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Assessing STI and HIV risks among autistic individuals: Implications for healthcare access and intervention

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ABSTRACT

Background: Sexually transmitted infections (STIs) are prevalent in the general population. Autistic individuals, both with and without intellectual disability (ID), are potentially at increased risk due to gaps in sexual health education, increased vulnerability to sexual abuse, victimization, and disparities in access to primary and reproductive health care.
Objective: This study aims to identify the prevalence of STIs and HIV among a national sample of Medicaid-enrolled autistic individuals and their peers, identifying opportunities for intervention.
Methods: Characteristics of autistic Medicaid beneficiaries with and without ID were stratified to compare individuals with and without chlamydia, gonorrhea, syphilis, and HIV. Period prevalence of outcomes among Medicaid enrollees with autism spectrum disorder (ASD) only, ID only, and both (ASD and ID) were compared.
Results: Among autistic individuals, the prevalence of STIs and HIV was highest in the 22–30 age group and among Black enrollees, underscoring the importance of prioritizing their care through screening and preventive health measures.
Conclusions: The results emphasize gaps in addressing the sexual and reproductive health needs of autistic individuals. Policymakers should prioritize funding for clinician training and increased healthcare access to address the sexual health needs of this population, especially those from additionally marginalized communities. It is vital to provide inclusive care that addresses the unique challenges faced by autistic individuals in accessing appropriate sexual health resources.

1. Introduction

In the United States, around 1.5 million children have been formally diagnosed with autism spectrum disorder (ASD).[1,2] Estimates for autistic adults are less precise due to insufficient public health data, but it's suggested that 1 in 45 adults, ages 18–84, may be autistic.[1] While ASD is lifelong, there is limited understanding of the sexual and reproductive healthcare needs of autistic adults. The Centers for Disease Control and Prevention (CDC) have reported over 2.5 million cases of syphilis, gonorrhea, and chlamydia in the U.S., with an 80 % increase in syphilis cases over five years.[3] However, these data do not specifically address autistic individuals.

STIs, if treated, can often be cured, but untreated STIs can lead to severe health issues such as reproductive health problems, increased HIV risk, and cancers.[4] Those with limited access to preventive health services, including many autistic individuals, are particularly vulnerable. Research indicates that subgroups such as those with lower socioeconomic status, mental health conditions, substance use disorder, or low social support are at elevated risk for STIs.[5–8] Emerging evidence also suggests that individuals with intellectual and developmental disabilities (IDD), including autism, face increased STI risks.[9–11]

Despite autistic individuals engaging in sexual behaviors at similar rates to their non-autistic peers nearly 40 % of autistic youth receive no sexual education in school or community settings.[12] Many autistic individuals also face healthcare access disparities, hindering their ability to obtain STI information and testing.[13] This lack of sexual health education and care increases their risk for adverse sexual experiences, higher infection rates, and untreated STIs.[14] Yet, specific prevalence estimates for STIs among autistic individuals are lacking.

Previous research on STI prevalence among the disabled population

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has often grouped disabilities together, limiting our understanding of specific IDD diagnoses.[9,15] Schmidt and colleagues investigated STI prevalence among privately insured individuals with IDD and found that beneficiaries with IDD were statistically less likely to have an STI diagnosis. However, individuals with IDD aged 20–24 had significantly lower odds of STI testing than their same-age non-disabled peers.[9] Parekh and colleagues used data from the National Survey on Drug Use and Health to investigate the prevalence of STIs among women of reproductive age with sensory, cognitive, or physical disabilities and found that women with disabilities had higher prevalence of STIs.[30] Given the paucity of research regarding STIs and disability, the present study provides baseline prevalence estimates for autistic individuals and those with ID enrolled in Medicaid, serving as a foundation for more targeted research.

