

YOUTH MENTAL HEALTH DATA IN THE CONTEXT OF OMB SPD 15

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INTRODUCTION

This brief is focused on recommendations for the Office of Management and Budget's (OMB) Statistical Policy Directive (SPD) No. 15 in the context of youth mental health. For over a decade, youth in the United States have been experiencing a mental health crisis that can only be understood and mitigated through the collection and evaluation of standardized and representative data. OMB is the largest agency within the Executive Office of the President that ensures federal agencies carry out operational tasks and responsibilities according to the law and the President's strategic plan. OMB issues data policies and standards to facilitate data collection and sharing to inform public and private decision-making. As a result of local and national efforts during the Civil Rights Movement calling for greater fairness in the treatment of members of the Black/African American community, OMB issued SPD No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity in 1977. This policy ensures federal agencies use standardized methods to collect data on race and ethnicity. As a result, records can be evaluated more easily to better serve states, individuals, and other stakeholders.

In 1997, SPD No.15 was revised with public input from multiple sources with the goals of promoting self-identification over observatory identification by a third party to more accurately reflect the ethnic and racial categories that people identify as representative and to better reflect the identities of individuals of more than one race. In 2024, OMB again updated SPD No. 15 to reflect increasing racial and ethnic diversity in the U.S. to include the rising number of individuals who identify as more than one race or ethnicity and changing immigration and migration patterns. Noteworthy, this diversity extends beyond race and ethnicity.

Determined to meet the initial objective of ensuring the fair treatment of all those served by the government, OMB should revisit collection standards to also ensure that language, sexual orientation and gender identity (SOGI), and disability status are considered for minimum standard classification. More illustrative analyses can accurately pinpoint who is best served and who needs to be better served to promote a healthy public by assessing data based on the intersection of all the aforementioned categories. Standardized, precise data [across all three domains] create[s] opportunities for insurers, health care providers, employers, and patient advocates to design and implement targeted solutions to better meet the needs of perpetually underserved groups.¹

Throughout the United States, there are health disparities impacted by race, ethnicity, economic and social factors, which includes disparities in rates of mental health conditions, poverty, unemployment, and access to quality care. These disparities are also apparent based on an individual's language, sexual orientation, gender identity, and disability status. Supporting equitable health and mental health outcomes for children and adults is a goal of government, according to Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, the Individuals with Disabilities Education Act, Section 4302 of the Affordable Care Act, and numerous federal regulations. The first step to eliminating health disparities and promoting equity in mental health is collecting consistent data across the United States to evaluate and implement systems-wide changes.

1. Blue Cross Blue Shield Association, National Minority Quality Forum. (2023, March 28). Standardizing Data to Advance the Health Equity Movement: A Multi-Sectoral Strategy. Data Equity Coalition. https://dataequitycoalition.com/wp-content/uploads/2023/07/NMOF_Brief_Paper.pdf

Equity in Mental Health

Mental health is an essential part of overall health. Mental and physical health are inextricably linked, as poor mental health increases the risk of chronic health conditions like diabetes, heart disease and stroke. In addition, having a physical health condition can increase the risk for mental illness.² Mental health equity by definition is reflected by how certain populations experience identification of a mental health condition, and the treatment and recovery from that condition, differently than others due to structural reasons outside of their control. The Satcher Health Leadership Institute estimates that 116,722 excess premature mental and behavioral health related deaths occurred among marginalized racial and ethnic populations between 2016 and 2020.³ Marginalized communities, including communities of color and LGBTQ+ communities, face more structural inequities and barriers to accessing mental health care. These barriers include behavioral health workforce shortages, the lack of a specialized culturally and linguistically responsive workforce, infrastructure for young people and their families, limitations in insurance coverage, unequal treatment of mental health services in payment and cost-sharing, financial barriers, and higher rates of social determinants of health challenges such as unmet nutrition, housing, and transportation.

The Satcher Institute calls on policymakers to make investments in infrastructure and a specialized workforce and make a commitment to assist populations experiencing barriers to care or who have a mistrust of the medical system. Addressing these factors through policy will lessen the overrepresentation of premature deaths of those among minoritized racial and ethnic groups and calls for greater examination of the intersectionality of SOGI and disability status. Standardization of measurements of race, ethnicity, and language (REL); SOGI; and disability status are needed to properly assess how systems are better or worse for specific populations and allow mental health stakeholders to relate information across systems to holistically address the needs of individuals experiencing mental health challenges.

