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Human immunodeficiency virus diagnosis and care among adults with intellectual and developmental disabilities who are publicly insured

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Abstract

Background This study aimed to assess the prevalence of human immunodeficiency virus (HIV) testing, HIV diagnosis and receipt of HIV care among adults with intellectual and developmental disabilities (IDDs) who are publicly insured in the USA.
Design This study is a cross-sectional analysis of Medicare–Medicaid linked data of adults with IDD who were publicly insured in 2012 (n = 878 186).
Methods We estimated adjusted prevalence ratios of HIV testing, diagnosis and receipt of antiretroviral therapy (ART). We also identified the relationship between predisposing (age, gender, race and ethnicity), enabling (Medicare, Medicaid or both; rural status; geographical location; and county income) and need-related characteristics (IDD diagnosis and other co-occurring conditions) associated with these outcomes.
Results Only 0.12% of adults with IDD who had no known HIV diagnosis had received an HIV test in the past year. The prevalence of HIV diagnosis among adults with IDD was 0.38%, although differences by type of IDD diagnosis were observed. Prevalence of HIV diagnosis differed by type of IDD. Among adults with IDD who were living with HIV, approximately 71% had received ART during 2012. The adjusted analyses indicate significant racial disparities, with Black adults with IDD making up the majority (59.11%) of the HIV-positive IDD adult population.
Conclusions Adults with IDD are a unique priority population at risk for HIV-related disparities, and the level of risk is differential among subtypes of IDD. People with IDD, like other people with disabilities, should be considered in prevention programming and treatment guidelines to address disparities across the HIV care continuum.

Keywords developmental disabilities, healthcare disparities, HIV, intellectual disability, medical assistance (Medicare/Medicaid)

Introduction

People with disability are an internationally recognised priority population for human immunodeficiency virus (HIV) prevention and treatment [World Health Organization (WHO) 2021, 2022]. This recognition stems from well-established systemic and interpersonal barriers to engaging health care, including HIV prevention programmes and HIV

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care (WHO 2021). There are few HIV-related epidemiological research focused on people with disability (WHO 2021) and fewer inquiries of people with intellectual and developmental disabilities (IDDs).

IDDs are conditions typically present at birth or shortly after that have an impact on a person's cognitive, physical or psychosocial development. Estimates in 2019 suggest that there were 178 million people with IDD globally (Institute for Health Metrics and Evaluation 2019). IDD-specific conditions include Down syndrome, autism spectrum disorders (ASDs), fetal alcohol spectrum disorders and other intellectual disabilities (IDs). IDDs have broad effects on a person's development, which may lead to societal beliefs and biases about the sexual and social interactions of people with IDDs. Because of these perceived differences, public health and medical research has largely classified people with IDD as asexual or sexually inactive (Thompson *et al.* 2014; Streur *et al.* 2019). Perceiving people with IDD as asexual is inaccurate and creates a public health gap for those living with IDDs as they achieve or desire sexual or other intimate relationships.

Risk factors for HIV are present among people with IDD. Although people with IDD do engage in and desire consensual sexual contact or intimate relationships (Black & Kammes 2019), sexual health education and HIV prevention efforts for this population are lacking (Lunsky *et al.* 2017; Medina-Rico *et al.* 2018; Exell *et al.* 2022). Family members and healthcare providers are uncomfortable or unsure about discussing sexuality (Medina-Rico *et al.* 2018; Brown & Mccann 2019; Roach *et al.* 2019; Streur *et al.* 2019). Additionally, an estimated 32.9% of people with IDs are sexually assaulted (Tomsa *et al.* 2021). These factors increase the risk of HIV for people with IDD.

Barriers accessing health care and receiving patient-centred care are well documented among people with IDDs (Morris *et al.* 2019; Smith *et al.* 2021). These access barriers, provider beliefs and HIV risk underscore the need for epidemiological research on HIV prevention and care among people with IDD (Lunsky *et al.* 2017; Tun & Leclerc-Madlala 2017). Existing research is outdated or focused on single-site contexts but indicates that people with IDD have lower prevalence of HIV testing than people without IDD (Neri *et al.* 2007). Multiple studies assessing health outcomes among people living with HIV and IDD have been published from Canada. In Ontario, there were no differences in HIV prevalence between people with and without IDD (Lunsky *et al.* 2017). However, people living with HIV and IDD were more likely to have mental health disorders, including psychotic disorders and substance use disorders (SUDs) (Lunsky *et al.* 2017; Durbin *et al.* 2017a). People living with HIV and IDD in Canada were also more likely to have social needs related to food security, public transportation and self-care that impact HIV care delivery (Durbin *et al.* 2017b).

Objective

Given the lack of recent or large-scale research on HIV testing and care among adults with IDD in the USA, this study was designed to examine (1) the prevalence of HIV diagnosis and testing among publicly insured US adults with IDD and (2) the receipt of HIV-related care [i.e. antiretroviral treatment medication (ART)] among adults with IDD in our sample diagnosed with HIV. We estimated prevalence of HIV-related outcomes and examined factors associated with HIV-related healthcare use. To better explicate receipt of care among people with different IDD diagnoses and to refine recommendations, we evaluated differences in receipt based on type of IDD diagnosis.

