Original Report:
Research Findings

EVALUATING THE AVAILABILITY AND QUALITY OF HIV/AIDS SERVICES AND SUPPORTS FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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We used a community-based participatory research (CBPR) framework to conduct a needs assessment of the availability and quality of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) services for persons with intellectual and developmental disabilities (PWIDD) in the Atlanta metropolitan area. We present the findings of a three-phase research project. Findings from the research informs organizations and policymakers on how to provide persons with disabilities better access to HIV/AIDS care. *Ethn Dis.* 2019;29(Suppl 2):435-440; doi:10.18865/ed.29.S2.435

Keywords: HIV/AIDS; Intellectual and Developmental Disabilities; Community-Based Participatory Research

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INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), human immunodeficiency virus (HIV) infection has increased exponentially in the southeastern United States.[1] In 2016, nearly 77% of all new HIV infections in the southeastern United States were among African American, Hispanic/Latinx, Asian, and non-White individuals.[1] Relatedly, the southeastern US has a higher incidence of disability than any other US region; however there is limited understanding of the intersections of disability, race, and HIV and acquired immunodeficiency syndrome (AIDS).[2] Of concern, disability has received limited attention from sexual health researchers, even though individuals with disabilities are at increased risk for HIV infection due to poverty, inadequate sexual education, vulnerability to exploitation and assault, and barriers to accessing needed services and supports.[3-5]

A variety of factors (eg, inadequate funding, service provider attitudes) may result in limited or no HIV testing, prevention programming, and sexual health services for persons with intellectual and developmental disabilities (PWIDD).[3,6] Combined, these factors create disparities in access to HIV/AIDS services for a significant portion of the population (including 1%-3% with intellectual and developmental disabilities). PWIDD are often excluded from HIV prevention or intervention efforts due to misconceptions that they are not sexually active or do not engage in other high-risk behaviors.[6-8] However, PWIDD are at an increased risk for acquiring HIV because they often are isolated from the general public, rarely receive any sex education, and are at a higher risk of being raped or sexually abused.[3] Furthermore, there are few health-based interventions designed for PWIDD.[9] Although there are a variety of research-based frameworks (eg, universal design for learning, cognitive load theory) for modifying educational and testing materials or creating disability-centered programs, materials on HIV are often not accessible to persons with lower intellectual and cognitive functioning.

STUDY DESIGN

The aim of our present study was to evaluate the availability and quality of HIV/AIDS services and supports for ethnically and racially diverse PWIDD in the metro-Atlanta area. Georgia has the highest national prevalence rates of

HIV, and approximately two-thirds of all Georgians living with HIV/AIDS reside in metro Atlanta.[10,11] In recognition of the contextual and intersectional nuances between race/ethnicity, gender, HIV/AIDS, and disability status, we implemented a community-based participatory research (CBPR) approach with three phases. We implemented a mixed-method community needs assessment to identify both the strengths and limitations of available HIV/AIDS prevention and supports. In conducting the research, we addressed the following questions.

Research Question 1: What HIV/AIDS-related services and supports are available from local HIV/AIDS service agencies and disability service agencies?

Research Question 2: What challenges, barriers, and facilitators do local HIV/AIDS service agencies and disability service agencies perceive to implementing effective HIV/AIDS services and supports for PWIDD?

Research Question 3: What accommodations and modifications are being implemented to make HIV-related outreach and educational materials accessible for PWIDD?

In the first two phases of the study, focus groups, empowerment evaluation, strategies, and survey methods were used to address Research Questions 1 and 2. The third phase of the study utilized document analysis to address Research Question 3.

METHODS: PHASE ONE

Participants

To engage community partners in the design and implementation of the research, we contacted local HIV/AIDS and disability-serving organizations via email and phone to recruit stakeholders for a community assessment team (CAT). CAT members (N = 13) included five females, six males, and two transgender persons. Eleven CAT members racially identified as Black/African American, one as White and one as bi-racial. Ten CAT members identified as living with HIV, one reported living with a disability, two were family members of individuals living with HIV, one was a family member of individuals with a disability, three were service providers for individuals living with HIV, and three were service providers for individuals with disabilities. Eight participants identified as heterosexual and five identified as lesbian, gay, bisexual, or queer (LGBQ). In addition to participating in Phase 1, CAT members were invited to contribute to subsequent phases of the research and participate in a follow-up meeting at the conclusion of the project to discuss outcomes and next steps.

