

# The Critical Lack of Data on Alcohol and Marijuana Use by Adolescents on the Autism Spectrum

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## Abstract

Alcohol is the most commonly used substance among adolescents, and marijuana is the most commonly used illicit drug. Emerging evidence suggests that at least some autistic individuals may be at increased risk of substance use disorder compared with allistic counterparts, potentially to control social anxiety or facilitate social interaction. However, to the best of our knowledge, U.S. population-based estimates of substance use by autistic youth are limited. The aim of this perspective article was to highlight the lack of data sets that collect information about alcohol and marijuana use by autistic youth in the United States. We used a four-step investigation to identify potential data sources that could provide an estimate of the prevalence of alcohol and/or marijuana use in autistic youth, without regard to whether those estimates would be robust. We identified a total of 19 potential U.S. data sources. Of these, only one included information about both autism and alcohol and/or marijuana by youth. There is too little research on substance use by autistic adolescents, and rigorously collected data would benefit the field. Our recommendations include increased federal funding for data collection from autistic youth on substance use, additional questions on nationally representative surveys that assess autism status in multiple ways, and the use of robust measures of substance use that allow for characterization of substance use according to multiple dimensions. As the number of autistic youth identified increases and these youth transition into adulthood, better understanding of their substance use patterns is critical for developing health promotion efforts that appropriately and fully serve the needs of autistic youth.

**Keywords:** adolescent, alcohol, marijuana, prevalence, substance use

## Lay Summary

### *Why is this topic important?*

Alcohol is the most commonly used substance among adolescents, and marijuana is the most commonly used illicit drug. Previous studies suggest that at least some autistic individuals may be at increased risk of substance use disorder compared with allistic counterparts, potentially to control social anxiety or facilitate social interaction. However, to the best of our knowledge, estimates of substance use by autistic youth in the United States are limited.

### *What is the purpose of this article?*

This study was performed to highlight the lack of data sets that collect information about alcohol and/or marijuana use by autistic youth in the United States. We systematically reviewed U.S. data sources on child and/or adolescent health, disability, and/or substance use to identify sources that could generate estimates of the prevalence of substance use among autistic adolescents in the United States, even if those estimates may not be stable due to small sample sizes or other methodological weaknesses.

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*What is the perspective of the authors?*

The authors are a team of allistic researchers. M.B.-M. and S.B.-F. are pediatricians. E.F.R. and A.A. are public health researchers. S.B.-F. has an extensive background in providing clinical health care services to children with autism and is an autism researcher. R.A.N.P. and A.C.S.-R. are master's level public health research assistants. E.F.R., A.A., and M.B.-M. are adolescent health research experts. E.F.R. has an adolescent daughter on the autism spectrum. Our collective positionality is that we identify as people who are not autistic and who select to focus on research that we hope will benefit autistic people and society in general.

*What did the authors find?*

Based on our four-step investigation, we identified 19 U.S. data sources that had the potential to generate estimates of the prevalence of alcohol and/or marijuana use in autistic youth. Only one included information about both autism and substance use.

*What do the authors recommend?*

The National Institutes of Health (NIH), and the National Institute of Alcohol Abuse and Alcoholism (NIAAA) and National Institute of Drug Abuse (NIDA), specifically, should prioritize funding data collection from autistic youth and adults on alcohol and marijuana use, misuse, hazardous use, dependence, and use disorders. In addition, it is critical that nationally representative surveys and data sources include robust questions on autism and substance abuse. This includes assessing autism status in multiple ways (e.g., self-report, diagnosis by a clinician, neuropsychology reports). Substance use questions should include age of first drink or use, frequency of use, quantity of use per day or within a certain number of hours, expectancies, consequences of use, and indicators of alcohol use disorder.

*How will these recommendations help autistic individuals?*

These findings highlight a critical gap in the literature on substance use among autistic youth. Substance use is recognized as a pressing adolescent health problem, and autistic youth deserve evidence-based substance use prevention strategies. Without an estimate of substance use by autistic youth, it is difficult to justify to funding entities the expenditure of resources on the development of evidence-based substance use prevention strategies to benefit them.

