the need for diagnosis and treatment of adults with ADHD.

First, in the US -- unlike Canada,⁵⁴ Europe,⁵⁵ the UK,^{56,57} and Germany,⁵⁸ there are no US-based nationally recognized and broadly endorsed consensus- or evidence-based recommendations targeted to the key health professionals most likely to offer such diagnoses and treatment: US adult psychiatrists, primary care providers, and adult-oriented psychotherapists.

US-based national guidelines for adult ADHD have proven difficult to develop for several reasons: first, historically, ADHD has been perceived as a childhood-only disorder, with most children outgrowing the condition in adolescence or early adulthood. Consequently, only those professional associations with a mandate to diagnose and treat children have historically produced assessment/diagnostic and/or treatment guidelines, e.g., the American Academy of Child & Adolescent

⁵³ Kessler, R. C., Adler, L., Barkley, R. A., Biederman, J., Conners, C. K., Demler, O., Faraone, S. V., Greenhill, L. L., Howes, M. J., Secnik, K., Spencer, T., Ustun, T. B., Walters, E. E., & Zaslavsky, A. M. (2006). The prevalence and correlates of adult ADHD in the United States: Results from the National Comorbidity Survey Replication. *American Journal of Psychiatry*,*163*, 716-723.

⁵⁴ Canadian ADHD Practice Guidelines (4th Edition). Available at <u>www.caddra.ca</u>

⁵⁵ Kooij SJJ, Bejerot S<u>,</u>Blackwell A et al. European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. BMC Psychiatry. 2010; 10: 67. Published online 2010 Sep 3. doi: 10.1186/1471-244X-10-67

⁵⁶ Nutt DJ, Fone K, Asherson P, et al. British Association for Psychopharmacology. Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. J Psychopharmacol. 2007;21(1):10–41.

⁵⁷ ADHD: Diagnosis and Management of <u>ADHD</u> in Children, Young People and Adults. National Institute for Health and Care Excellence (NICE); National Guideline Centre, UK, 2009; 2018 (The British Psychological Society and the Royal College of Psychiatrists)

⁵⁸ Association of the Scientific Medical Societies in Germany (AWMF) Online. Interdisciplinary Evidence- and Consensus-based Guideline "Attention Deficit/Hyperactivity Disorder in Children, Young People and Adults" [in German] 2018 [cited 15 June

^{2019].} https://www.awmf.org/uploads/tx_szleitlinien/028-045l_S3_ADHS_2018-06.pdf.

Psychiatry⁵⁹ and the American Academy of Pediatrics.⁶⁰ Because the general age limits for those specialists' patient populations generally have ended at or before age 21, these organizations do not have the implicit mandate to develop guidelines for age groups outside this age range. Although the American Psychiatric Association⁶¹ and the American Psychological Association⁶² have developed guidelines for many other areas – anxiety disorders, major depressive disorder, bipolar disorder, alcohol use disorder, PTSD, and schizophrenia, etc., these organizations have not developed guidelines in the area of ADHD in adults.

A second major contributing cause for the lack of attention to ADHD in adult populations can be found in the criteria and specifications for what major training organizations must require from young doctors during their residencies. Specifications for training criteria of residents in family medicine, internal medicine, and general psychiatry are developed by "Residency Review Committees" (RRCs) of the Accreditation Council of Graduate Medical Education (ACGME). RRCs, one for each major medical specialty, develop a lengthy list of requirements that must be fulfilled in any medical residency for it to meet ACGME-accreditation criteria.63 Importantly, none of the RRC guidelines for internal medicine, family medicine, or general psychiatry address the need for residents-in-training to learn about ADHD in adults. The family medicine RRC criteria requires that residents learn to "diagnose and manage common mental illness in patients of all ages," but it is left to the individual residency program director to actually determine which disorders are "common."⁶⁴ Similarly vague, the RRC criteria for psychiatry specify that training programs must ensure that residents acquire "knowledge of all major diagnoses" within the DSM" as well as skills in "differential diagnosis."⁶⁵ Again, the specifics of what each training program requires are left to the program's training director. For internal medicine, a critical primary care specialty which might be the portal for identifying many adults with ADHD, there is no mention of requirements to screen,

⁵⁹ Pliszka S; AACAP Work Group on Quality Issues. Practice parameter for the assessment and treatment of children and adolescents with attention-deficit/hyperactivity disorder. J Am Acad Child Adolesc Psychiatry. 2007 Jul;46(7):894-921.

⁶⁰ Wolraich ML, Hagan JF Jr, Allan C, Chan E, Davison D, Earls M, Evans SW, Flinn SK, Froehlich T, Frost J, Holbrook JR, Lehmann CU, Lessin HR, Okechukwu K, Pierce KL, Winner JD, Zurhellen W; Subcommittee on Children and Adolescents with ADHD. Clinical Practice Guideline for the Diagnosis, Evaluation, and Treatment of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. Pediatrics. 2019 Oct;144(4). pii: e20192528. doi: 10.1542/peds.2019-2528.