Medicaid, a key insurance program for individuals with disabilities, including autism, provides extensive data on their health.[16] Medicaid claims have been used in various studies on autistic children, adolescents, and young adults.,[17–20] and more recently, on middle-aged and older autistic adults.[21–24] National Medicaid claims allow for diagnostic comparisons and prevalence estimates across diagnoses and conditions.

This study aims to estimate the prevalence of chlamydia, gonorrhea, syphilis, and HIV among Medicaid-enrolled autistic individuals and those with ID. These STIs were selected due to their prevalence in the general population, public health significance, and prior study inclusion.[25–27] We hypothesize that the prevalence of STIs among autistic adults with or without ID will be comparable to or higher than in the general Medicaid-insured population.

2. Methods

This report uses data obtained from the 2016 national Transformed Medicaid statistical Information System (T-MSIS) Analytic Files, which consist of a personal summary file containing individual demographic information and eligibility classification, as well as service files for various types of healthcare, including inpatient, outpatient/ambulatory therapy, long-term care, and prescription drug claims. The service files offer specific information about diagnoses, treatments, and expenditure details.

In line with prior research examining STI prevalence, this study sample included individuals with ASD and ID aged 14–50 who were enrolled in Medicaid for a minimum of 9 months in 2016 (n = 964,460) to account for administrative churning.[28,29] Within this sample, individuals with ASD and ID were identified using validated algorithms from the Chronic Condition Warehouse used in previous studies.[30] The algorithm requires 1 inpatient or 2 other (non-drug) claims with a diagnosis associated with autism spectrum disorder (ICD-9 codes 299. xx or ICD-10-CM F84. x) or intellectual disability (ICD-9 codes 317. xx – 319. xx or ICD-10-CM F70-F79). We queried for both ICD-9 and ICD-10 codes to ensure a full capture of codes after ICD-10 implementation in 2015.

Our primary outcomes of interest were the period prevalence (the proportion of a population with a condition during a specific time period) of syphilis, chlamydia, gonorrhea, and HIV. We recognize that hepatitis B and C can also be sexually transmitted; however, the overall prevalence of hepatitis B is low in the United States due to universal vaccination and screening and the predominant mode of hepatitis C acquisition is through injection drug use. Further, while HIV is primarily classified as a sexually transmitted infection (STI), we grouped gonorrhea, syphilis, and chlamydia together as STIs due to their collective prevalence, shared modes of transmission, and the common practice of combined reporting in other research and surveillance. We report HIV separately because it has distinct transmission characteristics, treatment options, and long-term health implications that warrant individual consideration. This separation allows for a more nuanced analysis of the data and aligns with previously established coding practices, facilitating future comparisons across studies.[24–26] ICD codes for syphilis, chlamydia, gonorrhea, and HIV are provided in the supplementary material.

We calculated descriptive statistics of autistic beneficiaries with and without ID stratified by these outcomes to compare individuals with and without the STIs and HIV. The period prevalence, defined in this study as the unadjusted proportion of individuals with at least one STI or HIV diagnosis in 2016, was calculated separately across three distinct groups.

2.1. Community involvement

Our research actively involved autistic collaborators and stakeholders from the inception of the study. Specifically, these collaborators contributed in several key phases of the research process, including the development of research objectives and the interpretation of findings. Their insights were crucial in shaping the study's objectives and methodology. Additionally, our research team includes autistic scientists who contribute their expertise and lived experiences, ensuring the study remains inclusive and reflective of the community's pressing questions. These members of the team supported abstracts and manuscript drafting, developing conclusions, and revising. Our team maintains ongoing communication with our collaborators, seeking their feedback at each stage of the research process. This collaborative approach aims to enhance the validity and impact of our findings, fostering a research environment that prioritizes the perspectives and well-being of autistic individuals.