The State of Youth Mental Health

Mental health challenges are the leading cause of disability and death among young people.⁴ From 2009-2019, the percentage of youth ages 12-17 who had experienced a major depressive episode in the past year nearly doubled, from 8.1% to 15.7%.⁵ Furthermore, the national suicide rate among youth and young adults ages 10-24 increased 57.4% from 2007 to 2018.⁶ After a brief decrease in 2019 and 2020, suicide rates rebounded to just below the peak in 2018 with a rate of 14.1 suicides per 100,000 population.⁷

2. Centers for Disease Control and Prevention (CDC), National Center for Injury Prevention and Control. (2023, April 25). CDC. <https://www.cdc.gov/mentalhealth/learn/index.htm#:~:text=Why%20is%20mental%20health%20important,%2C%20heart%20disease%2C%20and%20stroke>
3. Satcher Health Leadership Institute (SHLI), Morehouse School of Medicine. (n.d.). The Economic Burden of Mental Health Inequities in the United States Report. SHLI. Retrieved March 21, 2024 from <https://satcherinstitute.org/wp-content/uploads/2022/09/The-Economic-Burden-of-Mental-Health-Inequities-in-the-US-Report-Final-single-pages.V6.pdf>
4. Agency for Healthcare Research and Quality. (2022, October). 2022 National Healthcare Quality and Disparities Report. National Institute of Health. <https://www.ncbi.nlm.nih.gov/books/NBK587174/>
5. Substance Abuse and Mental Health Services Administration (SAMHSA). (2020, September 11). 2019 National Surveys on Drug Use and Health (Table 11.2B). SAMHSA. <https://www.samhsa.gov/data/report/2019-nsduh-detailed-tables>
6. Curtin, S. (2020, September 11). National Vital Statistics Reports, Volume 69, Number 11. Centers for Disease Control and Prevention. <https://www.cdc.gov/nchs/data/nvsr/nvsr69/NVSR-69-11-508.pdf>
7. Stone, D., Mack, K., Qualters, J. (2023, February 10). Morbidity and Mortality Weekly Report - Notes from the Field: Recent Changes in Suicide Rates, by Race and Ethnicity and Age Group – United States, 2021). Centers for Disease Control and Prevention.

Since the start of the COVID-19 pandemic in 2020, several studies focused on youth mental health during that period have documented increases in symptoms such as persistent feelings of sadness or hopelessness and suicidal thoughts and behaviors,⁸ symptoms of depression and anxiety, and even accelerated brain aging.⁹ According to the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Survey on Drug Use and Health (NSDUH), 15.2% of youth ages 12-17 who had serious thoughts of suicide in 2021 and 2022 reported their suicidal ideation was because of the COVID-19 pandemic.¹⁰

Despite this growing mental health crisis, systems have not adapted to deliver the care and services to best support youth with, or at risk of developing, a mental health condition. Without standardized data collection that accurately reflects youth in the U.S., it is impossible to fully understand the magnitude of mental health needs among historically marginalized and under-resourced populations and improve systems to better support them.

Disparities in Youth Mental Health by Race and Ethnicity

The U.S. becomes more racially and ethnically diverse with each generation and for the first time in recent history fewer than half of individuals in Generation Alpha (born from 2013 to present) identify as non-Hispanic white.¹¹ The disaggregation of mental health data by race and ethnicity is imperative to understanding current trends in mental health needs, barriers and/or disparities in access to care, and the root causes of mental health challenges among our nation's youth.

While the percentage for all youth experiencing a major depressive episode (MDE) in the past year increased 7.6% from 2009-2019, Hispanic or Latino youth experienced a 2.6% higher increase than non-Hispanic youth. Hispanic youth also experienced significantly lower increases in access to mental health care during this period. From 2009-2019, the percentage of non-Hispanic youth with a past-year MDE who received treatment for depression increased over 10%, from 35% in 2009 to 45.7% in 2019, while the percentage of Hispanic youth who received treatment for depression increased less than 4%, from 33% in 2009 to 36.8% in 2019.¹²

Disaggregating data by ethnicity also provides crucial information about the impact of events like the COVID-19 pandemic and resulting socioeconomic and societal changes across communities. The percentage of youth ages 12-17 who reported serious thoughts of suicide because of the COVID-19 pandemic appeared to remain steady from 2021-2022. However, when disaggregated by ethnicity, the percentage experiencing suicidal ideation due to COVID-19 decreased from 16.5% in 2021 to 13.1% in 2022 among non-Hispanic youth but increased from 11.2% in 2021 to 22% in 2022 among Hispanic or Latino youth. This data, combined with