⁶¹ See https://www.psychiatry.org/psychiatrists/practice/clinical-practice-guidelines, accessed 4 October 2019

⁶² https://www.apa.org/about/policy/approved-guidelines, accessed 4 October 2019

⁶³ https://acgme.org/Specialties, accessed 4 October 2019

⁶⁴https://acgme.org/Portals/0/PFAssets/ProgramRequirements/120_FamilyMedicine_2019.pdf?ve r=2019-06-13-073936-407, accessed 4 October 2019

⁶⁵https://acgme.org/Portals/0/PFAssets/ProgramRequirements/400_Psychiatry_2019.pdf?ver=201 9-08-26-134127-827, accessed 4 October 2019

diagnose, or manage <u>any</u> mental health condition,⁶⁶ even though many internists have now become comfortable with diagnosing and managing depression in their adult patients. Nurse Practitioner program accreditation standards do not address ADHD, nor is it addressed on certification exams.

A third major reason why adults with ADHD are often "missed" by health care providers, both by primary care providers and mental health specialists (e.g., psychiatrists, psychotherapists, etc.), is the fact that children with ADHD who become adults too often have accumulating consequences of their primary condition – depression, anxiety, substance use, personality disorders, and even medical conditions that advertently (without adequate training on "what ADHD looks like" over the life course) become the primary focus of the clinical encounter. Under such conditions, inadequately prepared health providers are likely to revert to what they know best.^{67,68,69}

A fourth and final reason can be found in the observation that although as many as 50% of US children and adolescents with ADHD are diagnosed with the condition during their youth, most these individuals - who must have had some knowledge of their ADHD condition, seem to be missing from the health care system as "ADHD cases" as adults. For example, the NIMH-sponsored MTA study, a 16-year multi-site longitudinal investigation of nearly 600 children diagnosed between ages 7-9.9 years and followed into young adulthood, found that fewer than 5% of these young adults continued taking medication as young adults, and recognized the need for continuing medical assistance in managing their condition. If we were to apply that same statistic to juvenile diabetes or severe asthma -- that somehow the health care system "lost" the great majority of these patients with severe chronic illness, or that 95% of such cases did not continue treatment, we might seek contributing factors: for example, as health care providers of children and youth, are we taking the right or sufficient steps to empower these young patients to take responsibility for their illness while still living in the parental home? How do we help those young patients, particularly as they move into adolescence and adulthood, to see that this is not just a problem according to their parents or teachers, but for themselves?

This is not only a failure of how we do (or do not) prepare children and adolescents to assume the responsibility of managing their ADHD, but also an

⁶⁶https://acgme.org/Portals/0/PFAssets/ProgramRequirements/140_InternalMedicine_2019.pdf?v er=2019-06-25-100749-597, accessed 4 October 2019

⁶⁷ Torgersen T, Gjervan B, Rasmussen K. ADHD in adults: a study of clinical characteristics, impairment and comorbidity. Nord J Psychiatry. 2006;60(1):38–43. doi: 10.1080/08039480500520665.

⁶⁸ Sobanski E, Bruggemann D, Alm B, Kern S, Deschner M, Schubert T, et al. Psychiatric comorbidity and functional impairment in a clinically referred sample of adults with attention-deficit/hyperactivity disorder (ADHD) Eur Arch Psychiatry Clin Neurosci. 2007;257(7):371–377. doi:

deficit/hyperactivity disorder (ADHD) Eur Arch Psychiatry Clin Neurosci. 2007;257(7):371–377. doi: 10.1007/s00406-007-0712-8.

⁶⁹ Katzman MA, Bilkey T, Chokka P, Fallu A, Klassen L. Re: is adult attention-deficit/hyperactivity disorder being overdiagnosed? Can J Psychiatr 2016;61(1):60–1.

apparent failure of adult health care providers to elicit patients' childhood histories of ADHD, and to take that into account when they are addressing their patients' current health concerns.

These major gaps in US health services – especially in recognition and treatment of the large population of adults with ADHD – will require not just "awareness", but also changes in US health care practices and health care quality standards, with the participation of the major professional organizations and residency training programs to bring about these changes.