3. Results

Descriptive statistics of autistic adults with and without ID, stratified by outcomes of interest, are presented in Table 1. In Table 1, "eligibility group" refers to the pathway through which individuals qualify for Medicaid, either through poverty-related criteria or disability-related criteria; autistic individuals may qualify under either pathway depending on their specific circumstances and state program. The last column indicates overall prevalence of any STI and HIV across all study subgroups (ASD, ID, ASD + ID). Overall, 5399 (0.56 %) Medicaid beneficiaries in our study population had a claim for an STI and/or HIV during the study period. Among this group of Medicaid beneficiaries with STIs/HIV, 36.04 % (N = 1946) fell within the 22–30 age group, 48.99 % (N = 2465) were Black, and 55.57 % (N = 3000) were Female. Chlamydia and HIV were the two most prevalent STIs among this Medicaid population.

Table 2 compares period prevalence of chlamydia, gonorrhea, syphilis, and HIV among adults with ASD only, ID only, and both ASD and ID. In this one-year study of Medicaid beneficiaries, we found that in total, 0.17 % had at least one encounter for chlamydia, 0.10 % for gonorrhea, 0.04 % for syphilis, and 0.30 % for HIV. Overall, 0.56 % Medicaid beneficiaries in our study population of adults with ASD, ID, and both ASD and ID, had a claim for an STI and/or HIV during the study period. Among adults with ASD only, 0.17 % had a claim for chlamydia, 0.07 % for gonorrhea, 0.03 % for syphilis, and 0.17 % for HIV. Among adults with ASD and ID, 0.06 % had a claim for chlamydia, 0.03 % for gonorrhea, 0.02 % for syphilis. and 0.13 % for HIV. Finally among those with ID without ASD in our sample, 0.21 % had a claim for chlamydia, 0.10 % for gonorrhea, 0.06 % for syphilis, and 0.41 % for HIV. This subgroup overall had a 0.73 % prevalence rate for any STI and/or HIV in the one-year period. Prevalence of any STI and/or HIV was highest among adults with ID without ASD, and lowest among adults with ASD and ID.

4. Discussion

Our findings reveal lower period prevalence rates of STIs and HIV among Medicaid-enrolled autistic adults with and without ID, though thousands are still affected. Most cases were found in the 22–30 age

Table 1
Descriptive characteristics of Medicaid-enrolled Autistic individuals (aged 14–50) with and without intellectual disability stratified by STI and HIV prevalence in 2016.

	Chlamydia				Gonorrhea				Syphilis			
	No		Yes		No		Yes		No		Yes	
	(N = 962,797)		(N = 1663)		(N = 963,669)		(N = 791)		(N = 964,029)		(N = 431)	
	N	%	N	%	N	%	N	%	N	%	N	%
Age Group												
14-17	197318	20.49 %	294	17.68 %	197460	20.49 %	152	19.22 %	197584	20.50 %	28	6.50 %
18-21	151427	15.73 %	579	34.82 %	151808	15.75 %	198	25.03 %	151954	15.76 %	52	12.06 %
22-30	277029	28.77 %	640	38.48 %	277358	28.78 %	311	39.32 %	277499	28.79 %	170	39.44 %
31-40	186923	19.41 %	116	6.98 %	186947	19.40 %	92	11.63 %	186949	19.39 %	90	20.88 %
41-50	150100	15.59 %	34	2.04 %	150096	15.58 %	38	4.80 %	150043	15.56 %	91	21.11 %
Eligibility Group												
Poverty	93743	9.74 %	389	23.39 %	93967	9.75 %	165	20.86 %	94072	9.76 %	60	13.92 %
Disability	793288	82.39 %	993	59.71 %	793772	82.37 %	509	64.35 %	793960	82.36 %	321	74.48 %
Other[b]	75766	7.87 %	281	16.90 %	75930	7.88 %	117	14.79 %	75997	7.88 %	50	11.60 %
Race												
White	536780	55.75 %	456	27.42 %	537045	55.73 %	191	24.15 %	537138	55.72 %	98	22.74 %
Black	175411	18.22 %	798	47.99 %	175779	18.24 %	430	54.36 %	176002	18.26 %	207	48.03 %
Asian/Pac	27626	2.87 %	24	1.44 %	27643	2.87 %	a	a	27647	2.87 %	a	a
Hispanic/Latino	118375	12.29 %	235	14.13 %	118512	12.30 %	98	12.39 %	118531	12.30 %	79	18.33 %
More than One	6014	0.62 %	20	1.20 %	6025	0.63 %	a	a	6032	0.63 %	a	a
Native Indian/AK	8175	0.85 %	21	1.26 %	8188	0.85 %	a	a	8193	0.85 %	a	a
Missing	90416	9.39 %	109	6.55 %	90477	9.39 %	48	6.07 %	90486	9.39 %	39	9.05 %
Sex												
M	607912	63.14 %	404	24.29 %	608073	63.10 %	243	30.72 %	608056	63.07 %	260	60.32 %
F	354885	36.86 %	1259	75.71 %	355596	36.90 %	548	69.28 %	355973	36.93 %	171	39.68 %