Methods

We implemented a cross-sectional design for both research questions. This study was reviewed and approved by Augusta University's Institutional Review Board (no. 1413487) prior to analysis. Positionality statements of the authors are available in Appendix A.

Data source

We used the 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS 2012). MMLEADS-2012 source data include Medicaid MAX claims and Medicare claims files, which are aggregated and de-duplicated to contain annual counts of services and costs of services on dual-eligible beneficiaries, beneficiaries enrolled in Medicaid on the basis of disability and Medicare-only

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beneficiaries. MMLEADS-2012 is the most recent aggregated data source containing necessary variables for our research questions. The more recent MMLEADS-2016 does not contain chronic health condition variables such as HIV. Because HIV has largely been unexplored among adults with IDDs, this research lays the groundwork for future examination.

Sample

The data included 1 610 400 beneficiaries of any age meeting Chronic Conditions Warehouse (CCW) criteria for a variety of IDDs: 'ASDs', 'IDs and related conditions' and 'learning disabilities', which included developmental conditions such as developmental disorders of speech and language, developmental disorder of motor function, central auditory processing disorder and dyslexia/alexia. Specific ICD-9 CM and ICD-10 codes associated with these IDDs can be found on the CCW website. We included only those adult beneficiaries aged 18–64 years with fee-for-service Medicare and/or Medicaid plans, because managed care plans did not have reliably observable claims for conditions from source data. A total of 548 912 individuals aged 17 and younger were excluded, and 132 672 adults aged 65 and older were excluded. We also excluded 50 630 adults with Medicare Advantage (managed care). The total analytic sample included 878 186 adults with IDD.

Outcome variables

Outcome variables are aligned with HIV prevention priorities and the diagnosis-based HIV care continuum, and diagnostic and procedure codes are in Appendix B and cohort-related codes in Appendix C.

Testing

We assessed the number of HIV screening tests paid for in part or full by Medicare or Medicaid over the course of the calendar year. Procedure codes were used to identify the number of HIV tests. This variable is available in the MMLEADS data, with the values of (0) no tests, (1) one test, (2) two tests, (3) three or more tests and null/missing. We dichotomised this variable for analytic purposes (i.e. no test versus any test).

Diagnosis

The diagnosis-based HIV care continuum calculates the proportion diagnosed based on the number of people with diagnosed and undiagnosed infection. We did not have undiagnosed infection cases; therefore, we identified people with IDD currently (as of 2012) diagnosed with HIV/acquired immunodeficiency syndrome (AIDS) through the use of CCW HIV algorithm, which uses a conservative 2-year look-back period to evaluate claims for at least *one inpatient claim* or *two non-drug claims* of diagnosis codes indicating that a person has HIV. The denominator for analyses was the full included sample of all adults with IDD. Because existing literature suggests that maternal HIV infection can result in fetal HIV infection and is linked to subsequent IDD after birth, we also calculated age of diagnosis from existing CCW variables that look back to 1999 to identify individuals meeting claims for HIV when they were aged 18 or younger.

Receipt of care

We operationalised receipt of care as those receiving ART through annual prescription drug fills identified in Medicaid and/or Medicare claims. The denominator for analysis was adults with HIV and IDD. Although receipt and retention of HIV care usually include having at least one CD4 or viral load test in a given year, MMLEADS-2012 did not contain those variables.

Predisposing, enabling and need characteristics

We used Andersen's behavioural model of health service use (Andersen & Davidson 2007), to define variables contributing to disparities in care. Predisposing variables were sex (male/female), race/ethnicity (White, Black, Asian/Pacific Islander, other and Hispanic) and age in years (categorical: 18–25, 26–35, 36–45, 46–55 and 56–65). Enabling variables were eligibility type (Medicaid only on the basis of disability, Medicare only or dual eligible) and contextual characteristics that influence the healthcare environment the person lives within. These included rural status (yes/no), US Census region

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(Northeast, Midwest, Southeast, West and other – e.g. Puerto Rico) and median county income (continuous). Need characteristics included type of IDD diagnosis [i.e. ID only (n = 676 124), autism only (n = 57 136), autism and ID (n = 117 356), or other developmental disability (DD) (n = 27 570)], dichotomous significant mental illness (SMI) defined as meeting any current CCW claims or criteria for depression, bipolar disorder or schizophrenia (yes SMI and no SMI), and dichotomous SUD defined as meeting current CCW claims or criteria for alcohol use disorders, opioid use disorders or other drug use disorders (yes SUD and no SUD) (Centers for Medicare and Medicaid Services 2022). The reference variables were age of 18–25 years, male, White, Medicaid with disability, non-rural status, living in the Northeast, having ID only, no SMI and no SUD.

Data analysis

Data were analysed using STATA/MP 16.1. Race/ethnicity had the greatest missingness (11.8%), but model testing including cases as 'missing' resulted in similar estimates as final models excluding those cases. Rural status was missing in 2.4% of cases. Because of the large sample size, missingness was deemed unproblematic and we deleted cases listwise. For the US Census region, the 'other' region (comprising territories such as Puerto Rico and others) had too few cases and was dropped in the analyses.