**Introduction***Background*

**A**LCOHOL IS THE MOST COMMONLY used substance among adolescents, and marijuana is the most commonly used illicit drug. In 2017, 33.2% of 12th graders reported past-month alcohol use and 22.9% reported past-month marijuana use.<sup>1,2</sup> Because adolescence is a critical developmental period for brain growth, adolescents' consumption of alcohol and/or marijuana can have long-lasting adverse health impacts.<sup>1,3,4</sup> Delayed initiation of alcohol and marijuana consumption can protect against harmful health consequences. Research on alcohol and marijuana use among specific populations is important to create effective targeted interventions. Autistic youth are a specific population that has not been sufficiently studied by alcohol and marijuana researchers. Autistic individuals experience increased risk of morbidity and early mortality compared with their non-autistics counterparts,<sup>5</sup> and substance use may exacerbate this inequity. Premature deaths among autistic individuals are largely attributable to injury (e.g., suffocation, asphyxiation, drowning, suicide), which may be impacted by factors such as substance use.<sup>6</sup> Moreover, chronic or frequent alcohol and substance use can worsen depression, anxiety, sleeplessness, and result in headaches and other stressors,<sup>7-10</sup> but research on substance use by autistic adolescents remains extremely

limited. As a result, it is unknown how commonly these alcohol-related problems may be experienced by autistic adolescents and young adults.

Historically, there have been assumptions that autistic individuals are either "rule-followers" (i.e., risk averse and rule-abiding) or unlikely to use substances because they lack social opportunities to do so.<sup>11,12</sup> In fact, the results of a small number of studies suggest that autistic individuals may be at lower risk of substance use compared with their nonautistic counterparts.<sup>11-15</sup> However, these studies were largely conducted among patients seen in or referred to psychiatry clinics, or among individuals with psychiatric diagnoses seeking treatment, likely biasing samples toward autistic individuals with higher intensity of traits.

Emerging evidence from outside the United States now suggests that at least some autistic individuals may be at increased risk of substance use disorder, potentially as a way to control generalized anxiety, social anxiety, attempt to alleviate depression, or as a tool to facilitate social interaction.<sup>16</sup> A recent study using a Swedish population-based registry found that autistic individuals appear to be more than twice as likely to develop substance-use-related problems (including substance use disorder) compared with their nonautistic relatives.<sup>17</sup> An Australian study of young adult twins found that autistic traits were associated with elevated levels of marijuana use as well as increased risk of developing marijuana

use disorders and alcohol dependence.<sup>18</sup> Moreover, because autism often co-occurs with attention-deficit/hyperactivity disorder (ADHD), and ADHD is associated with increased risk of alcohol and marijuana use and substance use disorders,<sup>19</sup> susceptibility for substance use disorder may be elevated in autistic youth because of co-occurring ADHD or other conditions.

Because information about substance use by underage autistic youth is limited, we sought to answer the question: how many U.S. data sources can provide estimates of the prevalence of alcohol and/or marijuana use in autistic youth?

### *Positionality*

In keeping with the format of Perspectives articles in this publication, we offer the following information about ourselves so that the reader can contextualize our position. We are a team of allistic researchers. The term “allistic” is preferred by some autistic self-advocates and is a synonym for neurotypical.<sup>20</sup> M.B.-M. and S.B.-F. are pediatricians. E.F.R. and A.A. are public health researchers. S.B.-F. has an extensive background in providing clinical health care services to children with autism and is an autism researcher. R.A.N.P. and A.C.S.-R. are master’s level public health research assistants. E.F.R., A.A. and M.B.-M. are adolescent health research experts. E.F.R. has an adolescent daughter on the autism spectrum and explicit permission from that child to report that as part of this particular journal article specifically. Our collective positionality is that we identify as people who are not autistic and who select to focus on research that we hope will benefit autistic people and society in general.