	HIV				Any STI			
	No		Yes		No		Yes	
	(N = 961,535)		(N = 2925)		(N = 959,987)		(N = 5399)	
	N	%	N	%	N	%	N	%
Age Group								
14-17	197529	20.54 %	83	2.84 %	197131	20.53 %	490	9.08 %
18-21	151751	15.78 %	255	8.72 %	151191	15.75 %	985	18.24 %
22-30	276693	28.78 %	976	33.37 %	276174	28.77 %	1946	36.04 %
31–40	186295	19.37 %	744	25.44 %	186263	19.40 %	987	18.28 %
41-50	149267	15.52 %	867	29.64 %	149228	15.54 %	991	18.36 %
Eligibility Group								
Poverty	93897	9.77 %	235	8.03 %	93373	9.73 %	763	14.13 %
Disability	791884	82.36 %	2397	81.95 %	791933	82.49 %	3951	73.18 %
Other[b]	75754	7.88 %	293	10.02 %	74681	0.0778	685	0.1268
Race								
White	536504	55.80 %	732	25.03 %	539818	56.23 %	1419	26.28 %
Black	174753	18.17 %	1456	49.78 %	174549	18.18 %	2645	48.99 %
Asian/Pac	27606	2.87 %	44	1.50 %	27627	2.88 %	76	1.41 %
Hispanic/Latino	118093	12.28 %	517	17.68 %	118035	12.30 %	876	16.23 %
More than One	6016	0.63 %	a	a	6172	0.64 %	46	0.85 %
Native Indian/AK	8189	0.85 %	a	a	8226	0.86 %	34	0.63 %
Missing	90374	9.40 %	151	5.16 %	85560	8.91 %	303	5.61 %
Sex								
M	606645	63.09 %	1671	57.13 %	606519	63.18 %	2399	44.43 %
F	354890	36.91 %	1254	42.87 %	353468	36.82 %	3000	55.57 %

[a] Censored values due to values being 1–11 or being the second lowest category.
[b] Other includes missing due to censorship concerns, if missing was >10 individuals, it was below 1 % of the category.

Table 2
STI and HIV prevalence among Medicaid-enrolled individuals (aged 14–50) with ASD only, ID only, and both ASD and ID, in year 2016.

	ASD without ID		ID without ASD		ASD and ID	
Chlamydia	410	0.17 %	1145	0.21 %	108	0.06 %
Gonorrhea	170	0.07 %	568	0.10 %	53	0.03 %
Syphilis	62	0.03 %	338	0.06 %	31	0.02 %
HIV	420	0.17 %	2277	0.41 %	228	0.13 %
Any STI and/or HIV	973	0.41 %	4033	0.73 %	393	0.22 %

group and among Black individuals, highlighting the need for targeted interventions. Racial disparities observed may be influenced by factors such as access barriers to healthcare, socioeconomic status, and cultural stigma, which can hinder effective sexual health education and testing.[25] These findings may be consistent with prior research indicating lower STI prevalence among autistic individuals and those with ID compared to the general population. For example, Giannouchos et al. reported higher STI rates among all Medicaid beneficiaries in South Carolina, with 6.3 % for chlamydia, 3.2 % for gonorrhea, 0.5 % for syphilis, and 0.8 % for HIV.[24] Disparities in STI prevalence and testing underscore the need for targeted sexual health education and inclusive healthcare practices.