Demographics for adults with IDD with and without HIV diagnosis were compared using chi-squared analyses with Cramér's V effect size measures. Each of our outcome variables (HIV testing, diagnosis and receipt of ART) was dichotomous. These outcomes were modelled using a generalised linear model with a Poisson distribution and robust standard errors to estimate adjusted prevalence ratios (aPRs) using predisposing, enabling and need covariates. We assessed multicollinearity of contextual enabling characteristics using variance inflation factors >5 and pairwise correlation coefficients >0.80. None of these variables were deemed problematic. Lastly, we performed a sensitivity analysis to assess if our estimates were robust to misspecification of the model distribution. Methods and results of the sensitivity analysis are available in Appendix D.

Role of funding source

The funder had no role in the design, analysis, interpretation or writing of this study.

Results

Sample characteristics

Demographic characteristics of the sample are provided in Table 1. People living with HIV and IDD were more likely to be between 36 and 55 years of age, recipients of Medicaid only (on the basis of disability) and living in non-rural counties compared with adults with IDD and no HIV diagnosis. Almost 60% of adults living with HIV and IDD were Black, even though Black individuals represented 20% of our entire IDD sample.

Human immunodeficiency virus testing among adults with intellectual and developmental disabilities with no known human immunodeficiency virus/acquired immunodeficiency syndrome diagnosis

Among publicly insured adults on fee-for-service Medicare and/or Medicaid without a current HIV/AIDS diagnosis (n = 874 838), more than 99% (n = 866 193) had available information about testing. Only 0.12% of the sample (n = 1060) had received at least one test for HIV in the past year. We report aPRs of HIV test receipt (Table 2). When compared with adults with ID only, adults with other DD had higher prevalence of testing [aPR = 1.56, 95% confidence interval (CI): 1.18–2.05] while adults with autism + ID had lower prevalence of testing (aPR = 0.65, 95% CI: 0.52–0.82). Higher prevalence of testing was also observed among adults with IDD who had SMI and SUD and are female, Black or Hispanic (compared with White), and dual eligible for Medicaid and Medicare. Lower prevalence of testing was observed among adults aged 35–44 and 55–64 years, living in rural environments and who did not live in the Northeast.

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Table 1 Demographic characteristics of adults with intellectual and developmental disabilities and HIV/AIDS diagnosis

Characteristic	Total sample (*n* = 878 186) *n* (Col %)	Adults with IDD not diagnosed with HIV/AIDS (*n* = 874 838) *n* (Col %)	Adults with IDD diagnosed with HIV/AIDS (*n* = 3348) *n* (Col %)	Effect size (Cramér's V)
Age (years)				
18–25	219 373 (24.98)	218 931 (25.03)	442 (13.20)	
26–35	196 482 (22.37)	195 895 (22.39)	587 (17.53)	0.024
36–45	154 254 (17.57)	153 442 (17.54)	812 (24.25)	
46–55	184 346 (20.99)	183 280 (20.95)	1066 (31.84)	
56–65	123 731 (14.09)	123 290 (14.09)	441 (13.17)	
Gender				
Male	510 049 (58.08)	508 117 (58.08)	1932 (57.71)	0.001
Female	368 133 (41.92)	366 717 (41.92)	1416 (42.29)	
Race/ethnicity				
White	550 746 (66.64)	549 816 (66.79)	930 (28.90)	
Black	170 317 (20.61)	168 415 (20.46)	1902 (59.11)	0.061
Asian/PI	17 289 (2.09)	17 263 (2.10)	26 (0.81)	
Other	12 650 (1.53)	12 605 (1.53)	45 (1.40)	
Hispanic	75 448 (9.13)	75 133 (9.13)	315 (9.79)	
Missing or unknown	51 736	51 606	130	
Eligibility				
Medicaid only (on the basis of disability)	384 096 (43.74)	382 550 (43.73)	1546 (46.18)	0.005
Medicare only	33 906 (3.86)	33 747 (3.86)	159 (4.75)	
Dual eligible (partial, QMB only, full)	460 184 (52.40)	458 541 (52.41)	1643 (49.07)	
Geography				
Not rural	692 540 (79.81)	689 617 (79.78)	2923 (88.98)	−0.014
Rural	175 192 (20.19)	174 830 (20.22)	362 (11.02)	
Missing	10 454	10 391	63	
US Census region				
Northeast	194 949 (22.36)	194 185 (22.36)	764 (22.92)	
Midwest	232 765 (26.70)	232 208 (26.74)	557 (16.71)	0.019
South	306 745 (35.19)	305 126 (35.14)	1619 (48.57)	
West	136 324 (15.64)	135 935 (15.65)	389 (11.67)	
Other	922 (0.11)	Suppressed	Suppressed	
Average (SE) median county income in 2012	$51 261 (14.25)	$51 263 (14.29)	$51 016 (215.89)	t = 1.06, P = 0.29

Data source: 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source and Centers for Medicare and Medicaid Services.

AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus; IDD, intellectual and developmental disability; PI, Pacific Islander; QMB, Qualified Medicare Beneficiary; SE, standard error.

Human immunodeficiency virus diagnosis among adults with intellectual and developmental disabilities

Of the 878 186 adults with IDDs enrolled in fee-for-service plans, 0.38% met current claims criteria for HIV/AIDS (n = 3348). A greater proportion of individuals with other DD (1.03%, n = 285) met current criteria for HIV/AIDS, compared with adults with autism + ID (0.12%, n = 1392), autism only (0.25%, n = 142) or ID only (0.41%, n = 2782). Among people living with HIV and IDD, approximately 6% (n = 212) had claims suggesting that HIV diagnosis was present prior to the age of 18 years.

All variables were tested in an adjusted prevalence model (Table 3). In adjusted analyses, need

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Table 2 Adjusted prevalence ratios of HIV testing among publicly insured adults with intellectual and developmental disabilities and no current HIV/AIDS diagnosis

Characteristic	aPR	95% CI (aPR)
Need characteristics		
Type of IDD		
ID only	Reference	
Autism only	1.03	0.78–1.36
Autism + ID	0.65*	0.52–0.82
Other DD	1.56*	1.18–2.05
Serious mental illness[†]	2.27*	1.98–2.59
Substance use disorder[‡]	2.49*	2.09–2.97
Predisposing characteristics		
Age (years)		
18–24	Reference	
25–34	0.98	0.82–1.18
35–44	0.72*	0.58–0.88
45–54	0.53*	0.43–0.66
55–64	0.45*	0.35–0.58
Female (male reference)	1.57*	1.38–1.77
Race/ethnicity		
White	Reference	
Black	2.49*	2.16–2.87
Asian/Pacific Islander	1.46	0.89–2.39
Other	1.50	0.93–2.40
Hispanic	1.65*	1.32–2.07
Enabling characteristics		
Eligibility		
Medicaid only	Reference	
Medicare only	1.33	0.90–2.00
Dual eligible	2.28*	1.95–2.66
Rural	0.74*	0.62–0.88
Geographical region		
Northeast	Reference	
Midwest	0.73*	0.62–0.86
South	0.49*	0.42–0.58
West	0.36*	0.28–0.47
Median county income in 2012	1.00	1.00–1.00

Data source: 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source and Centers for Medicare and Medicaid Services.
*$P < 0.05$.
[†]Serious mental illness included meeting criteria in 2012 for depression, bipolar disorder, and/or schizophrenia and related psychosis.
[‡]Substance use disorder included meeting criteria in 2012 for OUD diagnosis, hospitalisation, emergency department visit and/or medication-assisted therapy; alcohol-related disorders; and/or drug use disorders.
AIDS, acquired immunodeficiency syndrome; aPR, adjusted prevalence ratio; CI, confidence interval; DD, developmental disability; HIV, human immunodeficiency virus; ID, intellectual disability; IDD, intellectual and developmental disability; OUD, opioid use disorder.

characteristics including type of IDD diagnosis and co-occurring mental or substance use were significantly associated with diagnosis. Adults with other DDs continued to have higher prevalence than the ID-only group, and the autism + ID group had the lowest prevalence of being diagnosed. Higher prevalence of current HIV/AIDS diagnosis was associated with having SUD and SMI, being >24 years old, and of Black, Hispanic or 'other' race. Importantly, Black individuals had the highest aPR (5.61, 95% CI: 5.16–6.11). Lower prevalence was observed among dual-eligible adults and those living in rural areas and in the Midwest or West (as opposed to the Northeast).

Receipt of human immunodeficiency virus-related care among people living with human immunodeficiency virus and intellectual and developmental disabilities

Receipt of HIV-related care was defined based on receipt of ART among the sample of people living with HIV and IDD (n = 3348). Approximately 71% (n = 2389) of people living with HIV and IDD received ART for their HIV in the claim year. Need characteristics were significantly associated with receipt. A smaller proportion of adults on the autism spectrum (with and without ID) received ART (54.7% and 64.1%) compared with people with ID only (72.0%) and people with other DD (76.5%). This pattern was supported in adjusted analyses (Table 4), with those with autism + ID having lower prevalence of receiving ART when compared with those with ID only.

Discussion

This study used a dataset of publicly insured patients in the USA to provide the most comprehensive prevalence estimates of HIV prevention and care outcomes among adults with IDDs to date. Our results indicate that HIV prevention, diagnosis and receipt of care differ by type of IDD. When compared with people with ID only, people on the autism spectrum with co-occurring ID had lower prevalence of being tested and diagnosed and receiving ART.