8. National Center for HIV, Viral Hepatitis, STD, and TB Prevention. (n.d.). The Youth Risk Behavior Survey Data Summary & Trends Report: 2011-2021. Centers for Disease Control and Prevention. Retrieved March 21, 2024 from https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf
9. National Institute of Mental Health (NIH). (2023, January 26). COVID-19 Pandemic Associated with Worse Mental Health and Accelerated Brain Development in Adolescents. NIH. <https://www.nimh.nih.gov/news/science-news/2023/covid-19-pandemic-associated-with-worse-mental-health-and-accelerated-brain-development-in-adolescents>
10. Substance Abuse and Mental Health Services Administration (SAMHSA). (2023, November 13). 2022 National Survey on Drug Use and Health Detailed Tables, Table 10.2B. SAMHSA. <https://www.samhsa.gov/data/report/2022-nsduh-detailed-tables>
11. The Annie E. Casey Foundation (AECF). (2023, July). Population by Birth Cohort Generation and Race Ethnicity in United States. AECF. <https://datacenter.aecf.org/data/tables/11504-population-by-birth-cohort-generation-and-race-and-ethnicity?loc=1&loc=1#detailed/1/any/true/1095/8123|4038,4040,4039,2638,2597,4758,1353/22696>
12. Substance Abuse and Mental Health Services Administration (SAMHSA). (2020, September 11). 2019 National Survey on Drug Use and Health, Table 11.4B. SAMSHA. <https://www.samhsa.gov/data/report/2019-nsduh-detailed-tables>

data on high mortality rates and disproportionate economic effects from COVID-19 on Hispanic individuals,¹³ can provide more insight into the impact of the pandemic on Hispanic communities and the need for additional resources to address their mental health needs.

Significant disparities in the prevalence of youth mental health challenges and access to care by race are masked by aggregated data. From 2009-2019, the percentage of youth identifying as more than one race who experienced a major depressive episode in the past year increased 12.9% compared to only 7.6% among all youth. According to the Centers for Disease Control and Prevention's (CDC) Youth Risk Behavior Survey (YRBS), 16% of high-school students who identified as American Indian or Alaska Native and 14.5% who identified as Black or African American reported attempting suicide in 2021, compared to 10.2% of youth overall.¹⁴ Disaggregation by race can reveal not only disparities in the prevalence of mental health challenges among youth but also the lack of progress in eliminating disparities in access to care.

From 2009-2019, the percentage of youth with a past year MDE who received treatment increased from 37.7% to 50.3% for white youth and from 23.9% to 35.6% for Black youth. The disaggregation of this data reveals both that fewer Black youth are receiving treatment for depression than their white counterparts, and there has been less of an improvement in access to care for Black youth. This is demonstrated in a recent study showing little overall increase in youth impairment from 2019 to 2021 despite the fact there was a significant increase in the gap separating outpatient mental health care utilization by Black and white youth.¹⁵

Aggregated data across all youth can even signal improvements in youth mental health, while disaggregation reveals further disparity among underserved populations. In 2019 and 2020, overall suicide rates declined below the peak in 2018, even for youth and young adults ages 10-24. However, analyses disaggregated by race and ethnicity showed a significant increase in suicide rates among Black youth and young adults, from 8.2 per 100,000 in 2018 to 11.2 per 100,000 in 2021.¹⁶ Similarly, the overall percentage of youth with a past year MDE decreased from 2021-2022, while the percentage among Black youth increased by 2.6%. Failing to consistently disaggregate youth mental health data by race and ethnicity can falsely signal improvement when disparities are widening for underserved populations at risk for mental health challenges.

Disparities in Youth Mental Health by Sexual Orientation and Gender Identity

Although OMB SPD No. 15 was recently updated, it does not delineate standards for the collection of sexual orientation and gender identity data, which limits our understanding of mental health needs among LGBTQ+ youth. Many of the publicly available mental health datasets from federal agencies, including SAMHSA and CDC, do not include a "nonbinary" option for gender and present inconsistent categories for sexual orientation, limiting the ability of researchers and advocates to track trends in the mental health of LGBTQ+

13. Center for American Progress (CAP). (2021, March 5). Latinos Face Disproportionate Health and Economic Impacts from COVID-19. CAP. <https://www.americanprogress.org/article/latinos-face-disproportionate-health-economic-impacts-covid-19/>

14. Centers for Disease Control and Prevention (CDC). (n.d.). Unintentional Injuries and Violence: High School Students Who Actually Attempted Suicide. CDC. Retrieved March 21, 2024 from <https://yrbs-explorer.services.cdc.gov/#/tables?questionCode=H28&topicCode=C01&year=2021&location=XX>