Procedures

Over the course of two three-hour meetings (conducted approximately 30 days apart), CAT members explored and discussed HIV/AIDS-related resources in the metro-Atlanta region.[12] During the first meeting, we facilitated separate focus groups with three sub-groups of CAT members: 1) PWIDD and their family members and disability service providers; 2) people living with and family members affected by HIV; and 3) HIV service providers. The focus group questions centered on participants' experiences and knowledge of HIV/AIDS services in metro Atlanta, and the availability, utility and accessibility of those services for PWIDD. Focus group responses were recorded, summarized, and analyzed using grounded theory analytic strategies.

We presented the thematic results from the first meeting during the second CAT meeting as a form of member checking. We then implemented the "taking stock process" from Empowerment Evaluation.[13] This involved CAT members working in small groups to brainstorm actions they would implement to improve HIV/AIDS services for PWIDD if they were awarded a grant for $10,000. CAT members then voted their top 10 choices from the 37 different solutions or actions identified by the small groups. Finally, CAT members were asked to rate the potential impact and feasibility of the actions on the CAT members' overall top 10 list.

METHODS: PHASE TWO

Procedures

We identified and solicited HIV/AIDS, IDD, and other health/disability-related agencies that were within 25 miles of metro-Atlanta to complete a survey about barriers and facilitators to accessing effective HIV/AIDS services and supports for PWIDD. Requests for voluntary participation, along with electronic informed consent, were distributed to 74 agencies via email. If agencies were willing to participate, they were informed to access an electronic link within the email and complete a survey via *Qualtrics*. Fifty respondents (24 from disability-serving agencies, 24 from HIV/AIDS agencies, and 2 from agencies that covered both areas) completed the survey. Data were collected anonymously, and responses could not be linked to any specific agency. Data were then downloaded into SPSS 24.0 and descriptive statistics were calculated. Open-ended responses were analyzed using grounded theory methods.

Measures

We created the survey instrument informed by the qualitative data that were collected and analyzed during Phase One. Two service providers for PWIDD and those living with HIV/AIDS reviewed the final survey for content, clarity, and feasibility. The final survey instrument consisted of five sections.

The first section consisted of personal demographics of respondent (eg, age, gender, race/ethnicity). The second section pertained to demographics of the agency (eg, type of service agency, years of operation, types of clients served at the agency). The third section was a checklist of services provided by the agency (eg, HIV rapid testing, HIV/AIDS education, referral to mental/behavioral health, etc.). In the fourth section, 8 items related to perceptions of the organization's competence (ie, knowledge, skills, and attitudes) to deliver services to their respective populations. These items were developed by the research team in direct response to the findings analyzed in the initial phase of the study. Participants were asked to rate each item on a five-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). One example of these items is: "staff at my organization are comfortable addressing sexuality and HIV/AIDS-related issues with persons living with intellectual and development disabilities." For the fifth section, we included three open-ended questions that asked participants to identify barriers and facilitators to providing services to PWIDD and people living with HIV/AIDS. More specifically, these open-ended questions were: a) To the best of your ability, identify current barriers within your organization(s) that would prohibit delivery of effective HIV/AIDS services for individuals with intellectual/developmental/learning disabilities; b) What particular trainings have you and members of your organization received in order to provide effective HIV/AIDS services for individuals with intellectual/developmental/learning disabilities? and c) What do you and your organization currently do, if anything, in order to make HIV/AIDS related services and materials accessible for individuals with intellectual/developmental/learning disabilities?

METHODS: PHASE THREE

Procedures

To address research question 3, we evaluated how accommodations and modifications were being made to make HIV-related outreach and educational materials accessible for PWIDD. With the assistance of CAT members, we contacted community agencies in metro-Atlanta and collected (via mail or in-person) their informational fliers and educational materials about sexual health and STD education. After removing duplicates, 38 HIV/AIDS and sexual health materials were evaluated. Team members then completed independent ratings of the material using the Clear Communication Index (CCI), which is described below. Item-level ratings that were consistent between the two initial raters were recorded (inter-rater agreement=71.8%). For items that did not receive the same rating from both initial coders, a three-person team determined a final rating via review of the submitted material, the initial raters' scores, and the applicable CCI criteria.

Measure

Because CAT members indicated service providers generally used HIV/AIDS intervention/outreach materials without modifications to support PWIDD's understanding, the CCI was used to evaluate the comprehensibility of existing sexual health materials collected from community agencies.[14] Clear communication includes use of everyday language, visuals, clear explanations of numerical statements, and specific directions to implement recommendations. The CCI's 20 items are divided into four sections: core items, behavioral recommendations, numbers, and risk. Each item receives a score of 1 or 0, or not applicable. An overall CCI score of 90% is considered adequate for material to meet the requirements for clear communication. A score of 89% or less indicates that revision of the material may be necessary, to allow for better understanding by the targeted audience.