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Table 3 Adjusted prevalence ratios of HIV/AIDS diagnosis among publicly insured adults with intellectual and developmental disabilities

Characteristic	aPR	95% CI (aPR)
Need characteristics		
Type of IDD		
ID only	Reference	Reference
Autism only	0.99	0.82–1.19
Autism + ID	0.38*	0.32–0.46
Other DD	1.90*	1.66–2.17
Serious mental illness[†]	1.79*	1.66–1.94
Substance use disorder[‡]	4.32*	3.96–4.72
Predisposing characteristics		
Age (years)		
18–24	Reference	Reference
25–34	1.50*	1.31–1.71
35–44	2.72*	2.38–3.11
45–54	2.88*	2.52–3.29
55–64	1.9*	1.70–2.32
Female (male reference)	1.00	0.93–1.08
Race/ethnicity		
White	Reference	Reference
Black	5.61*	5.16–6.11
Asian/Pacific Islander	1.04	0.70–1.55
Other	1.85*	1.35–2.54
Hispanic	2.49*	2.17–2.85
Enabling characteristics		
Eligibility		
Medicaid only	Reference	Reference
Medicare only	0.96	0.81–1.14
Dual eligible	0.78*	0.72–0.84
Rural	0.59*	0.52–0.67
Geographical region		
Northeast	Reference	
Midwest	0.58*	0.52–0.65
South	0.92	0.84–1.02
West	0.81*	0.71–0.92
Median county income in 2012	1.00	1.00–1.00

Data source: 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source and Centers for Medicare and Medicaid Services.

*$P < 0.05$.

[†]Serious mental illness included meeting criteria in 2012 for depression, bipolar disorder, and/or schizophrenia and related psychosis.

[‡]Substance use disorder included meeting criteria in 2012 for OUD diagnosis, hospitalisation, emergency department visit and/or medication-assisted therapy; alcohol-related disorders; and/or drug use disorders.

AIDS, acquired immunodeficiency syndrome; aPR, adjusted prevalence ratio; CI, confidence interval; DD, developmental disability; HIV, human immunodeficiency virus; ID, intellectual disability; IDD, intellectual and developmental disability; OUD, opioid use disorder.

Table 4 Adjusted prevalence ratios of receipt of HIV-related care[†] among publicly insured adults with HIV and intellectual and developmental disabilities

Characteristic	aPR	95% CI (aPR)
Need characteristics		
Type of IDD		
ID only	Reference	Reference
Autism only	0.94	0.83–1.08
Autism + ID	0.77*	0.66–0.90
Other DD	1.07*	1.00–1.15
HIV diagnosis as youth <18 years	1.41*	1.29–1.54
Serious mental illness[‡]	0.95*	0.91–0.99
Substance use disorder[§]	0.87*	0.83–0.92
Predisposing characteristics		
Age (years)		
18–24	Reference	Reference
25–34	1.06	0.96–1.17
35–44	1.22*	1.10–1.34
45–54	1.30*	1.18–1.43
55–64	1.19*	1.07–1.32
Female (male reference)	0.97	0.93–1.01
Race/ethnicity		
White	Reference	Reference
Black	1.05*	1.00–1.11
Asian/Pacific Islander	0.86	0.65–1.14
Other	1.05	0.86–1.28
Hispanic	1.05	0.97–1.13
Enabling characteristics		
Eligibility		
Medicaid only	Reference	Reference
Medicare only	0.72*	0.62–0.83
Dual eligible	0.98	0.94–1.03
Rural	0.96	0.88–1.04
Geographical region		
Northeast	Reference	Reference
Midwest	1.02	0.95–1.10
South	0.99	0.93–1.05
West	1.16*	1.08–1.24
Median county income in 2012	1.00	1.00–1.00

Data source: 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source and Centers for Medicare and Medicaid Services.

*$P < 0.05$.

[†]Outcome is receipt of any antiretroviral treatment in 2012.

[‡]Serious mental illness included meeting criteria in 2012 for depression, bipolar disorder, and/or schizophrenia and related psychosis.

[§]Substance use disorder included meeting criteria in 2012 for OUD diagnosis, hospitalisation, emergency department visit and/or medication-assisted therapy; alcohol-related disorders; and/or drug use disorders.

aPR, adjusted prevalence ratio; CI, confidence interval; DD, developmental disability; HIV, human immunodeficiency virus; ID, intellectual disability; IDD, intellectual and developmental disability; OUD, opioid use disorder.

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Conversely, people with other DDs had higher prevalence of testing, diagnosis and ART compared with those with ID only. The significant disparities among people on the autism spectrum with co-occurring ID are concerning. There is substantial literature indicating that, among people with IDD, those on the autism spectrum with ID experience worse health and social outcomes. Providers who are inadequately trained to work with people with disabilities (Ratakonda *et al.* 2022) and who may also hold biases against providing care to people with disabilities are challenged with caring for this patient population (Lagu *et al.* 2022). Future studies should consider the unique contributions of social and cognitive factors within IDD diagnostic groups that may impact screening, diagnosis and treatment.

We also identified a significant burden of HIV among Black adults living with HIV and IDD. Despite Black adults representing 21% of the publicly insured IDD population in 2012 Medicare–Medicaid linked data, they made up almost 60% of people living with HIV and IDD. In adjusted analyses, Black adults with IDD had over 5.5 times higher prevalence of being diagnosed with HIV than White adults with IDD. This group also had slightly higher prevalence of receipt of HIV care. This pattern of results is similar to the general population of people living with HIV, with a higher prevalence of people living with HIV who are Black (Bowleg *et al.* 2022). However, systemic racism affecting Black people living with HIV and IDD cannot be overstated (Dale *et al.* 2019; Bowleg *et al.* 2022) and therefore requires an intersectional lens when developing prevention programmes or further epidemiological studies (Ham *et al.* 2023). Our findings require public health practitioners and healthcare organisations to partner with affected communities to best identify opportunities to reduce inequities in diagnosis and care.

