V.O.I.C.E Neurodiversity

Villages Overcoming Intersections: the Collaborative Empowerment for Neurodiversity

Navigating adversities, disparities, and complexities to promote resilience and agility

V.O.I.C.E. for Neurodiversity White Paper on Health Disparities Related to Undiagnosed and Unmanaged Neurodiversity in Under-resourced Communities

While neurodevelopmental disorders such as ADHD and Autism Spectrum Disorder (ASD) are well-documented, extensively researched conditions that have been on the Nation's (and overall public's) radar for decades, its impact when untreated or ignored is devastating on the individual and society. Multiple sources cite concerning statistics (see below).

- "In 2015, the total annual cost of untreated autism in the U.S. was estimated at **$268 billion**, including direct services, lost productivity, and family costs." *(Multiple Sources, Autism Speaks, Time)*
- "The lifetime cost for individuals with Autism can reach up to **$2.4 million**, compared to those without intellectual disabilities incurring around **$1.4 million."** *(Multiple Sources, Very Well Mind, Wang, C. et al)*
- "In 2018, the annual excess cost of ADHD among adults was approximately $122.8 billion with unemployment and loss of productivity accounting for nearly $96 billion. Direct healthcare costs contributed approximately $14.3 billion." *(jmcp.org), (Zhou, et al, 2023)*
- "For children aged 5–11 years, the annual societal excess cost of untreated ADHD was estimated at **$19.4 billion**, and for adolescents aged 12–17 years, it was **$13.8 billion**. A significant portion of these costs was attributed to educational expenses." *(PubMed)***,** *(Multiple Sources, Wang, C. et al)*
- 60% of Children with Autism also have a co-occurring diagnosis of ADHD *(Multiple Sources)*
- 61% of people with ADHD have chronic financial stress and problems *(R Barkley, 2008)*
- 21% of teens with ADHD skip school repeatedly, 35% eventually drop out of school, 45% have been suspended, 30% have failed or had to repeat a year of school (*multiple sources, CHADD, Barkley, 2019, etc.)*
- Substance abuse is 3 to 4 times greater than the national average for those with *untreated* ADHD (*multiple sources, NIH, CHADD, etc.)*
- "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 $10K less per year than in control cases followed at the same time" (*Barkley 2019)*

Intervention/Treatment:

Notably, research also supports this public health crisis can be mitigated when attended to early with prevention and intervention approaches. Early intervention entails pursuing diagnostic clarity as soon as symptoms of executive dysfunction and/or impaired functioning (i.e., social, relational, behavioral, academic, etc.) become undeniably noticeable. Typically, psychological testing and screening for co-occurring conditions (i.e., anxiety, depression, trauma, etc.) yields diagnoses that can be treated with evidenced-based

interventions. For ADHD, treatment can be singularly medication and/or reasonable accommodations in one's environments. It can also entail a blend of the aforementioned with one or more of the following: cognitive/behavioral therapy, parent training, executive functioning coaching. While stimulant medication is scientifically proven by various studies and randomized clinical trials to be effective for millions, it is an option and not always the selected course of treatment. When interventions are tailored to the individual based on their medical history, life experiences, and daily demands, they experience significant improvement and their quality of life is restored. For Autism, all of the aforementioned treatments are applicable, however, additional care such as occupational and speech therapy, and Applied Behavioral Analysis (ABA) services should be provided as needed. Whenever these conditions or means of care are under scrutiny or attack, research and the personal testimonies of impacted individuals always yields the truth of the matter.