RESULTS

Phase One: Focus Groups with CAT Members

Thematic analysis of recordings and field notes from the focus group sessions resulted in identification of the following themes.

Frustration with Services

Individuals impacted by HIV/AIDS and PWIDD expressed frustration with the quality of sexual health services, insufficient community resources, lack of "face time," and disrespect from professionals (ie, "They rush you out of their office"). Individuals from both subgroups indicated that health-related information needed to be conveyed using clear, understandable language.

Enhancing Sex Education

Families indicated there was a lack of sex education materials geared toward diverse learners, including PWIDD. They felt PWIDD and their families would benefit from materials that: 1) acknowledged and affirmed sexuality among PWIDD; and 2) included information on preventing sexual abuse and maltreatment. HIV/AIDS and disability service providers indicated the need for training on strategies (eg, providing accommodations/modifications) for making existing sexual health and prevention materials accessible to PWIDD. HIV/AIDS service providers also felt they needed training on understanding the needs of PWIDD. Disability service providers noted that some staff are uncomfortable discussing sexuality with PWIDD. There was also concern that providing sexual health or HIV prevention information might upset parents or policymakers.

Phase One: Empowerment Evaluation

CAT members brainstormed a list of 37 actions they would fund to address HIV/AIDS education and prevention with PWIDD. CAT members then voted on their top 10 potential actions and rated each action's potential impact and feasibility (Table 1). Only two of the brainstormed actions were rated as high impact (M >3.00) and highly feasible (M >3.00): 1) agencies hiring people with experience working with PWIDD to provide HIV/AIDS services; and 2) providing more sex education in schools, churches, and other community settings.

Phase Two: Quantitative Findings

Results from the 8-item perceptions of organization competence subscale indicated a mean score of 29.18 (SD = 6.37, range = 16-40). HIV/AIDS agency staff showed significantly greater confidence in their organizations' competence in providing HIV/AIDS services to PWIDD (M= 33.73, SD=4.93) than respondents from disability-serving agencies (M=26.44, SD=5.56), t(38)=4.18, P<.001. Frequency of services provided and noted disparities in types of services provided between agency types were also explored (Table 2).

Phase Two: Qualitative Findings

The most common barrier to care was a lack of applicable training and professional development (eg, recognizing PWIDD, supporting diverse learners), leaving staff with a sense of being "out of our expertise." One participant called for "additional resources and training for (HIV/AIDS agency) staff to support and educate individuals with developmental disabilities." For another participant, these gaps in training meant [their disability-serving agency] had a "lack of knowledge about HIV and how to deliver services." Another barrier frequently highlighted by participants was a lack of funding, which perhaps limited training opportunities. Par-

Table 1. Potential and feasibility of brainstormed actions

Potential Action/Solution	Potential impact[a]	Feasibility[a]
Improved transportation services	3.75	2.75
Improved support and access to housing	4.75	2.75
Change laws that limit individuals with criminal histories (eg, sex workers, drug users)	3.5	2
Develop tools and materials for educating people with different learning styles	3	2.75
Agencies hire people with experience working with IDD to do HIV work	4.75	3.75
Create a group home or community space for support	5	2.75
Education and training for doctors, medical personnel on providing accessible and respectful support	5	2.25
Individualized services for people who are transgender	4.75	2.75
Provide more sex education in schools, churches, etc.	4.75	3.25
Hiring more staff	5	2.75

a. Scale ranged 1-5, with "5" representing the greatest impact and high feasibility, and "1" representing low impact and low feasibility.

ticipants also recognized that conversations surrounding safe sexual practices were often avoided when working with PWIDD: "A barrier is often the cultural view of sexuality of the family of the person with a developmental disability. Many families are uncomfortable with the concept of discussing sexuality with a person with a disability." Participants further shared how they currently worked to make HIV/AIDS services and materials more accessible for PWIDD. They indicated providing free services, providing referrals when unable to directly provide care, making reading materials accessible, prioritizing individual client support, and conducting outreach to diverse communities.

Phase Three

We calculated descriptive statistics for the overall score and Parts A, B, C, and D on the CCI (Table 3) for the HIV prevention and sexual health materials collected from local organizations. The mean overall CCI score for the 38 materials reviewed was 74%; well below the CCI's 90% criterion for clear communication. Of the 38 materials reviewed, only eight scored 90% or better on the CCI, indicating most available materials do not provide sexual health and HIV prevention information in an accessible and understandable manner. However, the mean score for CCI Part B was 93.3%, which suggests the submitted materials might be more effective in describing behavioral recommendations (eg, using condoms), explaining their importance, and providing step-by-step directions for implementation.