Significantly higher prevalence of HIV diagnosis was observed among people with IDD who also had SMI or SUD, similar to the findings of Durbin *et al.* (2017a) and Lunsky *et al.* (2017). However, we found that people with these co-occurring mental health and substance use conditions also had lower prevalence of receiving ART. Substance use and SMI affect all parts of the HIV care continuum (Prince *et al.* 2012). For example, people who inject drugs are at higher risk of HIV transmission and are less likely to be adherent to ART (Campbell *et al.* 2013), and there is clear indication that pre-transmission mental health conditions (e.g. schizophrenia) and post-transmission mental health conditions (e.g. depression) influence both prevention and care coordination efforts (Sahota *et al.* 2020). For people with IDD, care coordination efforts are further complicated by ableist beliefs and practices, intersecting with the social, cognitive, communication and/or physical needs of people with IDD. We recommend training for all medical professionals on shared decision-making with patients with disability. In addition to shared decision-making methods, healthcare providers must be knowledgeable on strategies to ensure that people with IDDs are appropriately diagnosed and not misdiagnosed with a psychiatric condition leading to unnecessary polypharmacy. There are several opportunities to improve prevention and linkage/retention to care via policies and practices.

First, this population requires HIV and sexual health education that is tailored to their specific information accessibility needs, interpersonal relationships and health goals; this information should be delivered within developmentally appropriate time frames. Few studies examine use of sexual health curricula or materials for people with IDD, and this remains a significant gap in health care (Roden *et al.* 2020). Healthcare providers, who perceive people with disabilities as at risk for HIV, should ensure that care supports include accessible features of the physical, sensory and social environments (Drumhiller *et al.* 2020). Further, because of high rates of sexual assault, assessing interpersonal violence risk is essential for clinicians working with people with IDD. We also recommend expansion of age-appropriate and developmentally appropriate sexual health education, including interpersonal violence prevention education tailored for these populations.

Second, our research suggests that a number of factors not related to need or risk impact access to HIV screening and diagnosis, including predisposing characteristics (e.g. race/ethnicity) and enabling characteristics (e.g. type of coverage and rural status). These factors align with gaps in evidence to examine the contribution of specific and intersectional social determinants of health that may compound health disparities. For example, people with IDD generally

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identify that food security and transportation access are barriers to health (Durbin *et al.* 2017b); however, among those with additional chronic conditions requiring regular and sustained care such as HIV, these are more than inconveniences and become intersectional drivers of health outcomes. Our study supports the importance of examining social determinants of health and their specific contributions to HIV-related outcomes. We found that dual-eligible adults were more likely to be screened than Medicaid-only adults, and dual-eligible adults were significantly less likely to have been diagnosed. Investigating the potential protective effect of being enrolled in both Medicare and Medicaid is an important next step for understanding care navigation.

In terms of HIV treatment among people with HIV and IDD, we found that 71% were receiving ART, which is similar to the Joint United Nations Programme on HIV/AIDS (UNAIDS 2022) global report of 76% in the general population. However, our study found that a concerningly low 54% of adults on the autism spectrum with co-occurring ID and HIV received ART in the past year. People on the autism spectrum with co-occurring ID may experience social, cognitive and communication challenges that impede healthcare treatments. For example, executive functioning skills are needed to remember to take a daily medication and to refill a medication. There is a need to further explore alternatives to daily ART for people with IDD who have executive functioning not conducive to remembering to take medication. HIV clinical guidelines recommend the consideration of long-acting injectable (LAI) ART for people who experience difficulties accessing care (e.g. people with SMI) (Panel on Antiretroviral Guidelines for Adults and Adolescents 2022). LAI ART should be explored for people living with HIV/IDD, while also considering the injection-averse sensory experiences of some people with IDD. Little research addresses this, and future inquiry and clinical efforts focused on this area may seek guidance from the diabetes literature for people with IDD and how they effectively engage patients who require the use of injectable medications.

There are several policy implications as well. First, people with IDD - or any person with disabilities - are not explicitly discussed in clinical guidelines on the use of ART in adolescents and adults (Panel on Antiretroviral Guidelines for Adults and Adolescents 2022). Although there is significant discussion of neurocognitive impairment in the guidelines, it is necessary to explicitly recognise the unique circumstances in which other disabilities, such as those on the autism spectrum, may present to care and how their contexts may influence retention in care and adherence to ART. This includes the potential need for disability-related accommodations in healthcare environments. At an international level, there is a lack of HIV surveillance among people with disabilities – including those with IDDs. Non-governmental organisations and international partners (e.g. UNAIDS and WHO) should prioritise people with disabilities in HIV surveillance systems to help monitor disparities in care supporting the development of evidence-based prevention programmes.