Neurodiversity and Marginalized Communities:
Unfortunately, with health disparities and access to care inequities persistently compounding the experiences and health of ethnically diverse, often under-served and under-resourced persons of marginalized communities, the disproportionate effect is far worse than counterparts of resourced privilege. Trajectories of untreated neurodiversity in marginalized, under-resourced adolescents and young adults (especially those of diverse ethnicity and social status, oftentimes BIPOC individuals), yield disproportionally detrimental impairment to their quality of life. For this population, extensive negative outcomes tend to chronically unfold because access to diagnosis and treatment is systemically unavailable or embedded with obstacles (i.e., insufficient medical insurance, unavailability of qualified, culturally in tune providers, fewer appointments, inaccessible medications, etc.). When consideration is given to various other environmental and contextual factors that further complicate their experiences, it's conceivable that the prevalence of neurodiverse conditions in the BIPOC community is most likely far greater than what we know (hence the need for research). Too many BIPOC children unsuccessfully navigate untreated neurodiversity across critical developmental life stages and oftentimes reach adulthood with significant executive dysfunction undermining their efforts at emotion management, maintaining relationships, and consistent productivity in their occupational or academic capacity. They are at a disproportionately higher risk for lower socioeconomic status, unhealthy and at-risk coping, impaired/impulsive decision-making, compromised mental and physical health, increased probability for involvement in accidents, admission to detention centers/prison, and overall shorter life expectancy. Concerning statistics are provided; keep in mind these data can entail increased rates of incidence in BIPOC individuals.

- 40% of youth with diagnosable ADHD symptoms don't get treatment (*multiple sources)*
- 17.5% of the children surveyed by the CDC were not receiving medication or mental health therapy to treat their diagnosed ADHD (*CDC)*
- "While approximately 9% of white children are diagnosed with ADHD, the diagnosis rate among African American children can be as low as 6-7% due to access to care factors" *(multiple sources, Cénat, J.M., et al., 2022)*
- "Latino children were 1.5 times less likely to receive an ADHD diagnosis compared to white children" *(multiple sources, Cénat, J.M., et al., 2022)*
- Asian American children are less likely to be diagnosed with ADHD attributable to a reluctance to seek mental health services due to cultural attitudes toward education and mental health *(multiple sources, Cénat, J.M., et al., 20220)*
- Due to language barriers and limited access to mental health services, immigrant communities are often overlooked *(multiple sources, Golson, M.E., et al., 2022)*
- Higher rates of autism diagnoses are prevalent for BIPOC individuals compared to White children (24.3 per 1,000 aged 8 years). Black children had a prevalence of 29.3, and Latino children had a prevalence of 31.6 per 1,000 *(Benevides. T.W., et al, 2024)*

- 20% of people incarcerated have ADHD; it's believed that at least 1 out of 3 youth in detention centers met criteria for at least one form of **diagnosable neurodiversity** *(Morris,D. et al, multiple sources)*
- The U.S. releases over 7 million people from jail and more than 600,000 people from prison each year. Within 3 years of their release, 2 out of 3 people are rearrested and more than 50% are incarcerated again *(USA Facts, U.S. Dept. of Human and Health Services, U.S. Census Bureau)*
- When youth assessed as low risk are diverted to alternative programs verses being processed through formal court processing and traditional juvenile and jail systems, they are 45% less likely to reoffend *(Anne E. Casey Foundation)*

Key Take Away:
The interventions and treatment referenced above **are universally effective** for people diagnosed with neurodiversity. In response to the current comments and actions of MAHA, **access to care must be improved and the resources and policies in place to protect what is already available** (i.e., FDA-approved medications, Medicare and Medicaid services/coverages) **must be sustained and expanded**. **Research** that reveals a better understanding of the prevalence, incidence, and intersectional impact of neurodiversity in marginalized communities is **a critical effort that can not be extinguished.**

About Us:
Villages Overcoming Intersections: the Collaborative Empowerment (VOICE) for Neurodiversity (https://VoiceForNeurodiversity.org) is a national non-profit organization based out of Maryland. One major aspect of our mission is to address access to care inequities and disparities via collaborative research and building sustainable infrastructure and networks that connect persons challenged with neurodivergence to resources and relevant information, particularly those whose experiences are compounded by marginalization and lack of privilege or inclusion, because of cultural, ethnic, or other demographic difference. Dr. Brandi Walker, PhD, CEO/founder of VFN is a licensed clinical psychologist, board certified executive leadership coach, cultural humility and cultural competence educator, and organizational consultant on mental wellness and strategic planning. She is a Howard University and University of Maryland alumna and a recently retired Army commissioned officer. She actively conducts research on Neurodiversity, ADHD, and co-occurring conditions.

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