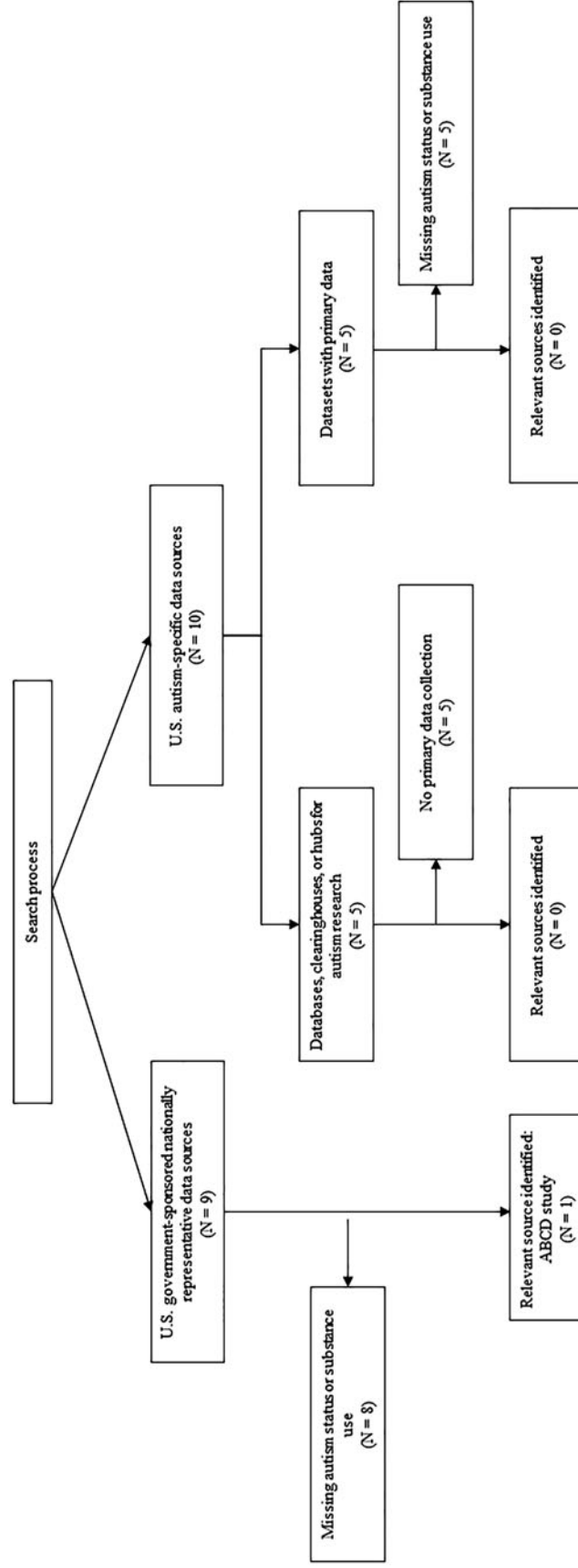
### **Data Sources on Alcohol and Marijuana Use for Autistic Adolescents**

Our inquiry into the availability of data sources to estimate the prevalence of alcohol and/or marijuana use by autistic adolescents began when we formulated a research question about the effectiveness of adolescent health-promoting interventions for autistic youth and young adults. To make a logical argument about the need for health-promoting (i.e., prevention-oriented) interventions, it was first necessary to make a statement about the prevalence of alcohol and marijuana use in our population of interest. As adolescent health researchers who have focused on general populations in the past, A.A., M.B.-M., and E.F.R. were accustomed to consulting data sets such as the Youth Risk Behavior Survey, the National Epidemiologic Survey on Alcohol and Related Conditions, and Behavioral Risk Factor Surveillance System, among others, to answer basic prevalence estimate questions about adolescent and young adult populations. We were surprised to discover that our usual go-to data sets did not include any information about autistic people. As newcomers to autism research, our next assumption was that we were simply unfamiliar with existing data sets that would yield the information we sought. To test out the idea that the information was available, we embarked on a structured process of exploring existing data sets. We also expanded our research team to include an expert in autism research (S.B.-F.) who could nominate autism-specific data sets that might contain the information we needed.

Working together, our team used a four-step process to identify potential data sources that might contain information about alcohol and/or marijuana use by autistic adolescents and/or young adults. First, we collaboratively generated a list of data sources that might contain both autism and substance use data. We brainstormed this list by drawing on the pre-existing knowledge of our research team combined with an Internet search. We excluded biobanks, biorepositories, or biological/imaging databases that do not collect any psychosocial data from autistic people and only collect biological data (e.g., brain tissues, imaging, protein variants, genetic data, and DNA samples). Second, two researchers independently visited the website of each data set to closely examine codebooks and questionnaires. Both researchers searched through the questionnaires for the variables of interest (i.e., a variable indicating the presence or absence of autism, and a variable indicating the presence or absence of alcohol use, marijuana use, or both). If we were unable to locate the survey online or were uncertain from the documentation that we reviewed whether the data set contained both autism and substance use information, we contacted the lead administrator of the data source using contact information acquired from the websites to inquire if the data would allow researchers to answer the following question: “What percentage of autistic youth drink alcohol and/or use marijuana?” Third, using a chain referral method, data set administrators were asked to name any additional data sources that might contain autism and substance use data. Fourth, to confirm that we were not misclassifying data sets, we conducted a literature review to verify that no research articles on autism and substance use had ever been generated by any of the data sets that we had classified as lacking the relevant data. Two researchers independently searched PubMed and Google Scholar using the keywords “autism and alcohol,” “autism and marijuana,” and “autism and cannabis” and examined the abstracts and full texts of peer-reviewed published articles that had analyzed the data sets we identified in steps 2 and 3. No misclassification errors were uncovered as a result of this literature review.