Conclusions and Recommendations

Taken in its entirety, the findings of this report clearly show that ADHD must now be viewed not just as a mental health problem that is the specific domain of mental health and special educational professionals, but as a *public health problem* producing a substantial impact on the health, quality of life, and economic viability of the US population. The disorder leads to numerous adverse health correlates and consequences, a markedly increased risk for childhood and midlife mortality, and an average reduction in life expectancy by later life of 9-13 years (range of 1 to 29 years), a figure that far exceeds any single one of the major life-reducing health problems (obesity, smoking, alcohol use, coronary heart disease, nutrition, etc.) as well as their combination. The reason it does so is that ADHD predisposes individuals to engage in lifestyle practices that lead to adverse health conditions, yet often prevents them from succeeding in health improvement and lifestyle efforts to mitigate these risks. That is why the severity of ADHD symptoms and particularly its deficits on the executive function (EF) of behavioral disinhibition, appears to explain up to 31% of the variation in estimated life expectancy if findings on clinical and control samples are extrapolated to the population. For instance, recent qualitative research that studied the daily life activities of adults with ADHD and their coping with sleeping problems and obesity found that ADHD related symptoms and EF deficits interfered with health related decision making on a nearly daily basis culminating in frequent unhealthy choices and the poor sense of self-efficacy that arose from them. Further justification for addressing the health related adversities linked to ADHD also comes from the markedly higher direct and indirect costs of these various health, education, and occupation-related adversities associated with ADHD – costs that have been shown to be in the billions of dollars annually, and up to hundreds of billions of dollars over the lifespan. This makes ADHD a far too costly disorder to continue to be under treated or even ignored in not just mental health settings but especially by primary care providers, government public health programs, third-party payers, and particularly among adults.

In sum, ADHD is a serious and expensive public health problem. To address it we offer five recommendations that should be implemented as a result of these findings. These recommendations form not only a call to action but a roadmap to improve the quality of life and longevity of those with ADHD as well as to reduce its substantial economic burden on families, insurers, employers, government programs, and society.

I. Patients with Adult ADHD and Parents Raising a Child with ADHD Must Become Better Informed About These Adverse Health Risks and Encouraged to Implement Management Programs to Reduce Them

The most pressing need at the moment is to ensure that individuals diagnosed with ADHD and family members who may be caring for them become more knowledgeable about the adverse health risks associated with the disorder. These patients and family members have been encouraged to focus on the familial, social, educational, and more recently occupational difficulties posed by the disorder. Now patients and family members must also be taught about the health risks, earlier mortality risks, and reduced life expectancies and the use of ADHD treatments to possibly mitigate these risks. Patients and family members need to use a broader lens in understanding ADHD as a public health issue and not just one of mental health or education. This can be achieved by a number of means, not the least of which is through wider dissemination of the findings contained in this white paper.

In addition to increased awareness about the long-term health risks, parents of children and adolescents must proactively work with their current health care providers to ensure that their children and youth become knowledgeable about the consequences of ADHD, and learn to take a more active role in assuming responsibility for managing their condition as they transition to independence and adulthood. Likewise, adults with ADHD need to alert their primary care and mental health professionals about their unhealthy related behaviors and activities and work closely with them to modify their risk for various adverse health outcomes.

Summit participants suggested several ideas for informing the public of the consequences of undiagnosed or untreated ADHD. The primary suggestion was to conduct a nationwide awareness campaign through various social media channels. The overall theme of the campaign should be addressing misconceptions, negative connotations, and myths regarding ADHD. The participants encouraged the development of a social media influencer network, a young leaders advocacy group, and a coordinated effort among the various ADHD organizations to create compelling stories of individuals living with ADHD. Of particular concern is the need to educate parents regarding the health risks for children and adolescents with ADHD. Adults with ADHD must understand that a group of symptoms might be attributable to ADHD. This campaign could be initiated with a coordinated effort to publish articles on the public health implications of undiagnosed or untreated ADHD in Attention magazine, ADDitude magazine, and other health related publications.

II. Mental Health Professionals Must Become Better Informed About These Health Risks and Encouraged to Adopt a Wider Focus on the Quality of Health

and Life of Their Patients and to Implement Appropriate Treatments to Reduce These Risks

Mental health professionals must be taught to determine whether adult patients have child or adolescent histories – as well as current behaviors - of possible ADHD, and be prepared to diagnose and address any current impairments related to ADHD and its consequences (including medical and mental health comorbidities) that have developed over patient's life course.

It is essential that evidence-based diagnostic and treatment guidelines be developed, with the input endorsement of key mental health professional societies (e.g., American Psychiatric Association, American Psychological Association, American Psychiatric Nurses Association, etc.). Such a strategy is necessary not just to increase awareness, but also to facilitate changes in day-to-day clinical practices of mental health professionals.

The Summit participants emphasized the need to advise mental health providers to screen for ADHD. Involving the American Psychological Association and the American Psychiatric Association in educating their memberships was key to reaching a large number of providers. Outreach should also be directed toward addiction treatment centers, sleep centers, smoking cessation clinics, and the criminal justice system. Encouraging all providers to use existing screening tools on all suspect clients may be time-consuming, but may reveal an underlying treatable diagnosis.