Strengths and limitations

There were several strengths and limitations to our study. First, our study provides population health prevalence estimates of HIV prevention and care outcomes among adults with IDD, a group whom is frequently excluded from discussions of HIV care. Although our data are from 2012, this data source combines both Medicare and Medicaid claims to produce a large US national sample of publicly insured individuals. A second strength is the large sample of adults with IDD. Many adults with IDD are recipients of either Medicaid or Medicare because of disability, and therefore, this sample from a data source that represents the type of healthcare coverage that most adults with IDD receive allows for the most valid and reliable estimates. Lastly, our statistical analysis plan accounted for a breadth of predisposing and enabling factors known to impact HIV care. Our results were also insensitive to changes in the model distribution and should be considered robust – particularly given the large, geographically diverse sample of Medicare and Medicaid enrolees with IDDs.

There were several limitations to our study. There have been changes in the healthcare landscape over the past decade (e.g., Medicaid expansion), making it even more important that continued use of claims data from recent or linked sources are used in future

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research. The age of these data suggests that more work needs to be performed, particularly as health policy and Medicaid expansion and waivers have changed in the past decade. Our study also excluded beneficiaries on managed care plans, which was 5.5% of the available adult sample in 2012. Taken in context of the age of our data (2012), we do not feel that the findings were greatly impacted because managed care penetration by state varied widely at that time and people with disabilities (100% of our sample) and those who are dual eligible (about 50% of our sample) generally remained on fee-for-service because of high costs of care (Kaiser Family Foundation 2012). Further, limited research suggests that managed care results in differences in outcomes compared with fee-for-service (Medicaid and CHIP Payment and Access Commission n.d.). Since 2012, managed care enrolment has grown and future researchers are encouraged to address this gap in their evaluations. Increased enrolment in managed care and plans for beneficiaries with complex care needs are important avenues for understanding how, when and why individuals with IDD and HIV are receiving health services. Second, the diagnosis-based HIV care continuum defines receipt of HIV care as the percentage of people diagnosed with HIV who had at least one CD4 or viral load test. We did not have access to variables quantifying these tests in this data source; therefore, we focused on filling ART medication throughout the year of coverage. Further, we were limited in the predisposing, enabling and need-related factors to include in our models. Future research should identify the most important and action-oriented factors to inform public health and healthcare practice; this research may, for example, focus on types of accommodation needs as a need-based characteristic. In terms of sample, people with IDD who do not have a medical diagnosis captured under the CCW algorithms for IDD are not included in our sample. This is a limitation not only of research with claims data but also of healthcare delivery: people with IDD who are not classified as such will not have IDD-specific recommendations provided in care. Lastly, there is a well-established literature on the risk of co-occurring IDD and HIV due to vertical transmission. Because of the lack of look-back period, we are unable to state with certainty that all cases of people with HIV and IDD in these data were not from vertical transmission. Despite this limitation, the majority of adults in our sample (94%) had claims suggesting that HIV diagnosis was made after 18 years of age.

Conclusions

This study presents population health estimates of HIV testing, diagnosis and receipt of care among publicly insured adults with IDDs in the USA. Our results indicate several opportunities to improve health equity for adults with IDD who are experiencing significant burden with respect to HIV transmission, including people who are Black, people who have serious mental illness and people who use substances. The intersectional identities among adults with IDD who experience this burden are those that are often most marginalised, ignored and neglected by systems of care. Our leading recommendation is that HIV care for adults with IDD must be individualised and patient-centred and address the social, physical and psychological needs of the specific patient.

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None.

Conflict of interest

The authors have no conflicts of interest or commitment to disclose; however, T. W. B. has performed significant work with populations with IDD (e.g. adults with autism).

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Data availability statement

The data used in this study are not publicly available, and therefore, the authors are unable to make the data available. The data are available for purchase from the Centers for Medicare and Medicaid Services (CMS), following a data use request from a third-party vendor. Those seeking to purchase data should visit the website for the Research Data Assistance Center (ResDAC) at http://www.resdac.org. Information on how to replicate the cohort-specific data used in this study is provided in Appendix C.

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Appendix A: Authors' positionality statement

Tyler G. James, PhD, MCHES, is a Postdoctoral Fellow in the Department of Family Medicine at the University of Michigan. He is identified as a neurodiverse health services researcher with disability and a social epidemiologist. His lens of research is influenced by his experience as a gay, human immunodeficiency virus (HIV)-negative, cisgender White man. In addition, Dr James has 8 years of experience in health education and health promotion, with his early health promotion work in HIV testing and linkage counselling focused on people with disabilities.

Michael S. Argenyi, MD, MPH, MSW, AAHIVS, is a Clinical Assistant Professor in the Department of Psychiatry at the University of Iowa Carver College of Medicine. He is identified as a physician with prelingual hearing loss and a White HIV-negative queer man. His lived experiences in a hearing world as a user of cued speech, American Sign Language and other modalities to optimise communication, multiple disciplines of education and postgraduate training, and clinical experiences as a healthcare provider influence his understanding of data and value of different clinical actions.