15. Olfson, M., McClellan, C., Zuvekas, S., et al. (2024, March 13). Mental Health Impairment and Outpatient Mental Health Care of US Children and Adolescents. JAMA Network. https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2816355?questAccessKey=6c0c7655-eed0-4cda-a1f0-3c4d1c4f2790&utm_source=silverchair&utm_medium=email&utm_campaign=article_alert-jamapsychiatry&utm_content=olf&utm_term=031324&adv=

16. Leavitt, R., Ertl, A., Sheats, E., et al. (2018, March 2018). Suicides Among American Indian/Alaska Natives – National Violent Death Reporting System, 18 States, 2003-2014. Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/volumes/67/wr/mm6708a1.htm#T1_down

youth across agencies. The generation of more standardized, precise mental health data by sexual orientation is critical as the data that is available indicates that LGBTQ+ youth have significantly higher rates of mental health challenges. According to the CDC's YRBS survey, 45% of high school students who identified as LGBQ+ reported seriously considering suicide, compared to 15% of heterosexual students in 2021. Rates for individuals seriously considering suicide were 32% higher for students with same-sex partners than for those with only partners of the opposite sex. Sixty-nine percent of high school students who identified as LGBQ+ reported persistent feelings of sadness or hopelessness, compared to 35% of heterosexual students.¹⁷

Mental Health America's (MHA) Online Screening and Prevention Program data indicates further inequities in mental health for LGBTQ+ youth, especially for transgender and nonbinary youth. In 2023, 88% of youth who identified as LGBTQ+ who took a mental health screen on MHA's website scored at risk for a mental health condition, compared to 80% of non-LGBTQ+ youth. Sixty-two percent of youth who identified as LGBTQ+ and took a depression screen reported experiencing frequent suicidal ideation, compared to 44% of non-LGBTQ+ youth. Rates of suicidal ideation were highest among youth who identified as pansexual (65%), followed by youth who identified as lesbian or gay (62%) and youth who identified as bisexual (60%).

Ninety percent of nonbinary youth who took a mental health screen on MHA's website scored at risk for a mental health condition, compared to 84% who identified as female and 78% who identified as male. Among those who took a depression screen, 65% of transgender youth reported experiencing frequent suicidal ideation, compared to 48% of cisgender youth. Rates of reported suicidal ideation were highest for transgender boys (67%), followed by youth who identified as transgender and nonbinary (67%) and youth who only identified as nonbinary (66%). As more youth continue to identify as LGBTQ+, updating the OMB SPD No. 15 standards to include standardization of sexual orientation and gender identity data is essential to understanding youth mental health needs and creating specific and targeted cross-agency interventions and supports for LGBTQ+ youth and their families.

Measures of Disability in Youth Mental Health

There is no standardized definition for mental health disability in data collection, which presents a challenge in planning for equitable resource allocation and distribution of support for children and their families. The Office of Population Affairs at the U.S. Department of Health and Human Services cites measures of mental, emotional, developmental, or behavioral problems from the National Survey of Children's Health (NSCH) as measures of disability among youth.¹⁸ From 2020-2021, 23% of children ages 3-17 had a mental, emotional, developmental, or behavioral (MEDB) problem.¹⁹ This data was only publicly available across four race and

17. National Center for HIV, Viral Hepatitis, STD, and TB Preventions. (n.d.). 2011-2021 Youth Risk Behavior Survey: Data Summary & Trends Report. Centers for Disease Control and Prevention. Retrieved March 21, 2024 from https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf

18. Office of Population Affairs. (n.d.). Trends in Prevalence of Disabilities among Youth. U.S. Department of Health & Human Services. Retrieved March 21, 2024 from <https://opa.hhs.gov/adolescent-health/physical-health-developing-adolescents/introduction-chronic-conditions/trends-disabilities-youth#ftn1>

19. Child & Adolescent Health Measurement Initiative. (n.d.). 2020-2021 National Survey of Children's Health (NSCH) data query, Indicator 2.10: Mental, emotional, developmental or behavioral problems, 3-17 years. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved March 21, 2024 from <https://www.childhealthdata.org/browse/survey/results?q=9353&r=1>

ethnicity categories (Hispanic, White non-Hispanic, Black non-Hispanic, Asian non-Hispanic, and Other non-Hispanic), and youth identified as “Other non-Hispanic” had the highest rates of MEDB problems, at 27%.²⁰

