## Community-Based Participatory Approach to Evaluating the Availability of HIV Supports in Atlanta for Individuals with Intellectual & Developmental Disabilities

Andrew Roach, PhD, NCSP; Ernest Alexander Hopkins III; Franco Dispenza, PhD, CRC; Melissa Zeligman, PhD; Breanna Kelly, MSW, MS, LCSW; Gatavius Price, MPH, Ramatu Muhammad, MD; Anne Stair, EdS; Molly Tucker, MSW

## Background and Significance

The HIV infection rate is increasing faster in the Southeastern U.S. than any other region, with the highest national prevalence rates occurring in Georgia (CDC, 2014; Hixson, Omer, del Rio, & Frew, 2011).

Approximately 2/3 of all Georgians living with HIV/AIDS reside in the Atlanta metropolitan area. Available HIV infection data for Georgia does not include specific information regarding individuals with intellectual and developmental disabilities (IDD).

Research suggests individuals with intellectual and developmental disabilities (IDD) are at increased risk for HIV infection for a variety of reasons, including inadequate sexual health education, vulnerability to abuse and exploitation, and barriers to accessing supports (Aderemi, Pillay, & Esterhuizen, 2013; Hanass-Hancock & Alli, 2014; Hanass-Hancock, Chappell, & Pretorius, 2014).

Our research team implemented a multi-phased community needs assessment to identify both the strengths and limitations of HIV/AIDS prevention and supports for individuals with IDD in the metro Atlanta region. [Note results from Phases 1 through 3 will be reported on this poster.]

## Research Strategy/Approach

We used a community-based participatory research (CBPR) framework consisting of four phases conducted in an iterative fashion across 12 months.

Phase 1: Convening the Community Assessment Team. Recruited a group of 20 community stakeholders to form a community assessment team (CAT). CAT members represented HIV/AIDS-service agencies, disability service providers, individuals living with HIV/AIDS, and individuals with IDD and their families.

Phase 2: Individual Service Provider Surveys. Survey items were developed in collaboration with the CAT members. Leaders and HIV/AIDS- and disability-service agencies were asked about current HIV/AIDS-related programming and practices with individuals with IDD.



Phase 3: Document Analysis. CAT members and other stakeholders submitted documents (e.g., informational fliers, educational materials) that were representative current HIV/AIDS prevention, education, and support efforts in local community agencies. Submitted materials were evaluated by the research team for readability/reading demand and clear communication features.

Phase 4: Action Planning with CAT members. The CAT re-convened to (a) examine data collected during the previous phases of the project; and (b) develop an action plan for next steps.