We identified a total of 19 U.S. data sources on child and/or adolescent health, disability, and/or substance use that might have contained both autism and substance use data (Fig. 1). Of these, 9 were government-sponsored and nationally representative adolescent health data sets not specific to autism and 10 were specifically for autism research.

The nine government-sponsored data sets are listed in Table 1. To the best of our knowledge, only one, the Adolescent Brain Cognitive Development (ABCD) study, can be used to estimate the prevalence of alcohol or marijuana use in autistic youth. ABCD is the largest long-term study of brain development and child health in the United States and is designed to assess brain maturation in the context of social, emotional, and cognitive development in addition to several health and environmental outcomes in a nationally representative sample of youth. ABCD has collected data on substance use and autism status from youth who were 9–10 years old in 2016–2017, and assessments will be performed annually for 10 years. This means that by 2021, ABCD data will be able to generate estimates of the prevalence of substance use among early-to-mid adolescents on the autism spectrum in the United States. However, a limitation of the



**FIG. 1.** Search process flowchart for the U.S. government-sponsored nationally representative and autism-specific data sources.

TABLE 1. U.S. GOVERNMENT-SPONSORED NATIONALLY REPRESENTATIVE AND AUTISM-SPECIFIC DATA SOURCES

<i>Name of data source</i>	<i>Abbreviation</i>	<i>Website</i>	<i>Type of data missing</i>
U.S. government-sponsored nationally representative data sources			
Adolescent Brain Cognitive Development	ABCD	<a href="https://abcdstudy.org">https://abcdstudy.org</a>	n/a <sup>a</sup>
Youth Risk Behavior Survey	YRBS	<a href="https://www.cdc.gov/healthyouth/data/yrbs/index.htm">https://www.cdc.gov/healthyouth/data/yrbs/index.htm</a>	Autism status
Monitoring the Future	MTF	<a href="http://monitoringthefuture.org">http://monitoringthefuture.org</a>	Autism status
National Longitudinal Study of Adolescent to Adult Health	Add Health	<a href="https://www.cpc.unc.edu/projects/addhealth">https://www.cpc.unc.edu/projects/addhealth</a>	Autism status
National Survey on Drug Use and Health	NSDUH	<a href="https://nsduhweb.rti.org/respweb/homepage.cfm">https://nsduhweb.rti.org/respweb/homepage.cfm</a>	Autism status
National Health and Nutrition Examination Survey	NHANES	<a href="https://www.cdc.gov/nchs/nhanes/index.htm">https://www.cdc.gov/nchs/nhanes/index.htm</a>	Autism status
CDC Survey of Pathways to Diagnosis and Services		<a href="https://www.cdc.gov/nchs/slaits/spds.htm">https://www.cdc.gov/nchs/slaits/spds.htm</a>	Frequency of alcohol and/or drug use
National Health Interview Survey on Disability	NHIS-D	<a href="https://www.cdc.gov/nchs/nhis/nhis_disability.htm">https://www.cdc.gov/nchs/nhis/nhis_disability.htm</a>	Frequency of alcohol and/or drug use <sup>b</sup>
National Survey of Children with Special Health Care Needs	NS-CSHCN	<a href="https://www.cdc.gov/nchs/slaits/cshcn.htm">https://www.cdc.gov/nchs/slaits/cshcn.htm</a>	Frequency of alcohol and/or drug use <sup>c</sup>
Autism-specific data sources			
Interactive Autism Network Research	IAN	<a href="https://iancommunity.org/cs/ian_research/overview">https://iancommunity.org/cs/ian_research/overview</a>	Frequency of alcohol and/or drug use
PEDSnet		<a href="https://pedsnet.org">https://pedsnet.org</a>	Frequency of alcohol and/or drug use <sup>d</sup>
Autism Genetic Resource Exchange	AGRE	<a href="http://research.agre.org/program/descr.cfm">http://research.agre.org/program/descr.cfm</a>	Frequency of alcohol and/or drug use
Autism Treatment Network	ATN	<a href="http://asatn.org">http://asatn.org</a>	Frequency of alcohol and/or drug use
Autism and Developmental Disabilities Monitoring Network	ADDM	<a href="https://www.cdc.gov/ncbddd/autism/addm.html">https://www.cdc.gov/ncbddd/autism/addm.html</a>	Frequency of alcohol and/or drug use