Table 2. Frequencies of services provided

Service Type	HIV/AIDS agency, n=22	Disability agency, n=26
HIV education	20	3
Sexual health education	17	8
Services to lesbian, gay, bisexual persons	17	6
Accessing/distributing sexual health supplies (eg, condoms)	17	3
Hire/employ persons with expertise in HIV/AIDS	19	4
Referrals to HIV/AIDS care	19	1
Referrals to HIV community support groups	16	1

DISCUSSION

Results from this multi-phase project highlighted gaps and areas for improvement in HIV/AIDS-related services for PWIDD in metro Atlanta, while also shedding light on several challenges in providing effective care for this population.

In Phase One, CAT members ranked "more staff" as the greatest need in community organizations. This same need was reiterated during Phase Two, when service providers shared they were least confident about having adequate staff to provide HIV/AIDS services to PWIDD. Specifically, staff working with PWIDD indicated they would benefit from trainings geared toward providing disability-sensitive care, including how to effectively broach topics of HIV prevention and safe sexual practices. These survey responses aligned with previous research that suggested service providers often neglect addressing HIV/AIDS due to misconceptions surrounding PWIDD's sexuality.[8] Additional trainings for HIV/AIDS and disability service providers might increase provider comfort in addressing safe sexual practices with PWIDD, which is necessary when considering the vulnerable nature of this population.[6,7] Budgetary restraints, however, may inhibit the hiring of additional staff or provision of research-based training to increase existing staff member competency.

Acknowledging that individuals living with HIV and/or disability already experience stigma and mistrust, Phase One participants felt affected from insufficient and often inaccessible community resources. Persons living with HIV, PWIDD, and family members shared that there was a lack of appropriate materials geared toward PWIDD. This was further validated during Phase Three document analysis, which demonstrated the lack of accessible sexual health materials available for PWIDD. Further, analyzed materials did not include representation of racially and ethnically

Table 3. Descriptive statistics for Clear Communication Index ratings

	M	SD
Overall score	73.7	16.6
Part A: core items	69.1	20.7
Part B: behavioral recommendations	93.3	19.5
Part C: numbers	82.0	30.2
Part D: risk	76.7	26.6

diverse PWIDD. Work completed by Groce and colleagues may assist in ensuring greater accessibility and representation in materials surrounding HIV/AIDS.[5] For example, organizations should work to include individuals with disabilities in their print materials, while also working to make sure their meeting spaces are accessible (eg, "Is your location easily accessible through public transportation?").

Limitations

Despite vigorous outreach to various disability organizations, we had a low participation rate of PWIDD in CAT membership (Phase One); as such, the results from that phase may not provide a representative account of the experiences and perspectives of PWIDD. In addition, the survey instrument (Phase Two) was grounded in data from the initial research phase and contextualized to validly gather information from service providers in the metro-Atlanta region. However, the survey instrument may not have adequately captured services being provided in other regions of the United States, and thus should be validated for other diverse regions. Similarly, the sexual health materials analyzed in Phase Three may not be representative of the quality of materials available in other regions.

FUTURE DIRECTIONS

While our study served to gather preliminary findings on the needs of local organizations and barriers to care, future research would benefit from: a) exploring the effectiveness of implementing the suggestions identified by community stakeholders; and b) replication in other geographic regions.

ACKNOWLEDGMENTS AND COMPLIANCE WITH ETHICAL STANDARDS

The authors would like to thank the following individuals for their assistance with this research: Ernest Hopkins, Gatavius Price, Molly Tucker, and Ramatu Muhammad.

Research involving human participants. Our research was approved by the Georgia State University institutional review board (IRB), and all procedures followed were in accordance with the ethical standards of the IRB and the Helsinki Declaration of 1975, as revised in 2000.

Informed consent. Informed consent was obtained from all participants included in the study.

Funding Support. This project was supported by the National Institute on Minority Health and Health Disparities (NIMHD), National Institutes of Health Grant Number U54MD008173. Contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of NIMHD or NIH.

CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Roach, Dispenza, Kelly; Acquisition of data: Roach, Dispenza, Zeligman, Stair, Kelly; Data analysis and interpretation: Roach, Dispenza, Zeligman, Stair; Manuscript draft: Roach, Dispenza, Zeligman, Stair; Statistical expertise: Roach, Dispenza; Acquisition of funding: Roach; Administrative: Roach, Dispenza, Zeligman, Stair, Kelly; Supervision: Roach, Dispenza

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