## Research Outcomes

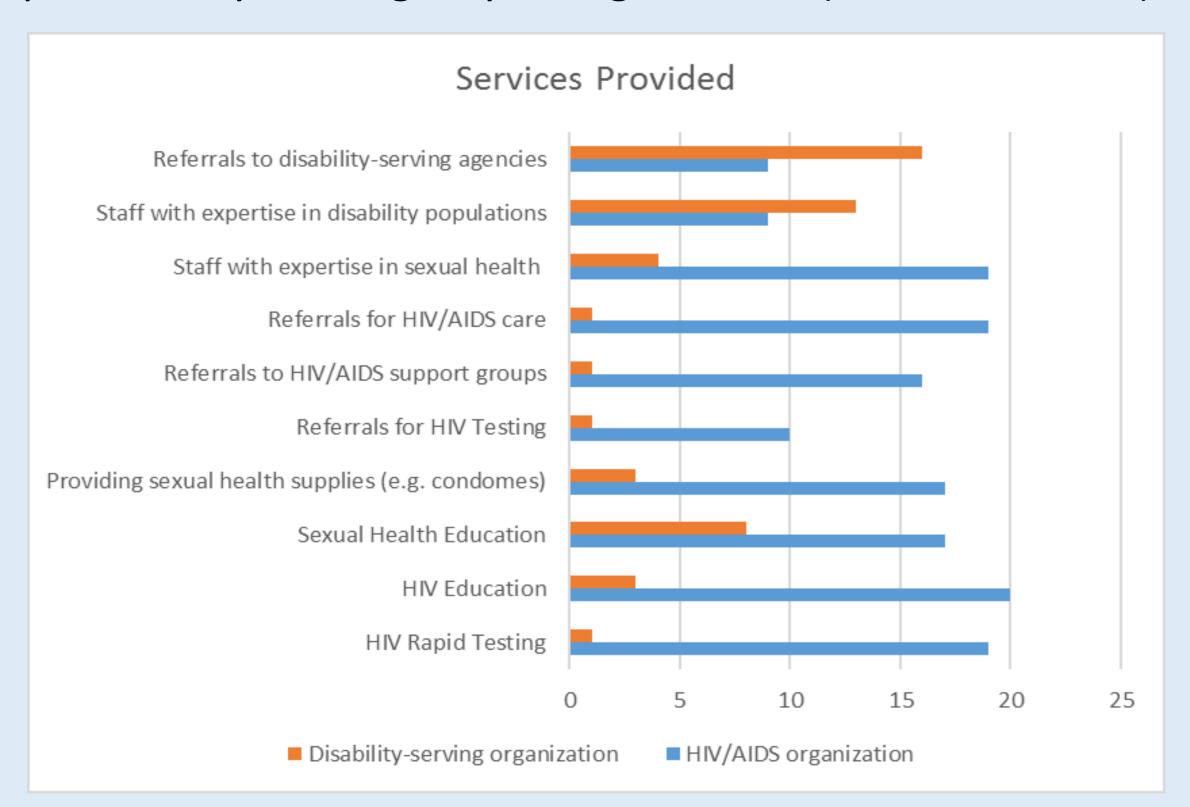
Phase 1: Focus Groups and Empowerment Evaluation with CAT members. Individuals with IDD and those impacted by HIV/AIDS indicated frustration with lack of resources/services in community. Felt that provider needed to give more time and respect (e.g., "Don't rush me out of office") and use clearer language. HIV/AIDS service providers indicated the need for more training on working with individuals with IDD, especially around accessibility and modification. Disability-service providers indicated that discomfort with discussing sexual health and worries about family reactions may be a barrier. Families indicated they needed materials and resources for talking about sexual health, including sexual exploitation, abuse and maltreatment.

Phase 1: Empowerment Evaluation. CAT members were asked to brainstorm possible actions for improving HIV/AIDS services and supports for individuals with individuals with IDD. CAT members then used sticker voting to evaluate the potential impact and feasibility of the ideas proposed.

<u>Impact</u>	Brainstormed Action	<b>Feasibility</b>
3.75	Transportation	2.75
4.75	Access to housing	2.75
3.5	Change laws that limit individuals with criminal histories	2
3	Tools for educating people with different learning styles	2.75
4.75	Hire people with experience working with intellectual disabilities to do HIV work	3.75
5	Group home community for support	2.75
5	Education for doctors, medical personnel	2.25
4.75	Individualized services for people who are transgender	2.75
4.75	More sex education in schools, churches, etc.	3.25
5	More staff	2.75

\* Note: Scale ranged 1-5, with 5 representing the greatest impact and high feasibility, and 1 representing low impact and low feasibility.

**Phase 2: Survey Results.** Respondents (N = 55) from both HIV/AIDS (n = 22) and disability-serving (n = 26) agencies. Respondents were mostly female (64%); mean age was 42 years old. Respondents were asked to identify services provided by their agency or organization (see table below).



Phase 3: Document Analysis. Thirty-eight (38) unique pieces of material were evaluated by at least two team members using the Clear Communication Index (CCI; Centers for Disease Control, 2014). Each piece also was reviewed to determine if it included (a) a depiction of an individual with a disability and (b) QR codes or hyperlinks to support accessibility. Readability was determined using a variety of indices.

None of the materials contained visual depictions of individuals with disabilities, and only 10 utilized QR codes or hyperlinks. The mean grade level of materials was 6.5 on the Flesch-Kincaid Grade Level, 8.5 on the Coleman-Liau Index, 6.4 on the SMOG Index, 5.9 on the Automated Readability Index, and 6.9 on the Linsear Write Formula. The number of components present on the total CCI and each of its four parts are presented in the table below. Materials with scores of 90% or higher are considered to have characteristics that enhance clarity and understanding.