Several factors may contribute to the observed lower STI rates in this population. Limited access to primary care, including STI screening, is a significant barrier.[31,32] Traditional STI testing venues may not be welcoming or accessible to autistic individuals due to a lack of autism-specific communication and behavioral techniques, sensory-friendly environments, and accommodations for unique needs. These barriers can result in lower screening rates and undiagnosed

infections. Additionally, healthcare providers may assume autistic individuals and those with ID are less sexually active, leading to fewer screenings despite evidence to the contrary.[12] These assumptions result in missed preventive care opportunities and long-term adverse health outcomes.

Methodological limitations, such as incomplete claims data and potential misclassification of diagnoses, could also explain the lower observed rates. Additionally, the timeframe from when the data was collected may affect the relevance of our findings. Furthermore, limitations associated with these types of datasets, including a lack of inclusivity regarding sex and gender, should be acknowledged, as they may impact the comprehensiveness of our analysis. Nevertheless, thousands of autistic individuals with and without ID still contract STIs. While the timeframe of data collection presents some challenges, the insights gained from Medicaid data remain valuable for understanding large-scale health trends and service utilization among autistic individuals. This data can take a significant amount of time to process and compile due to the complexities of administrative reporting and the need for rigorous quality control. Future research should examine the severity of these infections and ensure affected individuals receive appropriate treatment and follow-up care. Addressing disparities in access to care and screening practices requires multifaceted interventions, including anti-ableism training for healthcare providers, improving service accessibility, and developing inclusive resources for transitioning from pediatric to adult care.

5. Conclusion

Autistic individuals with and without ID may be at increased risk for contracting STIs and HIV, and the lower prevalence rates observed in this study likely underestimate the true burden due to disparities in access to care and screening practices. Medicaid is uniquely positioned to bridge these gaps by connecting individuals to comprehensive reproductive and preventive care. Today, United States Medicaid coverage of family planning benefits for adults includes STIs and HIV screening along with expedited partner therapy in some states.[33] However, the extent to which these services are provided and adapted to meet the diverse sexual health care needs of autistic individuals is unclear. Therefore, Medicaid should expand targeted sexual health programming specifically designed for autistic individuals and implement training for healthcare professionals on the unique needs and communication preferences of this population. Additionally, establishing clear guidelines for the inclusion of sexual health services within Medicaid programs will ensure that autistic individuals receive equitable access to necessary care. These steps are critical toward reducing STI prevalence and promoting safe, healthy sexual experiences for autistic individuals.

CRediT authorship contribution statement

Kiley J. McLean: Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Formal analysis. **Molly Sadowsky:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Arina Chesnokova:** Writing – review & editing, Supervision. **Kyle Chvasta:** Writing – review & editing, Writing – original draft, Supervision, Conceptualization. **Wei-Lin Lee:** Writing – review & editing, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Jonas Ventimiglia:** Writing – review & editing, Methodology, Formal analysis, Data curation, Conceptualization. **Lindsay Shea:** Writing – review & editing, Supervision, Software, Resources, Project administration, Funding acquisition, Data curation, Conceptualization.

Declaration of competing interest

The authors have no conflicts of interest to declare. This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreements UT6MC45902 Autism Transitions Research Project (ATRP) and UT2MC39440 Autism Intervention Research Network on Physical Health (AIR-P). The information, content, and/or conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. Preliminary findings were presented at the INSAR Annual Meeting in 2023.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2025.101780.

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