Amy Gravino, MA, CAS, is a Relationship Coach in the Rutgers Center for Adult Autism Services at Rutgers, The State University of New Jersey. She is identified as an autism sexuality advocate and professional speaker who is a White, HIV-negative woman with autism/disability. Her lived experiences

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in an ableist and neurotypical-dominated society as a person on the autism spectrum and graduate training in the field of applied behaviour analysis and clinical experiences working as the principal investigator of a sex education curriculum for adults with autism influence her understanding of how intersecting identities affect outcomes and the need to dismantle systemic and societal barriers that prevent people with disability from accessing care.

Teal W. Benevides, PhD, MS, OTR/L, FAOTA, is an Associate Professor in the Institute of Public and Preventive Health at Augusta University in Augusta, GA, USA. She is identified as a White, non-Hispanic cisgender woman. Dr Benevides has 19 years of professional experience as a licensed and registered occupational therapist and health services researcher working collaboratively with neurodiverse individuals across the life span to address health and well-being goals.

Appendix B: Diagnosis and procedure codes for outcome variables

Human immunodeficiency virus testing

This was defined using a variable available in the Medicare-Medicaid Linked Enrollee Analytic Data Source dataset (HIVTSTNG_CAT4). This supplied variable is based on procedure codes (i.e. Common Procedure Terminology and Healthcare Common Procedure Coding System) for tests for human immunodeficiency virus-1 or human immunodeficiency virus-2 (i.e. 86689, G0432, G0432-xx, G0433, G0433-xx, G0435 and G0435-xx).

Human immunodeficiency virus diagnosis

This was defined using the Chronic Conditions Warehouse human immunodeficiency virus algorithm, which uses a conservative 2-year look-back period to evaluate claims for at least one inpatient claim or two non-drug claims of ICD-9 (042, 042.0, 042.1, 042.2, 042.9, 043, 043.1, 043.2, 043.3, 043.9, 044, 044.0, 044.9 and 079.53) or ICD-10 (DX B20, B97.35 and Z21) diagnosis codes. Persons with ICD-9 795.71 or ICD-10 R75 required a second qualifying claim of a different qualifying code.

Appendix C: Research Data Assistance Center Medicare-Medicaid Linked Enrollee Analytic Data Source cohort information

The following information can be used to replicate the cohort identification strategy for the initial Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS 2012) dataset.

MMLEADS (2012) finder file specifications are as follows: In the condition file for the 2012 MMLEADS year, we included all beneficiaries meeting claims or criteria for 'autism spectrum disorders', 'intellectual disability and related conditions' and 'learning disabilities and other developmental delays' based on Chronic Conditions Warehouse algorithms.

We requested beneficiaries with the following values for variables:

- AUTISM_COMBINED (values = 1 or 3)
- AUTISM_MEDICAID (values = 1 or 3)
- AUTISM_MEDICARE (values = 1 or 3)
- INTDIS_COMBINED (values = 1 or 3)
- INTDIS_MEDICAID (values = 1 or 3)
- INTDIS_MEDICARE (values = 1 or 3)
- LEADIS_COMBINED (values = 1 or 3)
- LEADIS_MEDICAID (values = 1 or 3)
- LEADIS_MEDICARE (values = 1 or 3)

Appendix D: Sensitivity analysis

The models reported in the manuscript are generalised linear models with Poisson distribution and robust standard errors. The coefficients of these model results are exponentiated to estimate an adjusted prevalence ratio. The Poisson distribution is commonly used for count variables and rare events (e.g. human immunodeficiency virus cases). The sensitivity analysis models are generalised linear models with a log-binomial distribution and log link function. This model directly estimates the adjusted prevalence ratios. The generalised linear model with a log-binomial distribution is commonly applied in epidemiological studies, particularly when estimating prevalence ratios. However, the rare outcome nature of our outcome variables supported the use of the Poisson distribution. The results from the models are very similar.

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Table D1. Sensitivity analysis of models using a log-binomial distribution estimating adjusted prevalence ratios for three outcomes of HIV testing, diagnosis and treatment[†] among publicly insured adults with HIV and intellectual and developmental disabilities

Characteristic	aPR (95% CI) Testing (see Table 2)	aPR (95% CI) Diagnosis (see Table 3)	aPR (95% CI) Antiretroviral treatment (see Table 4)
Type of IDD			
ID only	Reference	Reference	Reference
Autism only	0.88 (0.68–1.14)	0.60* (0.51–0.71)	0.89 (0.78–1.01)
Autism + ID	0.64* (0.52–0.80)	0.29* (0.24–0.34)	0.76* (0.65–0.88)
Other DD	1.82* (1.41–2.36)	2.51* (2.23–2.84)	1.06* (0.99–1.14)

Data source: 2012 Medicare-Medicaid Linked Enrollee Analytic Data Source and Centers for Medicare and Medicaid Services.
*$P < 0.05$.
[†]Outcome is receipt of any antiretroviral treatment in 2012.
aPR, adjusted prevalence ratio; CI, confidence interval; DD, developmental disability; HIV, human immunodeficiency virus; ID, intellectual disability; IDD, intellectual and developmental disability.

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