III. Primary Care Providers Need to be Better Informed About the Important Role that ADHD Plays in the Adverse Health Conditions, to Assess for its Possible Existence When Treating People with Such Adverse Health Risks, and to Manage the Disorder so as to Better Improve the Adherence of Such Cases to Their Primary Care Interventions.

Family physicians, pediatricians, and other primary care providers who manage child and adolescent ADHD, must work carefully with parents and youth to develop strategies so that young patients develop a clear awareness of the impact of ADHD on their health and functioning (just as is done with juvenile diabetes and asthma), so that they are motivated to, and can make appropriate decisions to, pursue necessary ADHD health care when they transition to adulthood.

Importantly, it is essential that evidence-based diagnostic and treatment guidelines be developed, with the input endorsement of their key professional societies (e.g., American Academy of Family Physicians, the American College of Physicians, etc.). Because adults with ADHD might be managed in both primary care as well as mental health specialty settings, evidence-based guidelines must be collaboratively developed with both groups of specialty societies. Guidelines published in their respective disciplines' professional journals is an essential component for an effective long-term strategy to both increase awareness and to change actual clinical practices.

Summit participants encouraged involving medical organizations (AMA, AAP, AAFP, ANA, ACP) in distributing information from this white paper and in developing evidence-based guidelines based on this white paper. The information distributed should be specialty specific. In addition, the development of a quick and accurate screening tool should be a high priority. Given the shorter appointments in most provider offices, it should be emphasized that any family history of ADHD behaviors should trigger the screening. Any patient who is not responsive to treatment protocols or who exhibits poor control should cause the provider to consider ADHD and initiate screening.

Managing ADHD in children should include screening of parents. The growing trend of diagnosing adults with ADHD should be seen as an opportunity to properly treat for coexisting conditions.

Materials designed for physicians should distinguish the difference between opioids and stimulants and the difference in potential for abuse.

IV. Insurers and Other Health Care Payers Need to Become Aware of the Important Role that ADHD Plays in Markedly Elevating Risks for the Various Adverse Health Conditions Which Their Plans Must Manage and the Need to Fund Efforts to Identify ADHD in Plan Participants and Cover Its Costs of Treatment When Present.

Payers require data on treatment adherence leading to cost savings. The Summit participants encouraged the sharing of cost data with insurers. By sharing cost data on health correlates with ADHD, payers may recognize potential cost savings. The goal is to incentivize insured patients to adhere to ADHD treatment guidelines. For example, employers could benefit from having their ADHD-affected employees follow treatment guidelines. This would not only lead to increased employee productivity, but also a potential reduction in employer insurance premiums.

As a related issue, it is important to validate the effectiveness and cost savings, if any, using online (telemedicine) techniques to screen and treat ADHD. Telemedicine reimbursement varies by location, services provided, and payer. An effort to have all payers accept telemedicine would require additional data collection.

Insurers must understand the health impact of inadequate diagnosis and follow-up. A report from the HHS Office of Inspector General identified half a million children on Medicaid diagnosed with ADHD who did not get standard follow-up care in a timely manner and many did not receive any behavioral therapy.⁷⁰

⁷⁰ https://oig.hhs.gov/oei/reports/oei-07-17-00170.asp

In the United States, health insurers are primarily interested in health costs. Any correlated costs are the responsibility of the government. Thus, it is important to demonstrate cost savings would exist through proper diagnosis and treatment of ADHD.

Newer alternative payment arrangements trend toward value, outcomesbased payments. There may be an opportunity to include ADHD in these newer plans. More research is necessary to show cost savings on treatment plans, screening, case-management, and potential electronic patient reminders to followup appointments and prescription reminders.

V. Government Public Health Agencies and Programs Need to Become Aware of the Important Role that ADHD Plays in Markedly Elevating Risks for the Various Adverse Health Conditions Which Their Agencies and Programs Target for Management and the Need to Fund Efforts to Identify it in Program Participants and Cover Implement Treatments When Present Aimed at Reducing ADHD Severity as well as Health Related Impairments.

Given both the lifespan and cost data presented, the Summit participants encouraged outreach to government agencies and elected officials. In particular, ADHD experts should continue to publish evidence-based research in order to garner the attention of the US Preventive Services Task Force to develop evidencebased recommendations. It is necessary to gather additional data through a behavioral risk-factor survey to analyze ADHD and correlated health factors. Additional funding for ADHD-specific research is necessary.

To encourage ADHD research funding, advocacy efforts should be enhanced to educate members of Congress, state legislators and public health officials about the serious consequences of this treatable neurodevelopmental disorder.