Sixty-four percent of parents of children with a MEDB problem reported that their child had health conditions that affected their daily activity some or most of the time.²¹ Among parents of youth identified as having an emotional, behavioral, or developmental problem for which treatment or counseling was needed, 47% reported it was somewhat or very difficult to get necessary mental health treatment or counseling, and 5% reported that it was not possible to obtain care.²²

The American Community Survey (ACS) collected by the U.S. Census Bureau also includes measures of disability among youth. The measure that most likely includes mental health disability is cognitive disability, defined as “serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition.” In 2019, 4.4% of children ages 5-17 had a cognitive disability, making it the most common disability type among children of that age group.²³

The U.S. Department of Education also measures youth mental health disability, as children identified with emotional disturbance for special education and related services under the Individuals with Disabilities Education Act (IDEA). In the 2018-2019 school year, 5.45% of students with disabilities were identified as having emotional disturbance.²⁴ However, the percentage of students with disabilities identified with emotional disturbance decreased nearly 2% from 2008 to 2018,²⁵ while rates of youth mental health challenges increased, indicating this measure may also not capture the breadth of youth mental health disability. Standardized and consistent measures of mental health disability are critical to better understand the prevalence of mental health disability among youth in the U.S. especially by race, ethnicity and other intersectional identities. Collection of this type of data would give stakeholders the information needed to equitably design and allocate resources to adapt a mental health system that lags behind current demand and better support underserved children and families.

20. Child and Adolescent Health Measurement Initiative. (n.d.) 2020-2021 National Survey of Children’s Health (NSCH) data query, Indicator 2.10: Mental, emotional, developmental or behavioral problems, 3-17 years. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved March 21, 2024 from <https://www.childhealthdata.org/browse/survey/results?q=9353&r=1&q=1010>

21. Child and Adolescent Health Measurement Initiative. (n.d.). 2020-2021 National Survey of Children’s Health (NSCH) data query, Indicator 1.12: Effect of conditions on daily activities. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved March 21, 2024 from <https://www.childhealthdata.org/browse/survey/results?q=9329&r=1&q=1023>

22. Child and Adolescent Health Measurement Initiative. (n.d.). 2020-2021 National Survey of Children’s Health (NSCH) data query, Indicator 4.4a: Difficulties obtaining mental health care, age 3-17 years. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved March 22, 2024 from <https://www.childhealthdata.org/browse/survey/results?q=9390&r=1&q=1022>

23. Young, N. (2021, March). Childhood Disability in the United States: 2019, American Community Survey Briefs. U.S. Census Bureau. <https://www.census.gov/content/dam/Census/library/publications/2021/acs/acsbr-006.pdf>

24. Kkushiyama. (2024, February 5). OSEP Fast Facts: Children Identified With Emotional Disturbance. Individuals With Disabilities Education Act. <https://sites.ed.gov/idea/osep-fast-facts-children-IDed-Emotional-Disturbance-20>

25. *Ibid.*

RECOMMENDATIONS

There is an immediate need for action to standardize data collection on REL, SOGI, and disability for children and adolescents—especially those from persistently underserved communities. These communities continue to fall through the cracks of a limited system of care. Initial revisions were made to OMB SPD No. 15 in 1997 to better reflect the demographics of the changing U.S. population, and in 2024 revisions were made to expand race and ethnicity definitions, but more must be done to accurately capture the needs of today’s youth.

The first generation of majority non-white children has been born and adolescents report the highest levels on record of LGBTQ+ identification. Their mental health needs cannot be met without precise data to identify where there are disparities and how to address them. This begs OMB to require standardized data be collected for REL, SOGI, and disability status to support cross-agency and cross-systems efforts to analyze issues and create innovative solutions that promote better mental health outcomes for youth who experience inequity.

In addition to technical standards, collection of this data must also consider how to ensure it is safe from technological attacks as recent hacking events highlight the importance of data security. Standards are also needed to define how best to engage with individuals and their families in data collection. Trust between agencies engaging in data collection and communities is critical to ensuring the accuracy of data and creation of necessary partnerships with communities to carry out health interventions. OMB should include standards around methodology, including uniform data collection tools and framing of questions. These standards should be crafted in partnership with individuals with lived experience of mental health challenges from BIPOC and LGBTQ+ communities. Policymakers and stakeholders must keep data for youth mental health equity at the top of mind in decision-making for the youth who are experiencing challenges, and the youth who observe the challenges of their peers. Agencies and other stakeholders already come together to share data about health quality, cost, and outcomes. We call on OMB to ensure that these conversations and others can also be informed by REL, SOGI, and disability status, key information that can better paint a full picture of youth mental health in the United States.