<sup>a</sup>ABCD does collect information on both autism and alcohol/marijuana use.

<sup>b</sup>NHIS-D includes frequency of alcohol use questions only for individuals aged 18 years and older, not for all adolescents.

<sup>c</sup>NS-CSHCN asks a parent or guardian if there was a time when the child needed substance abuse treatment or counseling. This is not a good proxy for frequency of youth substance use.

<sup>d</sup>PEDSnet could identify use of alcohol/marijuana if a diagnostic code was entered for the patient (e.g., for alcohol dependence) or if the patient was given a drug to treat them for a substance use disorder.

ABCD data are that the number of autistic individuals contributing data may be relatively few ( $N = \sim 300$ ), and therefore, estimates based on this relatively small sample may be imprecise. Each of the other government-sponsored data sources are missing autism diagnosis status, substance use status, or did not collect substance use status in a way that would answer our research question (e.g., only asked if a child was referred to substance abuse treatment).

Of the 10 autism-specific data sources, none could be used to study substance use in autistic youth. Of the 10, only 5 contained primary data: Interactive Autism Network Research, PEDSnet, Autism Genetic Resource Exchange, Autism Treatment Network, and Autism and Developmental Disabilities Monitoring Network (Table 1). The other five were databases, repositories, clearinghouses, or hubs for autism research, which did not collect primary data (e.g., National Database for Autism Research, Simons Foundation Autism Research Initiative). Of the five sources with primary data, only one has information relevant to substance use. PEDSnet contains longitudinal data extracted from electronic

health records but can only identify use of alcohol or marijuana if a diagnostic code was entered for the patient (e.g., for alcohol dependence) or if the patient was given a drug treatment, which does not permit inferences about the frequency of substance use.

Although we strived to be exhaustive in our search for U.S. data sets, it is possible that we did not identify new or emerging research projects that will offer researchers the opportunity to study substance use in autistic youth. It is also possible that some of the data sets that do not presently collect autism status may do so in the future or data sets that do not collect substance use data may do so. It would be worthwhile to publish an update in several years. In addition, helpful inferences may be drawn from studies of non-U.S. youth if there are nationally representative data sets from other nations. However, because youth substance use patterns can reflect cultural norms and laws specific to a nation, population-based estimates of substance use by the U.S. autistic youth should be prioritized by substance use and autism researchers in our country.

## Recommendations

In this investigation, we were not able to identify any data sources that, to the best of our knowledge, can currently be used to estimate the prevalence of alcohol and/or marijuana use among autistic adolescents in the United States, and only one study (ABCD) that is expected to one day yield prevalence information. As adolescent health researchers and an autism researcher, we are concerned about the dearth of information available and inattention to this issue. Based on the results of this investigation, our recommendations are as follows:

- The NIH, and the NIAAA and NIDA, specifically, should prioritize funding data collection from autistic youth and adults on alcohol and marijuana use, misuse, hazardous use, dependence, and use disorders. While some affiliated with the NIAAA and NIDA may be under the impression that autism is a mental health issue, and therefore, all research involving autistic people should be funded by the National Institute of Mental Health (NIMH), this viewpoint has limitations. Just as the NIAAA and NIDA fund studies of alcohol and drug use in people with HIV (they do not refer all projects involving HIV+ individuals to the institute on infectious disease), studies on alcohol and drug use in minors (they do not refer all projects involving underage minors to the institute on child health and development), and studies on alcohol and drug use in elders (they do not refer all projects involving older adults to the institute on aging), they should not decline to fund studies on alcohol use and drug use by autistic adults based on the sole consideration that the population is presently considered under the purview of the NIMH. The percentage of the U.S. population that is autistic is at least as sizable as the percentage of the population that is transgender, or has breast cancer, or has been incarcerated. If the NIAAA and NIDA see these small-sized but vulnerable populations as worthy of study because of the populations' higher-than-average risk of alcohol and drug use, they should also recognize the possibility of higher-than-average risk by autistic people and see their way clear to prioritizing research on this population. Systematic exclusion of autistic people from the NIAAA- and NIDA-funded studies worsens health inequities and is unethical.
- Research studies that set out to create nationally representative data sources that will answer questions about autism and substance use need to be constructed in a way that will permit multiple indicator variables for the presence or absence of autism to be created. For example, one way to define the presence or absence of autism in a research participant would be based on that person's self-report. Another way to define the presence or absence of autism would be based on their diagnosis using the Autism Diagnostic Observation Schedule, which only a qualified clinician can carry out and which takes multiple hours of time. A third way to define the presence or absence of autism would be based on a review of a diagnostician's neuropsychology report. There are additional ways that the presence or absence of autism in an individual could be collected by a research study, and because each has advantages and disadvantages, and because different researchers may have reasons for

wanting to define autism according to more or less strict criteria, ideally research studies will use multiple methods for assessing autism status and therefore contain multiple indicator variables.

- Similarly, research studies designed to answer questions about autism and substance use should involve researchers with substance use expertise so that the questions about alcohol and marijuana use are reliable, valid, and allow characterization of drinking or drug use style according to multiple dimensions. For example, relevant questions about alcohol and marijuana use are age of first drink or use, frequency of use, quantity of use per day or within a certain number of hours, expectancies, consequences of use, and indicators of alcohol use disorder. A sole item on alcohol use and/or marijuana use will not provide enough data for a characterization of autistic individuals' drinking styles or prevalence of substance use disorder risk.
- We have received comments that there are European data sets that might answer questions about autism and substance use and that the existence of such data sets obviates or reduces the need for U.S. sources of information on this topic. On the one hand, we agree that studies based outside the United States with non-U.S. samples can helpfully inform the field—particularly large registry studies (such as Butwicki et al.) that permit the calculation of risk of substance use disorder in autistic adult populations. On the other hand, when it comes time to think about the details of how, when, and why autistic youth and young adults use alcohol and/or marijuana, and what would help them do so more safely, information that reflects the local context, culture, norms, and laws—at least at the level of the nation—is going to be important.
- We would like to make clear that at this time there is no evidence that interventions to prevent substance misuse by autistic people are needed any more than are interventions to prevent substance misuse by allistic people. Alcohol and drug use are known to have pharmacological effects that may be as beneficial for autistic people as they are for allistic people in some settings, including reductions in social anxiety and disinhibition.<sup>21,22</sup> However, because the benefits of alcohol and marijuana use can be outweighed by consequences that include physiological or psychological dependence, impaired decision-making, increased risk of injury, depression, anxiety, and increased risk of physical health problems including certain cancers, if autistic people or a subset of autistic people are using alcohol and drugs at higher rates than the general population, it is important that prevention efforts are initiated. Not only will this benefit the autistic population, it will also benefit a percentage of the people with problematic drug and/or alcohol use—that is, the percentage who are autistic.

## Conclusion

Autistic youth deserve the benefit of effective substance misuse prevention programming, but until the prevalence of substance use, its etiology, and risk and protective factors for use by autistic youth are clear, the development of prevention

programming will remain stymied. The Interagency Autism Coordinating Committee, which coordinates autism research efforts within the Department of Health and Human Services, has indicated that meeting the needs of autistic individuals as they transition to adulthood is a priority research area.<sup>23</sup> As the number of autistic youth increases and these adolescents transition into adulthood, better understanding of the substance use patterns of these individuals is of great importance for developing health promotion efforts that appropriately and fully serve the needs of autistic youth. We look forward to the availability of robust data that will permit inferences about substance use by autistic youth and subsequent development of appropriate health promoting strategies to benefit them.

#### Authorship Confirmation Statement

A.A. assisted in conceptualizing and designing the study, conducted analyses, drafted the initial article, and revised the article. M.B.-M., S.B.-F., and E.F.R. conceptualized and designed the study, reviewed results, and critically reviewed the article. R.A.N.P. and A.C.S.-R. conducted analyses and reviewed the article. All co-authors have reviewed and approved the article before submission. This article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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